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Review

Analysis of Content Shared in Online Cancer Communities: Systematic Review

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Abstract

Background: The content that cancer patients and their relatives (ie, posters) share in online cancer communities has been researched in various ways. In the past decade, researchers have used automated analysis methods in addition to manual coding methods. Patients, providers, researchers, and health care professionals can learn from experienced patients, provided that their experience is findable.

Objective: The aim of this study was to systematically review all relevant literature that analyzes user-generated content shared within online cancer communities. We reviewed the quality of available research and the kind of content that posters share with each other on the internet.

Methods: A computerized literature search was performed via PubMed (MEDLINE), PsycINFO (5 and 4 stars), Cochrane Central Register of Controlled Trials, and ScienceDirect. The last search was conducted in July 2017. Papers were selected if they included the following terms: (cancer patient) and (support group or health communities) and (online or internet). We selected 27 papers and then subjected them to a 14-item quality checklist independently scored by 2 investigators.

Results: The methodological quality of the selected studies varied: 16 were of high quality and 11 were of adequate quality. Of those 27 studies, 15 were manually coded, 7 automated, and 5 used a combination of methods. The best results can be seen in the papers that combined both analytical methods. The number of analyzed posts ranged from 200 to 1,500,000; the number of analyzed posters ranged from 75 to 90,000. The studies analyzing large numbers of posts mainly related to breast cancer, whereas those analyzing small numbers were related to other types of cancers. A total of 12 studies involved some or entirely automatic analysis of the user-generated content. All the authors referred to two main content categories: informational support and emotional support. In all, 15 studies reported only on the content, 6 studies explicitly reported on content and social aspects, and 6 studies focused on emotional changes.

Conclusions: In the future, increasing amounts of user-generated content will become available on the internet. The results of content analysis, especially of the larger studies, give detailed insights into patients' concerns and worries, which can then be used to improve cancer care. To make the results of such analyses as usable as possible, automatic content analysis methods will need to be improved through interdisciplinary collaboration.

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KEYWORDS

cancer; survivors; support groups; internet

Introduction

Background

In recent years, the concept of *online community* for patients and their relatives (ie, posters) has developed as a result of improved technical possibilities [1]. Literature cites various forms of online contact between patients, including bulletin boards, closed networks, mailing lists, newsgroups, discussion forums (moderated or otherwise), chat rooms, Facebook groups, Twitter follow groups, email groups, etc. [2-4]. Furthermore, patients—as well as their family members and friends—have come to relate to these environments, partly because of the popularity of Facebook and other social platforms [5]. Sharing experiences may help patients to understand their illness and compare their situation. They possibly learn from others [6], have more access to services, and support better (shared) decisions about health care, such as treatment options [7,8].

Nowadays, there are an increasing number of online health communities, for cancer and other diseases, each with its own specific aims. As a potentially life-threatening illness with a growing number of new patients and survivors [9], cancer can raise a wide range of specific informational and emotional support issues [10]. Also, patients have much experiential knowledge that can be relevant to others. They share such knowledge also in online communities. Through interaction with each other, they not only share experiences and raise awareness for certain issues among themselves but also among health care providers and the research community [11].

Research into (the effects on individuals) participating in online communities can roughly be divided into 2 main variants: first, researchers can ask community participants to complete one or more questionnaires, thereby measuring the effects of participation on the individual; second, researchers can analyze content that has been produced by individuals—a process known as “content analysis.”

In recent years, participation in online cancer communities by patients and their relatives (ie, posters) has become a subject of scientific investigation. We recently reviewed the impact of participation in online communities on patient-reported outcomes (questionnaires) [12]. However, as yet there has been no comprehensive overview of the quality of research into content analysis and subjects shared in cancer communities. Such an overview can be of great added value for patients, community service providers, health care providers, and researchers. They can learn from user-generated content, provided that their content is findable. We did not find any systematic review or study on this subject that has synthesized this information and identified trends across multiple online communities.

In this systematic review, we focus on content analysis of online cancer communities (group spaces) and not on blogs (personal spaces). The definition of content analysis as “a systematic, replicable technique for compressing many words of text into fewer content categories based on explicit rules of coding,” from Stemler’s paper [13], is an adequate starting point. Content analysis is a methodical means of gaining insight into several

key aspects of user-generated content. For example, content analysis clarifies which kinds of information patients share with each other, as well as which characteristics of posters and linguistic aspects may influence the content.

Objectives

The value of content analysis is that it enables people, for example, researchers and patients, to find relevant subjects in texts and to compare such texts with other texts over time. The content can be analyzed using qualitative, quantitative, or mixed methods [14,15]. Qualitative content analysis consists in methodically identifying themes and patterns in text by coding the content [16], whereas the essence of quantitative content analysis is counting words and recognizing patterns on the basis of the word counts, whereby involving context in the analysis, though sometimes difficult, is highly relevant [14,17]. By repeating content analysis in the same environment over a period of time, insight into possible trends can be gained.

In this systematic review, we address the following questions:

1. What is the quality of available research that analyzes user-generated content posted by cancer patients and their relatives?
2. If the quality of research is adequate, what kind of content do posters share with each other on the internet? For example, content of cancer, treatment, personal or emotional information.

Methods

User-Generated Content

For this systematic review, we have included peer-reviewed publications that describe content analysis of participation by posters in online cancer communities. In some cases, the online community is part of a broader online eHealth service, so that participants can also take part in other Web-based activities such as responding to questionnaires or participating in guided online support groups. An example of such a broader online eHealth service is the CHES application (Center for Health Enhancement Systems Studies) with information, social support, and problem-solving tools [18]. The focus of content analysis is not the posters themselves but what they write: their posts, also referred to as “user-generated content” in online cancer communities. Evaluating other forms of Web-based contact (eg, blogs, chat sessions, Facebook posts, and Twitter tweets) is beyond the scope of this review.

Search Strategy

We searched PubMed (MEDLINE), PsycINFO, the Cochrane Central Register of Controlled Trials, and ScienceDirect (the last search being in July 2017) on the following terms: (cancer patient) and (support group or health communities) and (online or internet), without any date parameters. PubMed automatically added the Medical Subject Headings terms (a hierarchically organized terminology for indexing and cataloging of biomedical information) with the synonyms of search terms necessary for a better selection of the PubMed literature. Subsequently, in July 2017, we tried to expand our results with the following additional terms: “online forum” or “message board” or “bulletin

board.” We manually went through the first 100 most relevant results, which did not yield any new papers for this review.

To focus on the subject of our review, we decided that studies would be included according to all of the following criteria: (1) the publication was an original peer-reviewed paper (eg, no systematic reviews, book chapters, dissertations, poster abstracts, editorials, or letters to the editor); (2) it was written in English; and (3) the aim was content analysis of user-generated content of cancer communities. Studies were excluded if one of the following criteria applied: (1) they involved patient populations other than cancer patients and survivors; (2) they studied a structured online health intervention or the community was moderated by professionals; (3) they developed case studies, concepts, or models of content analysis, or (4) they studied patient-reported outcomes as a result of Web-based participation.

These inclusion and exclusion criteria were applied to our initial 1619 papers. After removal of duplicates and records not meeting the inclusion criteria, 121 records remained. Hard copies of these studies were obtained, and these were reviewed by 2 investigators (ME and FM) independently of each other. Both investigators checked the papers in detail on our predetermined inclusion and exclusion criteria. Each made their own decisions, and if they did not agree, they then discussed with each other in order to reach a final decision. Both reviewers also used citation tracking to identify other papers potentially

eligible for inclusion. This did not yield any new records. The 2 investigators agreed with each other on the final selection of papers: 27 were found to be eligible for inclusion in this review. Figure 1 is a flowchart of this selection procedure.

Quality Assessment

Both investigators (ME and FM) assessed the methodological quality of each of the selected studies using a 14-item standardized checklist based on established criteria for systematic review that are presented in Table 1 [19-21]. After reviewing 5 papers, we tailored the criteria list for reviewing papers related to content analysis in cancer communities. Each item of a selected paper that matched our criteria received either half a point or a full point, depending on its importance. This was to prevent items of lesser significance being too heavily weighted. If an item did not meet our criteria or was described insufficiently or not at all, 0 points were assigned. Item 14 would be probably difficult to satisfy for qualitative research papers.

The highest possible score was 9. The papers were then sorted into arbitrarily defined quality categories. Papers scoring 75% or more of the maximum attainable score (≥ 7.0 points) were considered to be of “high quality.” Studies scoring between 55% and 75% (5.0-6.5 points) were rated as being of “adequate quality.” Studies scoring equal to or lower than 55% (≤ 4.5 points) of the maximum attainable score were considered to be of “low quality.”

Figure 1. Flow chart of the literature search.

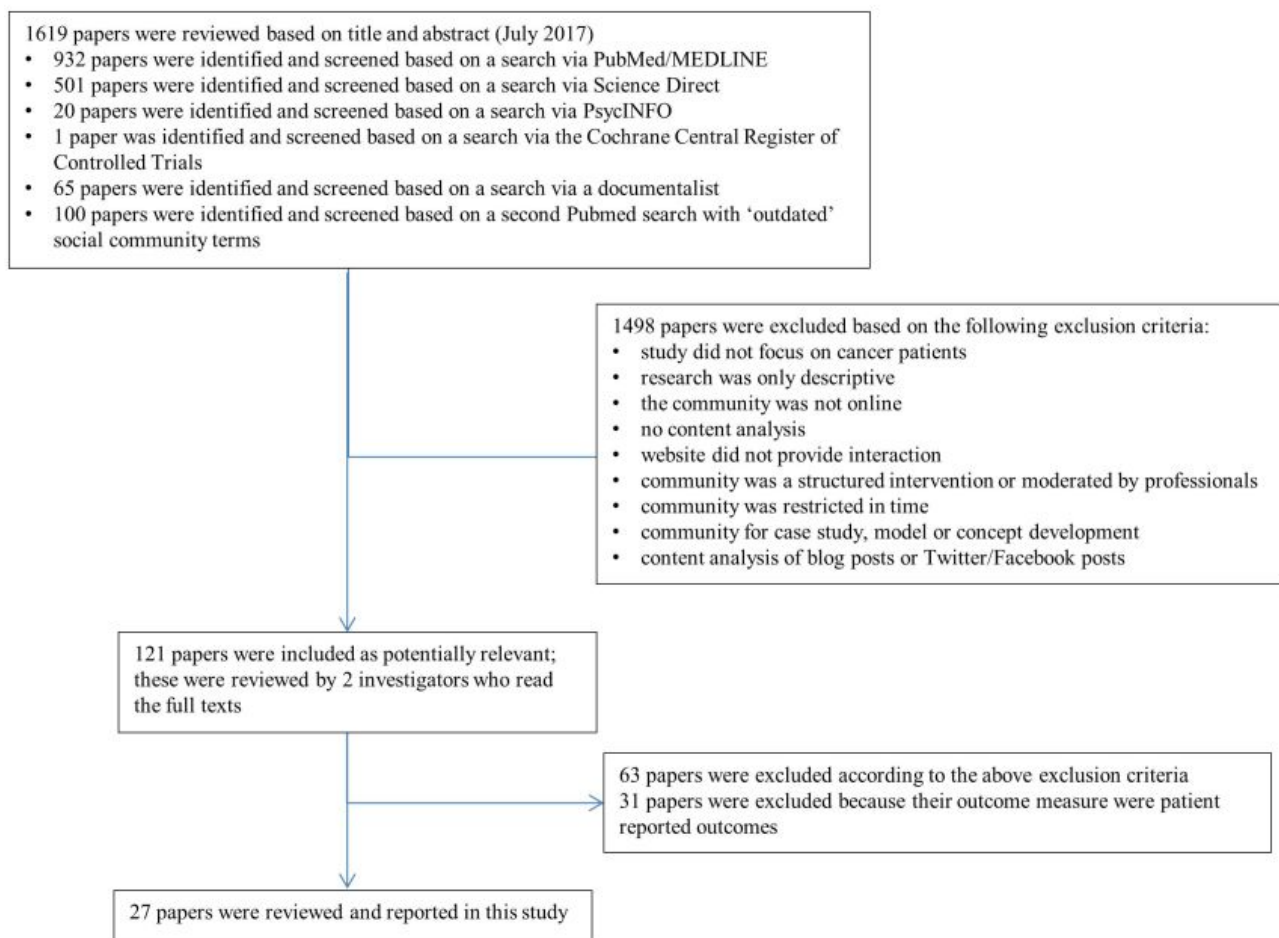


Table 1. List of criteria for assessing the methodological quality of studies.

Item no.	Item	Quality-points
1	Year of data collection is indicated	0.5
2	URL of website(s) or name of platform is indicated	0.5
3	Number of posts is indicated	0.5
4	Number of posters is indicated	0.5
5	A description is included of at least three variables of the community population (health/demographic)	0.5
6	A description is included of at least two community variables	0.5
7	Inclusion and/or exclusion criteria are described	1
8	Participation rates for patients are indicated and there are more than 50 posters	0.5
9	The study size is at least 1500 posts over 2 years (arbitrarily chosen)	0.5
10	The results of 2 or more groups are compared	1
11	The data collection process is described	1
12	The data analysis process is described	1
13	The data are described	0.5
14	Statistical proof for the main findings is reported	0.5
	Total	9

Results

Characteristics and Quality of the Included Studies

On the basis of our inclusion criteria, 27 studies were included in this review [22-48]. The quality scores ranged from 5.0 to 8.5 points, and the overall mean quality score was 6.8. The papers that present a combination of automated and manual analysis methods are of the highest quality (mean quality score=7.4; Table 2).

Of the 27 studies, 16 (59%) were found to be of high quality [24-29,31,37,39,41-44,46-48]. The remaining 11 studies (41%) were found to be of adequate quality [22,23,30,32-36,38,40,45] according to our criteria.

The studies were published between 1998 and 2016—most of them (15) in 2011 or later (Multimedia Appendix 1). The data collection occurred between 1996 and 2013 (Multimedia Appendix 1). Most of the studies (22) were conducted in the United States [23-29,31-37,39-41,43,44,46-48]. With 3 British studies [22,42,45] and 1 Australian [30], there were in total 26 from English-speaking countries (Multimedia Appendix 1).

In 17 studies [25-30,37,38,40,41], the researchers reported on which websites the analyzed content was found. Of those studies, 7 were part of the CHES program [31,32,39,43,44,46,47]. In 2 cases, the researchers determined

that the website URL could not be stated, for reasons of privacy [30,36].

Most studies described the number of posts ranging from about 200 [28] to 1.5 million [48] and the number of posters ranging from 75 [35] to 90,000 [48] (Multimedia Appendix 1). A total of 6 studies analyzed fewer than 1000 posts [22,26,28,33,35,41], and 6 studies analyzed more than 10,000 posts [31,32,40,42,47,48]. The studies analyzing large numbers of posts mainly relate to breast cancer, whereas those analyzing small numbers relate to other types of cancers.

Previous research [12] revealed that most of the active participants in online cancer communities are women, as proved to be the case in the studies included in this review. Among these studies, 11 examined the content only of a breast cancer community [27,31,32,39,41,43-48], 4 studies analyzed and compared posts of breast or prostate cancer communities [24,30,34,42], and one study compared posts about breast and intestinal cancer [40]. In 19 studies (70%), the posters' ages were not given.

A recognized method of analysis is the systematic manual coding of content (ie, written text or spoken word) and retrieval of relevant topics on the basis of that coding in order to enable reporting [49]. Recent computer-based developments have made it possible to automatically analyze texts published on the internet.

Table 2. Mean score by analysis method.

Method of analysis	Mean quality score
All papers	6.8
Manual coding: [22-25,27-30,33-36,38,41,45]	6.6
Automated coding: [26,40,42-44,46,47]	6.9
Combination: [31,32,37,39,48]	7.4

In 15 studies, researchers coded the content only manually [22-25,27-30,33-36,38,41,45]. In 7 studies, researchers used only a computer tool for analysis [26,40,42-44,46,47], and in 5 studies a combination of manual and automatic analysis was used [31,32,37,39,48]. The CHESS authors mainly used Infotrend [31,32,39,46,47] and Linguistic Inquiry and Word Count (LIWC) [43,44], whereas the others used LIWC [26,48], WordSmith [42], and Sandalowski [35]. Portier reported using an algorithm that he devised himself [40]. Meier clearly indicated that he used annual thematic coding (according to ATLAS.ti [50]) but automatically determined the frequency of in-text occurrence [37]. This approach facilitates not only the processing of knowledge of context during coding but also its inclusion in the analyses. Wang et al showed that automatic coding and analysis of a large corpus (>1.5 million posts) is similar in quality to the manual coding of a small corpus, though the former yields more detailed information [48].

Content Posters Share in Cancer Communities

After having listed the characteristics and quality of the included studies, we will now further investigate the findings of the studies.

Most of the authors used their own coding systems to analyze content (Multimedia Appendix 1). Therefore, there was no consistency in the employed codes, their categories, or the coding method. All the authors referred to 2 main categories: *informational* support and *emotional* support. Fifteen studies reported only on the content (ie, what the posters discussed) [23-25,27,30,31,33-36,38,42,43,45,46]. Six studies explicitly referred to social aspects (such as interaction between users) in addition to content [22,28,29,37,39,47]. Six studies focused on emotional changes, mainly as a result of posting and reacting to others' posts [26,32,40,41,47,48]. In these cases, reply posts in reaction to previous posts within the same thread were found to produce an emotional change after some time—usually a positive change. Research by Mursch and Behnke-Mursch [38] showed that 15% of the posts discussed alternative treatment, an aspect that was not referred to in any of the other studies. For example, analysis revealed that fewer words of negative connotation tended to be used in later reply posts. A key question was whether it was reasonable to conclude from this decrease in negatively connoted words that the initial poster, following peer reaction to his or her original post, was feeling more positive.

To summarize, posters shared information on a wide variety of topics. In addition to informational support, often they also provided and obtained emotional support. Posters shared information, opinions, and experiences in relation to aspects, including their illness, the treatment, its side effects and other consequences, the quality of clinicians, alternative treatments, their emotions, and their relationships.

Patient Characteristics

Some of the researchers combined results of content analysis with patient characteristics. Most of the studies that predicted content differences based on characteristics of posters were of high quality. In general, male patients tended to be more oriented toward informational support and female patients more toward

emotional support [24,29,30,42]. In cases where posts by friends and family were separately analyzed on platforms, women tended to be more active than men. Friends and family were more oriented toward informational support than patients were [24,29,30], and in this context there was hardly any difference between men and women. When the patient had an unfavorable prognosis, posters were also more oriented toward informational support than when the patient had a favorable prognosis [25]. Posters who frequently used religious words in their posts had higher functional well-being scores [43]. Namkoong et al [39] found that there was a greater feeling of community “bonding” when people not only read but also wrote content. It should be noted that “being there for others” is extremely important for the sense of well-being. Wang et al [48] asserted that when there was emotional bonding, posters remained active in the community for longer than when there was only informational exchange. His research also showed that posters tended to request informational support directly and emotional support indirectly.

Linguistic Approaches

Some high-quality papers also took a linguistic approach. Shaw et al [44] suggested that posters who more often used the personal pronoun “I” also tended to express negative emotions more often. Seale et al [42], who analyzed word use in offline qualitative interviews with 97 cancer patients (secondary use) and compared these with online posts, found that online posters used a broader vocabulary range than those interviewed offline. In addition, men used a greater variety of words when discussing medical matters, whereas women did so when discussing emotions. Regarding posts by young adults, Crook et al [26] showed that shorter sentences tended to yield more reactions. Use of the personal pronoun “I” yielded more reactions than the use of “we.” Verb tenses were also relevant: posts in future tense tended to have fewer reactions than posts in present or past tenses.

Quality of User-Generated Content

In one study, the quality of user-generated content (correct/incorrect statements in the posts) was an important issue. Esquivel et al's study [27] (of high quality) showed that incorrect advice was given relatively infrequently (10 of 4600 posts, ie, 0.22%) and was corrected quite soon after posting (ie, within 9 min to 9 hours). Esquivel et al can comment on the correctness of content because they had the posts coded by breast cancer experts. Sillence [45] gives another nuance: posters relatively infrequently (9%) made direct requests for advice. More frequently, there were requests for information or a personal opinion (34%), problems were disclosed (35%), or a question was formulated as a “same-boat” experience (20%).

Limitations of Content Analysis

A practical limitation of automated content analysis is probably the “intelligence” of the tools. Counting letters and words is relatively trivial, but in order to generate context-relevant feedback, the tool must combine characteristics of the post and relate them to the coded label. This requires the use of machine learning methods, which must be devised and written by computer scientists in close collaboration with content experts

for the different research areas. Portier et al [40] refer to an algorithm that they used ([Multimedia Appendix 1](#)), whereas Meier et al [37] clearly indicate that they have done the thematic coding manually (according to ATLAS.ti) and have automated the process of determining the frequency of occurrence of certain terms in the text. Most of the papers on automated content analysis did not provide insight into topic lists or content themes. Only Wang et al [48] describe their working method in the greatest detail and offer developed knowledge, including their topic lists. An effectively functioning algorithm that can analyze contextually (in this case, knowledge about cancer and the healthcare system) would represent an enormous advance.

Discussion

Principal Findings

Patients and their relatives increasingly share experiences in online cancer communities, making this a very valuable resource not only for patients but also health care providers, researchers, and healthcare professionals. This paper made a systematic inventory of the kind of information that patients share online and of the methods used by researchers to analyze these user-generated content. We reviewed 27 studies, of which 15 studies were manually coded, 7 automated, and 5 used a combination of methods. The best results can be seen in the papers that used both analytical methods. All the authors referred to two main content categories: informational support and emotional support.

Quality of Research

This review has shown that entirely automatic analysis of user-generated content of cancer posters is still relatively rare. Of the 27 authors [26,31,32,37,39,40,42-44,46-48], 12 analyzed content using an automated instrument of analysis, with or without manual coding. When they used such an automated instrument, they analyzed greater numbers of posts, often more than 10,000.

It is difficult to compare the various methods of analysis, and therefore, also their results. Researchers stated the names of the computer tools (see [Multimedia Appendix 1](#) for methods of analysis and tools, [50-55]) they used but only briefly described how they worked. Some of the automated tools count words; others consider how far words are apart; still others use standardized wordlists and/or categories or make their own wordlists or themes ([Multimedia Appendix 1](#), content themes). The researchers who coded manually mostly analyzed a smaller number of posts with more possibilities of contextual interpretation. The automated analysis gave information about patterns, changes in word use, and communication processes. This diversity of used methods of analysis—manual, automated, or a combination—and code themes ([Multimedia Appendix 1](#)) made it impossible for the reviewers to compare the results, let alone analyze how the type of tool affects the results obtained. We have found very few references to reviews of such tools [56].

Qualitative Research With Professionals Enables Context

Automated analysis of content accuracy seems to us to be almost unfeasible without knowledge of the content. To determine the degree of accuracy, detailed knowledge of the subject area and correct interpretation of the posts is essential, and therefore, it requires that experts are involved in the process. Correct interpretation of the content is still very difficult for the automated analysis systems [14]. Esquivel et al [27] solve this problem by using 3 clinicians, including a breast cancer surgeon, to manually code the posts on accuracy. This methodological intervention enables research into a subject area about which there is much discussion in society. Understandably, some oncologists fear that patients may spread inaccuracies or falsehoods regarding their form of cancer online and thus unnecessarily alarm fellow sufferers. However, Esquivel et al study finds hardly any such inaccuracies or falsehoods [27], probably because people are generally “sensible” and do not request “advice” but information and experiences [45].

When professionals know that the accuracy of user-generated content is feasible, they can refer their patients to online communities. The information is not evidence-based, but it helps individual patients to empower [57] and can probably help to find some information about how others learned to cope with their rare problems [6,57]. There is a possibility for professionals to become a member of the community and share their knowledge. Another possibility is that professionals give answers on patients’ questions such as on [kanker.nl](#) [58]. This content is common knowledge of the total community.

Future Opportunities

The results of this review reveal interesting opportunities, not only for relevant applications that can benefit patients and health care professionals [8] but also for academic researchers. Professionals can learn from patients’ narratives [59,60] and when professionals know that the accuracy of user-generated content is feasible, they can refer their patients to online communities [27]. To make user-generated content discoverable for cancer patients is a challenge. Search engines help patients find information, but the precision on the internet and within a website can be improved. For this, the algorithms have to be improved. User-generated content on the internet gives researchers access to experiences of patients, in a relatively simple way. They can provide insight into how patients deal with their illness over a longer period of time. The collection of data via questionnaires is often time intensive and has mostly a limited number of measurement moments [11].

Automated analysis also enables to compare validated medical information on the internet, with user-generated content on the same topic in discussion groups and blogs, or on Twitter and Facebook [61-63], and find omissions in medical information. Given the large amount of work involved in developing algorithms and their complexity, and in order to prevent knowledge and care institutions from becoming dependent on commercial companies, we think that more interdisciplinary collaboration within academia is highly recommended.

Future Research of User-Generated Content

Content analysis of user-generated content in online communities is an emerging form of academic research. After all, it was not until about 20 years ago that (cancer) patients started sharing information about their illnesses online: for example, in 1995 via mailing lists of Association of Cancer Online Resources or Acor website (only cancer) [64] and in about 2005 in an entirely new way on PatientsLikeMe [65] (on all kinds of diseases). The balance between informational support and emotional support varies between the included studies, though the cause of such variance cannot be explained. To what extent this is due to the research methodology used and/or coding system and/or amount of posts or posters is also unclear. In-depth research is needed to draw conclusions on this matter. For example, we do not know whether content generated by a small community differs from content generated by a large community. Differences in activity of the community can also be understood in terms of different platform focuses. In addition, whether a community is moderated or not can also influence how and about what aspects the participants share.

Limitations of This Study

A limitation of this review is that we compared both qualitative and quantitative research using the same checklist of quality criteria. Especially Q-criterion 14 (statistical proof for main findings reported) is arguably more applicable to quantitative

than to qualitative research (although 6 out of 15 qualitative research method papers did in fact satisfy this criterion).

We did not include papers of other user-generated content types. The body of academic literature includes few publications on analysis of other types of user-generated content such as that of bloggers as well as Facebook and Twitter posters for cancer. They too share experiences that may be relevant to other patients and caregivers. Some of them have many followers, and therefore, also a relatively large impact. Also, sources such as blogs, Facebook, and Twitter can quite easily be incorporated by using automation.

Conclusions

In conclusion, this review found that all included papers are of moderate (11 papers) or high (16 papers) quality. The papers with a combination of manual and automated content analysis are of the highest quality. With increasing number of cancer patients [9] who generate more content on the Internet, it is becoming increasingly important to make that knowledge of patients about their illnesses available to others. For the near future, the mixed method—combination of qualitative and quantitative analyzing methods—gives the best results. Maybe in the future, automated content analysis can be helpful to do this fast and also in an accurate manner.

The results of this review reveal interesting opportunities, not only for relevant applications that can benefit patients and healthcare professionals but also for academic researchers.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Characteristics of the peer-reviewed publications and quality score.

[PDF File (Adobe PDF File), 83KB - [cancer_v4i1e6_app1.pdf](#)]

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Abbreviations

CHESS: Center for Health Enhancement Systems Studies

LIWC: Linguistic Inquiry and Word Count

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Original Paper

Use of Social Media in the Assessment of Relative Effectiveness: Explorative Review With Examples From Oncology

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Abstract

Background: An element of health technology assessment constitutes assessing the clinical effectiveness of drugs, generally called relative effectiveness assessment. Little real-world evidence is available directly after market access, therefore randomized controlled trials are used to obtain information for relative effectiveness assessment. However, there is growing interest in using real-world data for relative effectiveness assessment. Social media may provide a source of real-world data.

Objective: We assessed the extent to which social media-generated health data has provided insights for relative effectiveness assessment.

Methods: An explorative literature review was conducted following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines to identify examples in oncology where health data were collected using social media. Scientific and grey literature published between January 2010 and June 2016 was identified by four reviewers, who independently screened studies for eligibility and extracted data. A descriptive qualitative analysis was performed.

Results: Of 1032 articles identified, eight were included: four articles identified adverse events in response to cancer treatment, three articles disseminated quality of life surveys, and one study assessed the occurrence of disease-specific symptoms. Several strengths of social media-generated health data were highlighted in the articles, such as efficient collection of patient experiences and recruiting patients with rare diseases. Conversely, limitations included validation of authenticity and presence of information and selection bias.

Conclusions: Social media may provide a potential source of real-world data for relative effectiveness assessment, particularly on aspects such as adverse events, symptom occurrence, quality of life, and adherence behavior. This potential has not yet been fully realized and the degree of usefulness for relative effectiveness assessment should be further explored.

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KEYWORDS

social media; relative effectiveness; real-world data; patient reported outcomes

Introduction

Within the context of rising health care costs, limited budgets, and the onslaught of innovative yet expensive medications, the value of health technology assessment (HTA) for decision-makers, regulators, pharmaceutical companies and

patients is becoming increasingly important. HTA is defined as “the systematic evaluation of the properties and effects of a health technology” [1]. Health technologies are defined as “interventions developed to prevent, diagnose or treat medical conditions, promote health, provide rehabilitation, or organize health care delivery” [2]. An important element of HTA is

relative effectiveness, ie, the extent to which an intervention – provided under routine clinical conditions – does more good than harm in comparison to one or more alternatives [1]. Traditionally, a relative effectiveness assessment (REA) conducted directly after-market authorization of a new drug is extrapolated using health outcomes (eg, mortality) obtained from randomized controlled trials (RCTs), which are often considered the gold standard for this type of analysis. However, the tightly-controlled conditions and highly selective patient groups within RCTs may result in findings that are not generalizable to routine clinical settings where patients are more heterogeneous. In routine practice, pregnant women, children, elderly people and patients with comorbidities may eventually receive the new drugs examined in RCTs, while these patient populations are generally excluded from such RCTs. Therefore, researchers may additionally resort to real-world data (RWD) as a supplementary source of evidence to assess relative effectiveness. Real-world data can be defined as “an umbrella term for data regarding the effects of health interventions that are not collected in the context of conventional randomized controlled trials” [1]. Patient registries and electronic health records are established examples of RWD sources, but another potential source of RWD may be social media.

Social media are often used by patients as a source to search for information on their health conditions, share their experiences and find social support [3,4]. For example, many patients use Twitter to stay up to date with the latest health care developments and increase their knowledge on their disease, while Facebook is more often used for social support and exchanging experiences [3]. Social media users who have a chronic condition are more likely to use the internet for such purposes than are healthy social media users [5]. By assessing the content viewed, generated and exchanged by patients through social media, a considerable amount of information on patient perspectives and experiences can be gathered. Although social media have been used for different aspects of research, such as patient recruitment [6-8], dissemination of interventions [9,10] and education [11], little is known about its contribution to REA.

In 2008 a study showed that blogs could be used to collect patient experiences regarding diabetes and diabetes management to provide information for HTA by enhancing the evidence available in published literature [12]. More recently, several pharmaceutical companies have begun to make use of social media to gain insight into patient perspectives on adverse events (AEs) [13,14] and to assess their switching behaviors [15]. Similarly, the Association of the British Pharmaceutical Industry (ABPI) has published guidelines on best practices for the monitoring and management of AEs through such sources [16]. Moreover, the Food and Drug Administration (FDA) is increasingly focusing on the use of health data from social media by collaborating with PatientsLikeMe; a platform where patients can share their health data online to gain insight into patient perspectives on adverse events [17,18]. Considering these initiatives, it may become possible for health data reported by patients on social media to contribute to the REA of new therapies.

The aim of this article is to assess the extent to which health data generated from social media have provided insights for REA. We conducted an explorative review to identify examples in oncology where health data were collected using social media. Oncology was chosen due to the considerable number of innovative drugs being developed at a rapid pace in this area. For example, the European Medicines Agency reported in 2015 that one-third of the medicines with a new active substance recommended for market access were for cancer treatment [19]. As mentioned earlier, REAs of drugs are traditionally based on health outcomes such as overall survival and progression-free survival. However, considering the often-marginal differences in overall survival and progression-free survival for oncological drugs, information on AEs, adherence and quality of life is becoming even more important in REA [20]. Collecting these aspects from RCTs can be difficult, therefore other data sources such as social media may be useful. For the purposes of this explorative review, social media were defined as “a group of Internet-based applications that allow the creation and exchange of user-generated content” [21].

Methods

An explorative review was performed based on the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines [22]. To identify scientific literature, a search for peer-reviewed published articles was carried out in MEDLINE through the PubMed interface for the period between 1 January 2010 and 28 June 2016. The following search query was used: *(Facebook[tiab] OR Twitter[tiab] OR blog[tiab] OR blogging[mesh] OR “social media”[tiab] OR ehealth[tiab] OR e-health[tiab] OR “online community”[tiab] OR “online communities”[tiab] OR “online patient”[tiab] OR “health data”[tiab] OR (online [tiab] AND research[tiab] AND platform*[tiab]) OR (personal*[tiab] AND health[tiab] AND record*[tiab]) OR (online[tiab] AND patient[tiab] AND communit*[tiab]) OR (online[tiab] AND data[tiab] AND shar*[tiab])) AND (oncolog*[tiab] OR cancer[tiab] OR carcinoma[tiab] OR metast*[tiab] OR neoplasms[mesh] OR melanoma[tiab] OR tumor[tiab] OR tumour[tiab])*. The reference lists from the literature, which were included based on title and abstract, were hand-searched to identify additional literature. To extend the literature search, the top four health informatics journals according to SCImago Journal and Country Rank [23] were included, namely GigaScience, BMC Medical Research Methodology, Open Bioinformatics Journal, and Journal of Medical Internet Research. The websites of these health informatics journals were hand-searched by assessing theme issues and by using the following keywords: “oncology, cancer, carcinoma, metastasis, neoplasm, tumor, tumour, blog, blogging, social media, e-health, online or health data”.

A Google search was conducted in July and August 2016 to identify grey literature, such as relevant websites, by combining the following keywords: “social media”, “online patient”, “online research platform”, “relative effectiveness”, “health research”, “effectiveness research”, “pharmacovigilance”, “adherence”, and “to measure quality of life”. Before each search, the history of the browser was cleared to ensure findings would not be influenced by previous search queries. Due to the

vast number of websites retrieved through the Google search, only websites that collect health data online, focus on patient-reported outcomes, or provide online information on drugs and conditions were deemed relevant for further analysis. The selection of relevant websites was also based on consensus between the authors RK and Rth. These websites were hand-searched to identify grey literature by browsing through the website in search of relevant reports or documents and by using the following keywords: “social media”, “internet”, “Facebook”, “Twitter”, “pharmacovigilance” or “health research”. These keywords were different from those used for the Google search due to the character of the platform (ie, a Google search is inherently different from searching a website). The following websites were included: PatientsLikeMe, Microsoft HealthVault, Dossio, CureTogether, WhatNext, MyGly, Drug Information Association, WEB-RADR, National Patient-Centered Clinical Research Network, College ter Beoordeling van Geneesmiddelen, Handle My Health, European Alliance for Personalized Medicine, Lareb, WHO Monitoring Centre for Pharmacovigilance Uppsala, PEW Research Center, Social Media Research Foundation, Treato, MediGuard, Healthy.me, and iVitality.

The review was conducted by four reviewers (RK, AM, Rth and KM) and the resulting literature was independently screened by the reviewers for eligibility. The titles and abstracts from scientific literature were assessed by RK, AM and KM, while grey literature was assessed by RK and Rth. Literature was considered eligible for inclusion when it was: 1) published between 1 January 2010 and 28 June 2016, 2) available in English, 3) examples were provided where social media were used to collect health data, 4) literature focused on cancer or cancer treatment, and 5) literature was either a peer-reviewed original research article or a report that was available in the public domain. We excluded literature that did not meet all inclusion criteria. Relevant full articles and reports were retrieved and reviewed for inclusion.

Two reviewers (RK and AM) independently extracted data from all included articles and reports using a predefined data abstraction form. Information on study characteristics (eg, study design, study period, type of social media used), and the strengths, limitations and acceptability of using social media to generate health data were extracted. Disagreements in data extracted were resolved by consensus amongst RK and AM.

A descriptive qualitative analysis of the extracted data was carried out, since the topics, methods and outcomes of included literature were notably diverse.

Results

A total of 2351 citations were identified from scientific literature (n=879), a hand search of reference lists from scientific literature (n=56), grey literature (n=97), and a hand search of health informatics journals (n=1319). From these, a total of 2290 citations were excluded based on title or abstract, additionally 26 duplicates were excluded. Of the 35 full scientific publications and documents assessed, 27 were excluded: 15 citations did not provide an example of health data collection, 9 were not oncology-specific, and 3 provided insufficient

information on the collection of health data. Data were abstracted from a total of 8 scientific publications (Figure 1).

Table 1 provides an overview of the eight scientific publications included. Different types of cancer and medications were assessed in each of the publications. The focus of all eight articles was testing the feasibility and added value of generating health data from social media, such as AEs, QoL, adherence, symptom occurrence and experience from social media.

Table 2 shows that publications differed substantially in study design, study period, the number of posts analyzed and the number of respondents included in the analysis. Forum topics and discussions were assessed in four papers, in two studies a survey was posted on the Facebook page of either a patient community or support group, in one study Twitter conversations were assessed and in one study an online patient platform was used to disseminate a survey. Of the eight studies, a total of four studies collected health data on AEs [24,25,28,30]. More specifically, three of these publications presented the AEs identified on the forums included [24,28,30], while the fourth publication focused on comparing AEs mentioned online to AEs reported to the FDA [25]. Another three studies collected health data on quality of life (QoL) [26,27,31]. Each study used different QoL instruments, such as the Concerns About Recurrence Scale scores [31], and short form-36 health survey [26]. Finally, one study focused on identifying symptom (co-) occurrence [29]. In addition to the main outcome measures, van der Heijden et al, McCarrier et al, and Zaid et al [26,27,31] collected data on socio-demographic factors and disease specific characteristics. Furthermore, Beusterien et al collected health data on physical functioning and emotional impacts [24], and Mao et al collected information on adherence by mapping decisions about continuing or stopping treatment [28].

The four publications that used forums to collect health data varied substantially in the explanation for their forum selection (Table 3). For example, Beusterien et al used two search engines and two different computers for their forum search which they repeated every other day for two weeks. Additionally, they used selection criteria to include the two forums (ie, site active >5 years, >12,000 posts on forum, >20 individuals currently browsing, and >10 new posts per day) [24]. Meanwhile, Marshall et al selected one forum without clarifying selection criteria for the selected forum [29]. The other four publications, making use of Twitter, Facebook or an online patient platform, selected this social media platform due to the access of a large volume of health data [25] or access to a patient community [26,27,31].

Regarding the use of automated processes to collect health data from social media, two publications specifically indicated to have used a web crawler [28,29] and one publication made use of the Twitter application programming interface [25]. Two of the included publications indicated to have collected all the forum posts related to search terms without specifically indicating the collection method used [24,30] and three publications used the social media platform to distribute a survey [26,27,31]. Automated techniques were used by Freifeld et al, Mao et al and Marshall et al to analyze the health data collected [25,28,29]. Freifeld et al used a tree-based dictionary-matching

algorithm to identify specific text from the forum posts collected, and furthermore used a Natural Language Processing (NLP) semi-automated classifier was used to identify AEs [25]. Mao et al also used NLP to identify AEs [28], and Marshall et

al used NLP in a data mining algorithm to identify symptoms [29]. The remaining five publications made use of content analysis [24,27], descriptive or quantitative analysis (eg, chi-squared test) [26,31], or labelled forum posts manually [30].

Figure 1. Flowchart of the literature review process.

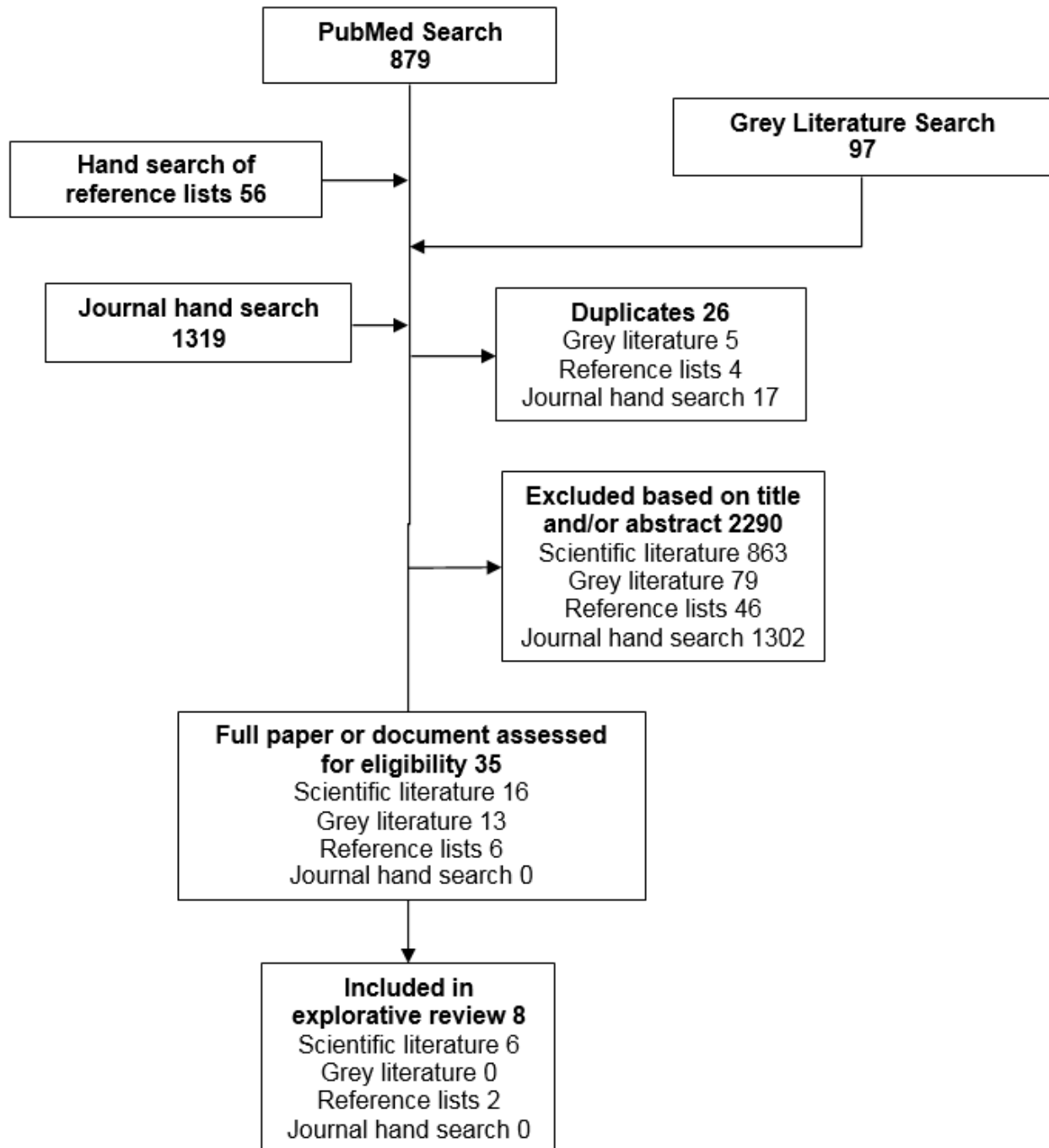


Table 1. Overview of included scientific publications.

Study	Aim	Cancer Type	Drug
Beusterien et al 2013 [24]	To better understand patient experience with colorectal cancer chemotherapies in the real-world setting	Colorectal cancer	Chemo-therapeutic agents
Freifeld et al 2014 [25]	To evaluate the level of concordance between Twitter posts mentioning AE ^a -like reactions and spontaneous reports received by a regulatory agency	N/A ^b	Methotrexate ^c
van der Heijden et al 2016 [26]	To investigate whether we could use crowdsourcing via Facebook and online surveys for medical research purposes on pigmented villonodular synovitis	Pigmented villonodular synovitis	N/A
McCarrier et al 2016 [27]	To explore the feasibility of using social media-based patient networks to gather qualitative data on patient-reported outcome concepts relevant to chronic lymphocytic leukaemia	Chronic lymphocytic leukaemia	N/A
Mao et al, 2013 [28]	To understand frequency and content of AE's and associated adherence behaviors discussed by breast cancer patients related to using aromatase inhibitors	Breast Cancer	Aromatase inhibitors
Marshall et al, 2015 [29]	To identify and examine symptom patterns generated by data extracted from a breast cancer forum, and compare these findings to an analysis of symptoms reported by breast cancer survivors enrolled in a research study and who responded to a symptom checklist	Breast Cancer	N/A
Pages et al, 2014 [30]	To describe the characteristics of AE's reported by patients exposed to oral antineoplastic agents in an online discussion, and compare these with those reported by health professionals as recorded in the French pharmacovigilance database	Cancer	Oral antineoplastic agents
Zaid et al, 2014 [31]	To determine the feasibility of using social media to perform cross-sectional epidemiologic and quality of life research on patients with rare gynaecologic tumours	Neuroendocrine carcinoma of the cervix	N/A

^aAE: adverse events.

^bN/A: not applicable.

^cThis study assessed adverse events reported in social media for a total of 23 drugs and 4 vaccines, including 1 drug (methotrexate) specific for oncology.

In [Table 4](#) the strengths and limitations of health data generated through social media that were identified in the eight included publications are presented. Five publications identified the ability to assess patient perspectives as an important strength [24,25,28-30]. The ability to access patients who have rare diseases or are distributed over wide geographic areas was considered a major strength by five publications [26-29,31]. Furthermore, Freifeld et al, Marshall et al and Pages et al emphasized that social media should complement conventional (pharmacovigilance) methods, since a difference between results from social media and conventional methods may be present [25,29,30]. For example, patients were shown to report different AEs compared to health professionals who traditionally provide this information [30]. Other strengths identified included the efficient collection of patient-reported outcomes [24], the short time-period needed to survey patients [29,31], and the identification of new or unlabelled AEs [30].

Limitations of social media-generated health data mainly focused on validating authenticity, selection bias, information bias, and the inability to actively probe patients for responses. Validating authenticity focuses on the difficulty of verifying the accuracy of information provided through social media [26,29], such as verifying whether posters have the disease [27,31] or are indeed on the drugs [24,27] they discuss. Regarding selection bias, publications reported differences in the patient population that use social media compared to those who do not; for example, patients using social media are

conventionally more highly educated [24,29], are more likely to be female [26,27], may have a different symptom experience [28], and are generally younger [27,29,31]. With regards to information bias, Freifeld et al and Pages et al reported duplication of posts [25,30], Mao et al reported multiple posts by the same patients [28], and Freifeld et al indicated that patients may not identify AEs correctly [25]. Finally, several publications mentioned the inability of using social media to actively probe patients for responses [24,27,29]. For example, patients may use alternative wording than that which researchers anticipate, which could lead to misclassifying symptom experiences [29].

Regarding the acceptability of using social media to generate health data, Pages et al indicated that pharmaceutical companies are already using this type of data to gather information on AEs from patient perspectives [30]. Furthermore, Beusterien et al indicated that in patient-reported outcomes research, patient perspectives are commonly accepted with regards to disease and treatment impact [24], and both Freifeld et al and van der Heijden et al noted the importance of insights into the patient perspective provided by social media research for regulatory authorities [25,26]. However, Freifeld et al was also cautious on the use of social media to generate health data [25]. Reasons for their caution was the need to still establish its role in pharmacovigilance as social media are not yet used in routine surveillance. Additionally, they indicated that data acquisition from social media and automation need to be improved.

Table 2. Study characteristics of included scientific publications that use social media to collect health data.

Study	Study design	Study period	Posts analysed	Respondents	Type of social media used to collect health data	Type of health data collected
Beusterien et al 2013 [24]	Cross-sectional	52 days	1522	264	2 disease-specific forums	Adverse events, physical functioning & emotional impacts
Freifeld et al 2014 [25]	Retrospective	7 months	6,900,000	N/A ^a	Twitter	Adverse events
van der Heijden et al 2016 [26]	Prospective	70 months	N/A	272	Facebook (patient community)	Socio-demographic factors, disease-specific characteristics ^b , functional outcome, and QoL ^c
McCarrier et al 2016 [27]	Cross-sectional	4 months	N/A	50	Online patient platform	Socio-demographic factors, disease-specific characteristics ^d , experience of symptoms, perceptions about treatment, and QoL
Mao et al 2013 [28]	Retrospective	8 years	1,235,400	N/A	12 disease-specific forums	Adverse events and adherence
Marshall et al 2015 [29]	Retrospective	8 years	50,426	12,991	1 disease-specific forum	Symptom occurrence, co-occurrence, and similarity index of 25 preselected symptoms.
Pages et al 2014 [30]	Retrospective	1 year	111	66	5 health forums	Adverse events
Zaid et al 2014 [31]	Cross-sectional	30 days	N/A	57	Facebook (support group)	Socio-demographic factors, disease-specific characteristics ^c , and QoL

^aN/A: not applicable.

^bDisease-specific characteristics include clinical presentation, findings on imaging and biopsy material, type and localization of disease, surgical and adjuvant treatment, local recurrences, and post-operative complications.

^cQoL: quality of life.

^dDisease-specific characteristics include self-reported current chronic lymphocytic leukaemia stage, performance status, and past and current treatment.

^eDisease-specific characteristics include clinical presentation, initial work-up, treatments, past and current disease status, follow-up, and recurrence pattern.

Table 3. Selection of social media platform and use of automated techniques by included literature that use social media to collect health data.

Study	Clear explanation for selection of social media platform	Web crawler used for collecting social media health data	Automated technique used for analysis of health data
Beusterien et al 2013 [24]	Yes	No	No
Freifeld et al 2014 [25]	Yes	No ^a	Yes
van der Heijden et al 2016 [26]	Yes	No ^b	No
McCarrier et al 2016 [27]	Yes	No ^b	No
Mao et al 2013 [28]	Yes	Yes	Yes
Marshall et al 2015 [29]	No	Yes	Yes
Pages et al 2014 [30]	Yes	No	No
Zaid et al 2014 [31]	Yes	No ^b	No

^aThe Twitter application programming interface (API) was used to identify relevant tweets.

^bA survey was distributed via the social media platform.

Table 4. Strengths and limitations specific to the use of social media to generate health data.

Study	Strengths	Limitations
Beusterien et al 2013 [24]	Patient perspective; efficient and comprehensive collection of PROMS ^a	Validating authenticity: selection bias; no active probing of patient responses; incomplete information of sample
Freifeld et al 2014 [25]	Patient perspective; complementary to pharmacovigilance; rapid information on AEs ^b	Information bias; volume of posts; noisy data
van der Heijden et al 2016 [26]	Access to patients with rare diseases; collection of PROMS; convenient to fill in; long-term follow-up	Validating authenticity; selection bias; low participation rate
McCarrier et al 2016 [27]	Alternative approaches to qualitative data collection; support development of PRO ^c instruments; access to patients with rare diseases; motivated patients; lower costs per enrolled patient	Validating authenticity; selection bias; no active probing of patient responses; not achieving concept saturation; larger sample sizes needed
Mao et al 2013 [28]	Patient perspective; access to patients distributed over wide geographic areas; increased generalizability due to more diverse patient population; observed frequency key AEs reflected those reported in traditional studies	Selection bias; information bias; frequency data is not an indication of prevalence AEs
Marshall et al 2016 [29]	Vast quantities of data; easily accessible information; short time-period; access to patients with rare diseases; low costs; patient perspective; complementary to traditional studies	Validating authenticity; selection bias; noisy data; no active probing of patient responses; incomplete information of sample; data quality or format inadequate; ethical considerations; misinterpretation of posts
Pages et al 2014 [30]	Patient perspective; complementary to pharmacovigilance; identification new or unlabelled AEs	Information bias
Zaid et al 2014 [31]	Access to patients with rare diseases and that are distributed over wide geographic areas; short time-period; motivated patients	Validating authenticity; selection bias

^aPROMS: patient-reported outcome measures.

^bAE: adverse event.

^cPRO: patient-reported outcome.

Discussion

This explorative review demonstrates that, within the field of oncology, social media could be used for assessing AEs by collecting health data from forums and to evaluate QoL through Facebook or online patient platforms. Social media provides an opportunity to efficiently assess patient perspectives and collect health data from patients with rare diseases that are distributed over wide geographic areas. However, validating the authenticity of health data from social media is difficult, and is prone to selection and information bias. Furthermore, this type of data should be used complementary to traditional forms of research. Finally, this review provides additional insights, compared to reviews that focus on social media to inform pharmacovigilance [32,33], by focusing on the use of social media to inform relative effectiveness assessments.

Arguably, the results found in this review on social media-generated data in oncology may not be generalizable to other fields of medicine, since different types of health data, social media or analysis may be of importance in other fields of medicine. However, many studies conducted in fields of medicine other than oncology similarly focused on identifying AEs [32-38], suggesting our results are at least partially generalizable. Although little is known about assessing QoL through social media in other fields of medicine, there is potential for this mode of health data collection since QoL is often difficult to measure in RCTs and observational studies

[20]. Finally, as our results show, another aspect of relative effectiveness that may be assessed through social media is treatment-switching and adherence behavior. A few pharmaceutical companies have been assessing this aspect already, thus demonstrating its potential [14,15,39]. Given the possibility of social media to generate data on AEs, QoL, and treatment-switching and adherence behavior, there is a great potential for social media-generated health data to enrich REA by incorporating information on these aspects.

One caveat of using social media to collect health data that requires special attention is the lack of clear methodological guidance. Standardized approaches to collecting health data from social media are necessary to ensure comparability and reproducibility between studies. For example, posts may either be extracted manually or by automated processes. The interpretation of these posts could also be done manually or by automated processes. However, some argue that automated processes may be unable to successfully interpret sarcasm in text posted on social media [25], while others argue that automated natural language processing could assist in analyzing the vast amounts of data available on social media [33,40,41]. Another methodological issue involves the use of correct search terms, as posts may include misspellings, non-medical terms, and slang [25,33,42]. Additionally, several studies reported important methodological limitations to consider when assessing data from social media, which include validating authenticity (eg, posts may be not genuine) [43-45], selection bias (eg, social media users may differ in age, gender, ethnicity and physical

location compared to non-users) [42,44,45] and information bias (eg, patients may be taking a specific drug but fail to report the drug or its effects) [43,45]. To manage these methodological limitations, it is important to systematically assess the risk of bias to determine the quality of the health data collected through social media. Extracting relevant health data from social media may be difficult and challenging due to the issues described above. Clear and uniform methodological guidance may improve the extraction, interpretation and subsequent use of social media to collect health data. An additional caveat that may hamper the use of social media for collecting health data for REA is the perceived risk of easy manipulation. A recent example of manipulation in social media was the circulation of fake news on social media during the 2016 elections in the United States of America [46-48]. These kind of examples affects the ability of social media users to discern what is true and correct information. However, although manipulation may occur, many still use social media to find information and to exchange experiences. Therefore, harnessing and analysing the vast amount of health data available on social media remains important.

Although caveats can be recognized in the use of social media-generated health data, the added value of collecting information on patients' perspectives and experiences towards relative effectiveness (eg, AEs, quality of life, switching-behavior) should be highlighted. For example, health data collected through social media may uncover AEs that occur after long-term use of new drugs, or they may detect AEs earlier compared to traditional methods [44,49], or provide insights that are not available in published literature (eg, diabetes patient experiences with laser therapy) [12]. Additionally, social media may be a better source to identify AEs that are mild or symptom-related compared to more traditional methods [44]. However, health data collected through social media should be used in conjunction with traditional methods to ensure the collection of a comprehensive overview of aspects that can provide information for REA.

Important for the comprehensiveness of this review is that we assessed both academic and grey literature, which minimizes the possibility of missing important insights. Additionally, we ensured the quality of the review through data abstraction conducted by two authors, which allowed a better substantiation of deductions made.

One limitation of this review was the focus on oncology, which may have resulted in missing literature on other aspects related to REA that could potentially be collected using social media. For example, PatientsLikeMe, an online patient platform that allows patients to share health data or exchange experiences on conditions and medications, published a few studies on the effectiveness of off-label drug use [43,50]. Additionally, PatientsLikeMe published a study focused on assessing the impact of menopause on disease severity in patients with multiple sclerosis. [51] These types of data may contribute to providing information for REA. The focus on oncology in this review was deemed appropriate since many new drugs are developed in the field of oncology, studies that assess these new drugs can be small and incomplete, and the European Medicines Agency and the European Network for Health Technology Assessment are also putting focus on the assessment of oncological drugs.

A second limitation relates to the search strategy employed in this explorative review. Firstly, the broad definition of social media that was used in this review may not allow for differentiating between passively collecting data (eg, by collecting posts from a forum) and actively collecting data (eg, by posting a survey on Facebook). There may be a difference in the information available from passively collecting information that patients discuss and post on social media, compared to actively posing questions to these patients in a survey. Secondly, by employing one database for our scientific and grey literature search we may have missed studies published in relevant journals that are not indexed by PubMed or grey literature that was not identified by the Google search engine. To overcome this limitation to some extent, we hand-searched the reference lists of included studies, based on title and abstract, and identified a few articles that had not been captured in the PubMed and Google search.

Social media may be a potential source of RWD for REA, particularly on aspects such as AEs, occurrence of disease-specific symptoms, adherence behavior, and QoL. This potential has not yet been fully realized due to methodological limitations that accompany social media-generated health data, like information bias and selection bias, as well as the limited acceptability of such data. However, the degree of usefulness of such data for relative effectiveness assessment should be further explored. Moreover, methodological guidelines and tools should be developed to address the limitations mentioned above.

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Conflicts of Interest

None declared.

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Abbreviations

HTA: health technology assessment
NLP: Natural Language Processing
QoL: quality of life
RCT: randomized controlled trial
REA: relative effectiveness assessment
RWD: real-world data

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Viewpoint

Patient-Centered Mobile Health Data Management Solution for the German Health Care System (The DataBox Project)

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Abstract

This article describes the DataBox project which offers a perspective of a new health data management solution in Germany. DataBox was initially conceptualized as a repository of individual lung cancer patient data (structured and unstructured). The patient is the owner of the data and is able to share his or her data with different stakeholders. Data is transferred, displayed, and stored online, but not archived. In the long run, the project aims at replacing the conventional method of paper- and storage-device-based handling of data for all patients in Germany, leading to better organization and availability of data which reduces duplicate diagnostic procedures, treatment errors, and enables the training as well as usage of artificial intelligence algorithms on large datasets.

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KEYWORDS

medical informatics; health data management

The development of intelligent storage, sharing, and analysis solutions for health care data has evolved over the recent years [1-4]. DataBox is a research project based in Germany and funded by the federal ministry for health as well as the federal ministry for education and research. It aims at improving health data management for patients and health care providers by creating a platform that is accessible from landline phones, computers, mobile phones, and tablets. DataBox provides individual data spaces for storage, analysis, and sharing of health data. The collaborating partners are the National Center for Tumor Diseases in Heidelberg (project lead), Köln University Hospital, Charité University Hospital in Berlin, and the German technology companies SAP and Siemens Healthineers. The ethics committees of the three collaborating centers approved the project.

Currently, patients in Germany receive a printed report by their physician at the end of their stay, often accompanied with other sheets of paper, compact disks, or other physical storage devices

containing diagnostic data such as radiological files. Patients are expected to manually carry all this information with them when switching health care providers. This status quo often leads to loss of data, duplicate diagnostic procedures, and treatment errors as well as a lack of instant access to available health data for patients not only during a hospital stay, but also in acute care situations. This lack of data is not only caused by patients losing some of these printed reports, disks, or storage devices or not bringing them to their new care provider, but also due to incompatibility of provided file types between health care providers.

DataBox aims at solving these problems by providing individual data spaces which are accessible for patients of all levels of digital literacy (from landline phones to smartphone devices). Patients can instantly access their individual health data as soon as it is available and share it with selected health care providers of their choice. At the same time, health providers can use the

platform to upload health data and to open shared patient data with an integrated format-agnostic viewer.

The digital format of the data enables the training as well as usage of artificial intelligence algorithms on large datasets, ultimately increasing the understandability and value of digitalized health care data for the patient. Machine learning, and more specifically, deep learning algorithms for supervised and unsupervised data analysis, are on the rise in the medical field [5-20] and may be enhanced in their precision by large organized datasets.

The need to give citizens back the control of their data is the current task for health care according to the General Data Protection Regulation [21]. DataBox not only improves access by instantaneously synchronizing the health data in a secured cloud with individual data spaces but also lets the patient choose who may access it.

In the first 18 months (starting in January 2018), the DataBox project will focus on 4,000 lung cancer patients from Germany. However, the vision of the initiators of this government funded project is to replace the status quo as outlined above for the whole German health care system after the 18-month test period.

Authors' Contributions

TJB is the technical lead of the DataBox project and the Head of App Development at the National Center for Tumor Diseases (NCT). SR is the current project manager, DR is the former project manager and CK is the initiator of the DataBox project and Head of the Department of Translational Oncology at the NCT which has the project lead.

Conflicts of Interest

None declared.

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Original Paper

Toward Timely Data for Cancer Research: Assessment and Reengineering of the Cancer Reporting Process

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Abstract

Background: Cancer registries systematically collect cancer-related data to support cancer surveillance activities. However, cancer data are often unavailable for months to years after diagnosis, limiting its utility.

Objective: The objective of this study was to identify the barriers to rapid cancer reporting and identify ways to shorten the turnaround time.

Methods: Certified cancer registrars reporting to the Indiana State Department of Health cancer registry participated in a semistructured interview. Registrars were asked to describe the reporting process, estimate the duration of each step, and identify any barriers that may impact the reporting speed. Qualitative data analysis was performed with the intent of generating recommendations for workflow redesign. The existing and redesigned workflows were simulated for comparison.

Results: Barriers to rapid reporting included access to medical records from multiple facilities and the waiting period from diagnosis to treatment. The redesigned workflow focused on facilitating data sharing between registrars and applying a more efficient queuing technique while registrars await the delivery of treatment. The simulation results demonstrated that our recommendations to reduce the waiting period and share information could potentially improve the average reporting speed by 87 days.

Conclusions: Knowing the time elapsing at each step within the reporting process helps in prioritizing the needs and estimating the impact of future interventions. Where some previous studies focused on automating some of the cancer reporting activities, we anticipate much shorter reporting by leveraging health information technologies to target this waiting period.

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KEYWORDS

neoplasms; registries; SEER program; workflow; computer simulation; data collection; epidemiological monitoring

Introduction

Data Quality in Cancer Registries

Despite multiple reports from the National Academy of Medicine (NAM; formerly Institute of Medicine) dating back to 1999, achieving higher quality cancer care remains a challenge [1]. In its latest report, the NAM recommended leveraging health information technologies to create a Rapid Learning System in which the latest evidence and knowledge regarding cancer case outcomes is fed back into cancer care delivery processes and treatments [1]. One specific recommendation is to leverage cancer registries together with electronic health record (EHR) systems to enable timely capture and reporting of data [2,3]. Current approaches can take more than a year after diagnosis before data are available at state-based cancer registries for wider use [4]. Despite the rich data available in cancer registries, the lengthy reporting time poses a major barrier to using these data for real-time, actionable outcome and quality reports [1-5].

Understanding Cancer Reporting Process

There is limited evidence on the reporting process, the barriers to more rapid reporting, or precisely how EHR systems might be used to improve timeliness. Existing studies largely examine factors associated with the timeliness of cancer data [6-10]. For example, a study in the first group by Gagen and Cress investigated the association between reporting delays and gender, race, type of reporting facility, cancer site, and stage at diagnosis [10]. Of these factors, the type of reporting facility (eg, hospital, physician's office, and laboratory) was associated with reporting time; cases reported by hospitals had shorter reporting times compared with those reported by physician offices or laboratory centers [10]. At least one prior study focused on EHR systems' impact on cancer registries. Among a convenience sample of cancer registrars, Houser et al asked attendees at a conference whether they used EHR systems to access data, as well as their perceptions of the benefits and challenges associated with EHR usage [11]. Although this study found that EHR systems were being used and viewed favorably by the majority of sampled conference attendees, the study did not provide detailed insights into the sequence of reporting tasks or the workflow efficiency.

While providing an important foundation, prior research has not described the precise challenges associated with the sequence of steps involved in the cancer reporting process or potential solutions to address specific challenges. Cancer reporting is complex, labor-intensive, and typically performed by certified cancer registrars referred to as certified tumor registrars (CTRs). Registrars are data information specialists who capture the complete medical history for cancer patients including diagnosis, treatment, and health status and then report this information to cancer registries [12]. Cancer registrars must compile patient data from various sources, analyze these data, and enter the data into a complete, uniform abstract. These abstracts must then be transmitted along a reporting chain spanning hospitals, state health agencies, and the national Centers for Disease Control and Prevention (CDC). Reporting turnaround time is largely dependent upon the activities

performed at the hospital level by cancer registrars such as data searching, collection, and abstraction. Reduction in the reporting time cannot be achieved without a comprehensive understanding of the reporting workflow and challenges faced by CTRs at the hospital level. To address similar challenges, many studies have shown the value of workflow evaluation in navigating the complexity of health care systems. Workflow evaluation has been used in health care settings such as emergency departments, primary care, pharmacy, and radiology departments [13-17]. These studies commonly utilize some combination of field observations and in-depth interviews. Although field observations can reveal details that users might overlook, in-depth interviews can provide a deeper understanding of the processes and tasks involved, such as task descriptions, alternative routes, the rationale for given choices, and the difficulties encountered.

To investigate the reporting process and identify barriers to timely reporting, we conducted key informant interviews with CTRs across the state of Indiana. Insights from the interviews were translated into input for simulations of the reporting process to explore ways that the reporting time could be decreased. In addition, the study explored ways in which EHR systems and health information exchange (HIE) could be leveraged to improve cancer reporting data timeliness.

Methods

Study Design

To better understand the complex processes involved in cancer case reporting, we conducted a multi-phase study. First, we interviewed cancer registrars to identify barriers to timely reporting and developed a model of current reporting processes. Second, we developed computer simulation models to represent the current state and a potential, redesigned future state. The outputs of the two simulations were compared to determine the impact of health information technology innovations, including the use of EHR systems that might be implemented to increase the speed of cancer case reporting processes. The study was approved by the institutional review board at Indiana University.

System and Scope

In the United States, all 50 individual states have programs for cancer surveillance, involving the routine collection and compilation of specified clinical and demographic information about every newly diagnosed, reportable cancer [18,19]. Hospitals report cancer cases to state-level registries operated by public health authorities, which in turn report to nationwide registries to enable population-based analysis. Cases received by state registries are reported to the Surveillance, Epidemiology, and End Results program operated by the National Cancer Institute and/or the National Program of Cancer Registries operated by the CDC [18-23].

In this study, we examine the US state-level cancer reporting process by interviewing CTRs who report on behalf of hospitals to the Indiana State Department of Health (ISDH) cancer registry. The ISDH cancer registry collects information related to tumor cases diagnosed or treated within the State of Indiana as required by state law or federal regulations [22].

The information obtained by the ISDH cancer registry includes demographic, treatment, and diagnostic data that are used for a wide range of activities, including epidemiologic studies of cancer causes and outcomes that can inform public health policies [22].

Study Participants and Recruitment

In this study, recruitment was limited to CTRs who report case information to the ISDH cancer registry. Participants were invited to participate in either face-to-face or telephone interviews. Participants were identified through hospital staff directories and the Indiana Cancer Registrars Association. When recruiting participants, we directly contacted registrars reporting for larger hospitals (with 300 beds or more) within Indianapolis. To include registrars reporting for smaller hospitals and individual facilities, registrars from the Indiana Cancer Registrars Association directory were invited via email. Nonrespondents were reminded 2 weeks after the initial invitation. Snowball sampling, wherein initial contacts identify other individuals who may have insight into the topics of interest, was also used to expand the number of participants.

Recruitment occurred over a 5-month period between the end of March and August 2015. The recruitment process was concurrent with the development of the workflow and simulation models to validate model assumptions and compare the simulation output with the real system. Participants were identified and approached until saturation was achieved [24], that is, until no new themes or ideas were found. Upon completion of the interview, participants were thanked with a US \$20 gift card.

Interview Guide

Interviews were semistructured and task-oriented. The interview guide was developed to investigate the following areas: (1) understanding the workflow of cancer reporting, (2) estimating the time spent on each phase within the process, and (3) identifying the barriers to rapid reporting (Multimedia Appendix 1). Follow-up questions were asked for clarification and to confirm the representation of the developed model. Probing questions were asked to investigate additional information such as decision-making processes and alternative processes. For example, participants were asked to estimate the time required to complete abstraction of case information from the patient's record. Later, they were asked if there are any types of information that take longer than others to abstract, and if so, how often they encounter these data types. In addition to describing the present state of cancer registry reporting, participants were asked to freely envision and describe optimal cancer reporting mechanisms, enabling them to transcend concerns for current resources or structural limitations [25].

Analysis

Interview data were analyzed using a grounded theory approach [26-28]. We employed the following analysis steps: open coding, axial coding, and selective coding [26]. During the open coding step, keywords, phrases, and ideas were extracted to develop concepts and subcategories. Examples of these subcategories included barriers, facilitators, duration of each subtask, and reporting sources. During the axial coding, we grouped the concepts and subcategories into similar categories and considered the relationships among them. One relationship included the reporting step in which a barrier was encountered and a facilitator was used to overcome the barrier. For example, when CTRs reported difficulties accessing information from external hospitals, we examined whether the difficulties were encountered during the case finding or the abstracting phase. We further examined whether a barrier was encountered for all cancer types or a particular type of cancer, as well as whether a barrier was reported by CTRs from all hospitals or a subgroup of hospitals (eg, large hospitals). During selective coding, we used the derived categories to form higher-level themes. The analysis was performed using NVivo 10 (developed by QSR international).

Flowchart and Simulation Development

Data from the interviews were utilized to guide the development and refinement of information flow models. We identified sequences of reporting activities, data sources, roles, and the duration of each task. The procedure for the flowchart development followed the hierarchical task analysis technique [29]. The flowchart developed arranges the tasks within the reporting process and the flow of information for both the existing workflow (Figure 1) and the redesigned workflow (Figure 2).

Using AnyLogic 7.1, we developed a discrete-events simulation of the current workflow (Figure 3). We used the data collected during the interviews to inform the simulation development (Multimedia Appendix 2). The input data included the duration of activity, waiting time, and number of cases performed. The simulation model provided an indication of the time spent at each phase of reporting (eg, processing time, waiting time, and time cases spend in queue before being processed). The flowchart and simulation model development occurred concurrently with the interviews to test the model's assumptions and enable iteration. This allowed us to validate the model representation and assumptions with the data obtained from the interviewees.

The simulation model was validated through an iterative process of calibration and comparison with the existing workflow. This validation included ensuring the model represented real-life processes by comparing the total reporting time estimated by the registrars in interviews with the simulation output [30].

Figure 1. Cancer reporting flowchart for the existing workflow. ICD: International Classification of Diseases.

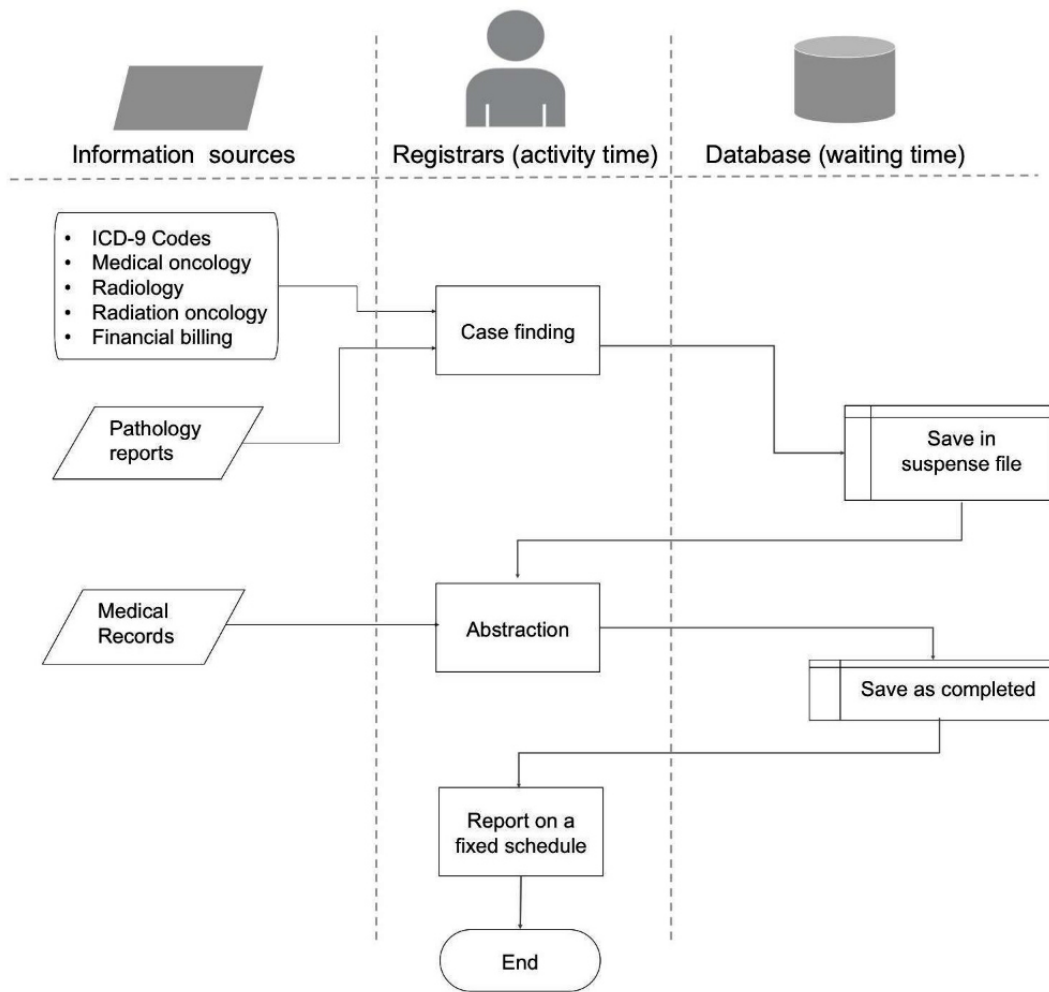


Figure 2. Cancer reporting flowchart for the redesigned workflow. ICD: International Classification of Diseases.

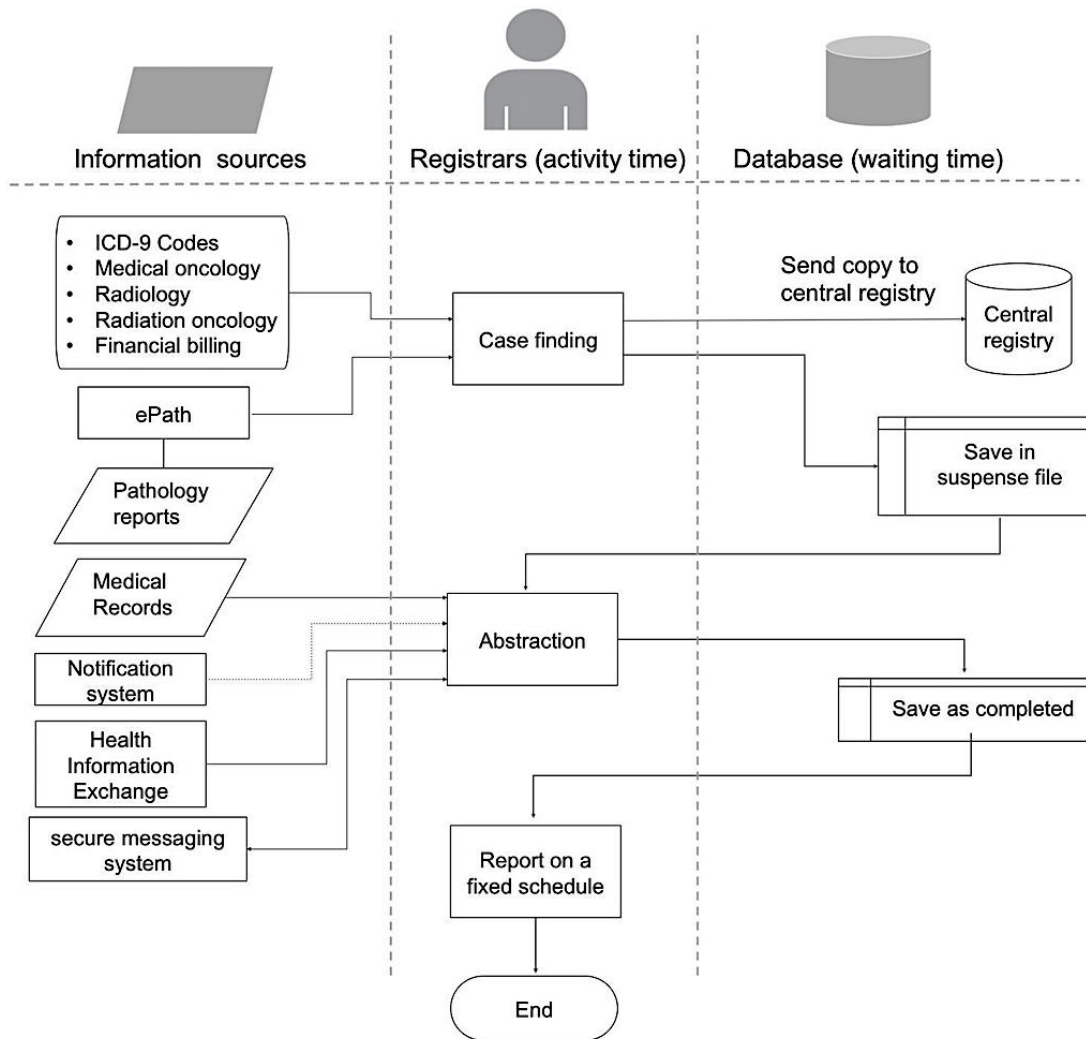
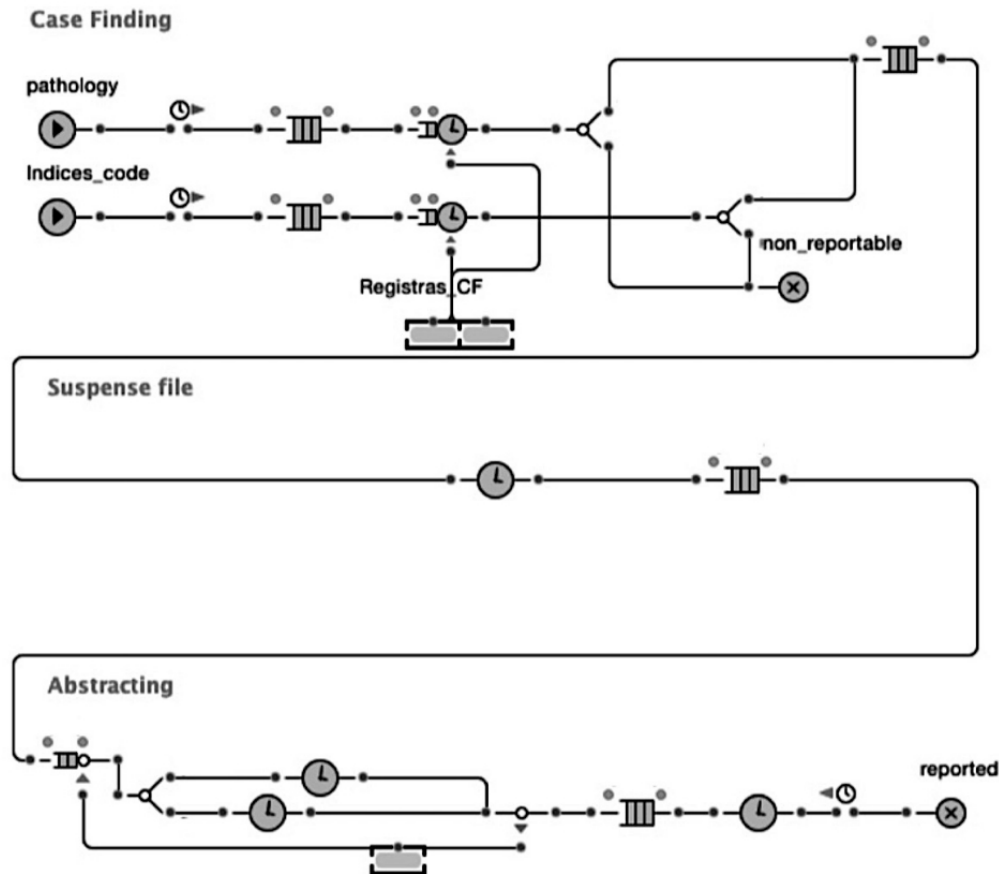


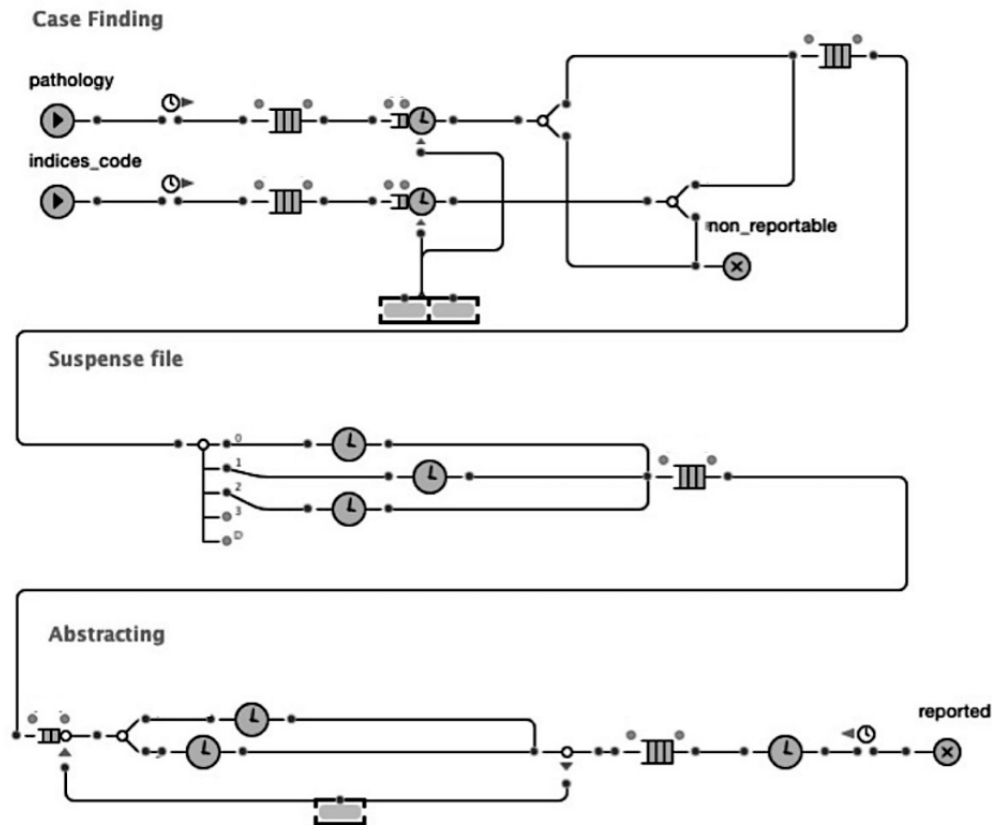
Figure 3. Simulation model for the existing workflow.



Thereafter, we simulated the redesigned workflow to estimate the difference in reporting time compared with the current workflow (Figure 4). In the existing workflow, registrars wait about 3-6 months for treatment to be initiated (Textbox 1). To predict the potential savings in reporting time, we needed to estimate the time between diagnoses and receiving treatment, which could not be estimated by the interviewed registrars. Registrars agreed that this time could vary based on factors such as cancer site, cancer stage, and hospital resources. To estimate this time, we used the findings from a previous study by Bilimoria et al that calculate the time between diagnosis and

treatment [31]. Bilimoria et al examined 1,228,071 patient records from 1995 to 2005 using data from the National Cancer Database, which represents around 1443 hospitals in the United States. Treatment waiting time was simulated using the (average; minimum-maximum) days for the three cancer types. The calculated values for breast, colorectal, and lung cancer were (24; 14-40), (37; 20-63), and (26; 13-46), respectively [31] (Multimedia Appendix 2). We also used the *Cancer Facts and Figures, 2012* to estimate the proportion of each cancer type at the ISDH cancer registry (ISDH, 2012).

Figure 4. Simulation model for the redesigned workflow.



Textbox 1. Estimated time for each reporting step.

Activity time (tasks performed by registrars)

- Task: Case finding from the pathology reports
 - Time: Daily 1 hour
- Task: Case finding from the International Classification of Diseases-9 list
 - Time: Monthly 1 day
- Task: Abstraction
 - Time: Daily 45 min to 1.5 hours per case

Nonactivity time (waiting time)

- Phase: Suspense file
 - Time: 3-6 months, varies among hospitals
- Phase: Completed cases reside at the local registry before submission
 - Time: An average of 15 days for hospitals with higher caseloads (>300 cases per year)

Results

Overview

A total of 14 registrars agreed to participate, and the average interview duration was 28 min (range 17-44 min). Half of the participating registrars reported for larger hospitals (300 beds and over). Out of the 14 registrars interviewed, 6 were reporting

for hospitals within Indianapolis and the others were reporting for rural hospitals.

The interview focused on the following areas: (1) understanding the workflow of cancer reporting, (2) estimating the time spent on each phase within the process, and (3) identifying the barriers to rapid reporting. The interview results were organized into the existing workflow description and barriers, recommended workflow, and simulation comparison.

Existing Workflow Description

Using the interview data, we mapped and described the existing reporting workflow. The reporting process comprises 3 major steps: case finding, abstraction, and reporting (Figure 1). The details of each step are described below.

Step 1: Case Finding

When registrars were asked “how does reporting start?,” they reported that the first step is case finding. This involves identifying new cases of cancer that have been diagnosed within a given period. This applies to all inpatients and outpatients diagnosed with or treated for a reportable tumor. Registrars reported that 90% to 95% of the reported cases are identified through pathology reports. Pathology reports are especially useful because they contain detailed information about the cancer diagnosis, histology, and behavior. Some facilities use additional sources for case finding, including hospital admission and discharge records, surgery schedules, cytology reports, oncology reports (medical and radiation), radiology reports, and billing records. Participants suggested that those sources are less informative than pathology reports. Nonetheless, registrars often use multiple sources or refer to medical records to find the information that they need. Data collected during case finding may include demographic information and basic information about the tumor such as site, histology, and behavior. The amount of information collected at this stage is subjected to the information availability and thus, may vary from case to case. Missing information is often completed during the abstracting phase, as the primary goal of case finding is the identification of potentially reportable cases.

Once a case is confirmed as reportable, it is added to a suspense file to await abstraction. In most facilities, case finding is performed daily or weekly (for pathology reports) and monthly (for all other sources). Cases may then reside in the suspense file for several months before abstraction. The rationale for this waiting period is to allow for tests and treatments to be performed and thus, available for inclusion in the report ultimately sent to public health authorities.

Step 2: Abstraction

Although case finding provides an initial awareness of a given case, abstraction is more comprehensive and detailed. Abstraction uses different parts of the medical record to collect demographic information, tumor-related information, and information about staging, diagnostic studies, and treatment. When registrars were asked to describe the abstracting process, we found that abstraction is less structured than case finding as registrars flexibly use different parts of the medical record to create a summary.

When registrars were asked, “where in the reporting cycle does the delay exist?,” they reported that abstraction could be delayed when data are not available in local medical records. This is more frequent when patients receive care at an outside facility. Registrars indicated that the percentage of cases that require contacting external facilities varies widely, from 10% to 40%. To access records at outside facilities, reporting registrars often reach out to people at the hospitals where care was provided. These individual contacts may range from health care providers

(eg, doctors or nurses) to cancer registrars working at the external facilities. Once all the required information is collected and the abstract is considered complete, it is then saved in preparation for submission.

The interviews revealed that both case finding and abstracting could be performed by the same registrar, especially at smaller hospitals where the number of registrars is limited. Larger hospitals, on the other hand, are more likely to divide the role such that registrars can focus on either case finding or abstracting.

Step 3: Submission

Registrars save the completed abstracts and send them in batches to the state registry at fixed time intervals. The submission is made electronically and takes less than 15 min for the entire batch. Facilities with a higher number of cases are required to report abstracts to the state registry at a higher frequency. For example, the ISDH requires hospitals with an average of 1 to 59 cases annually to report their cases once each year; hospitals with an average of 60 to 149 cases annually are required to report their cases quarterly; hospitals with an average of 150 to 299 cases annually are required to report their cases every other month; and hospitals with an average of 300 or more cases annually are required to report them on a monthly basis.

Time per Step

We asked registrars to estimate the time it takes to perform each task, and we aggregated the average time estimated (Textbox 1). During interview, we also asked registrars if they encounter a delay or have to wait during the reporting process. The interview results show that the reporting process cycle time contains both activity and waiting times. The activity time includes the time that registrars spend to access and retrieve data, review the records, and enter information into the system. Waiting time, on the other hand, refers to the time during which cases or records reside in the system while no activities are being performed. This includes the time that cases reside in a suspense file before abstraction as well as the time that completed reports reside in the local system before being sent to the appropriate state registry.

Existing Workflow Barriers

We aggregated the barriers identified during the interview and grouped them into the following themes. Most reported barriers were related to data exchange, followed by information quality-related barriers (Textbox 2).

Data Exchange

The most commonly reported barrier was accessing information at external hospitals. Many of the facilities providing oncology treatment are external or independent. Registrars reported that the percentage of cases that requires contacting external facilities varies from 10% to 40%. While describing the barriers encountered, one interviewee stated:

Getting the information from physicians and letting them know they are not breaking HIPPA if they give us this information. Telling them even if we are not face-to-face with the patients, we are still doing patient care.

Textbox 2. Summary of barriers reported by cancer registrars.

Theme: Data exchange

- Number of respondents: 8
- Key barriers identified:
 - Difficulty accessing information within facilities outside the hospital network
 - The lack of data exchange between electronic systems

Theme: Information quality

- Number of respondents: 6
- Key barriers identified:
 - International Classification of Diseases codes are not sufficient for confirming the repeatability of the flagged cases
 - Text reports using uncertain language such as “probable,” “suspected,” “likely,” “questionable,” and “possible”
 - Different treating physicians sometimes report contradicting information

Theme: Information processing

- Number of respondents: 5
- Key barriers identified:
 - Combine different events into a single coherent abstract
 - Interpret some of the information in the medical records and translate it to fit the registry requirement
 - Complicated cases with many procedures
 - Large number of nonreportable cases that are flagged to be reviewed

Theme: Administrative tasks

- Number of respondents: 3
- Key barriers identified:
 - Administrative tasks such as reviewing compliancy, serving on the tumor board and on cancer committees
 - Reporting for other institutions with different reporting requirements such as Commission on Cancer

Theme: Technical factors

- Number of respondents: 2
- Key barriers identified:
 - System session timeout
 - Some systems do not have the ability to distinguish the previously reported cases from the new cases

Another interviewee stated:

I tend to go onsite and meet people. I don't call a lot because some places are not happy giving that information. They want to know who I am and where I am from, so the contact I do have, I build a rapport with and I get the information from them.

When patients receive treatment at an external facility, the abstracting registrar sometimes contacts the registrar working for that facility instead of contacting the physicians or nurses. This is often expressed as a preferable alternative, because they are familiar with the reporting process and requirements. One interviewee also stated that the real obstacle comes with finding

out where patients receive treatment, as this is not always indicated in the medical records.

Another information exchange-related barrier was the system inability to exchange information between departments within the same hospital. An example of this would be hospitals that use multiple systems such as legacy systems, paper-based systems, or interoperable systems. One registrar stated that the hospital system does not support some of the technology they wish to use. Because the hospital system is not compatible with the oncology management reporting system, registrars are not able to use all of the features that require data sharing.

Information Quality

Registrars reported some issues associated with physician's notes, such as the lack of information and the ambiguous terminology. Most cancer diagnoses are confirmed through biopsy, but when pathology reports are not available, other information sources such as physician's notes or diagnostic imaging reports are used. The difficulty arises when uncertain language is used. Terms such as "probable," "suspected," "likely," "questionable," or "possible" lead registrars to seek more data sources to confirm diagnosis.

A less common barrier identified during abstracting is contradiction in the information found in the records. In some rare cases, registrars find contradictions in the different information sources, such as physician's notes and pathology reports or even within physician's notes if multiple physicians treat the same patient.

Information Processing

Registrars sometimes expressed some forms of mental load while dealing with information. They collect information from multiple sources and arrange them in chronological order, building a series of events. One interviewee described it as putting together pieces of a puzzle, where they try to find the answer to what they are looking into. The sequence of events has to follow a logical treatment path, using the available data. This process can get complicated when some of the expected events (such as treatment or procedures) are missing. Registrars then will try to find out which data are missing or which procedures were not performed. One registrar commented:

When you do that abstracting for patients you are writing their story, you are the author. You want to make sure you have all the facts, the dates, the treatment collection, date of birth, name, so when you write, your comments have to be clear as to what happened to that patient.

The second factor that contributes to the mental load is the interpretation of the physician's note. Terminology used may differ from that which is required by the central registries. Interpreting this information requires not only a solid understanding of the domain but also an understanding of the patient's individual situation and contexts. This can be more challenging for complicated cases with many procedures.

An additional challenge can be presented when using International Classification of Diseases (ICD) codes for case finding. During case finding, registrars search the hospital database for the predetermined set of codes and keywords that may indicate a tumor. This may result in many nonreportable cases also being retrieved by the system. Registrars indicated that only 2.5% to 11% of the cases identified through disease indices are reportable. To filter them, registrars manually review the results to verify their eligibility for reporting.

Administrative Tasks

Some registrars indicated that administrative tasks, such as reviewing compliancy and serving on a tumor board and on cancer committees, could be time-consuming. In addition to reporting to state registries, some hospitals voluntarily report to the Commission on Cancer (CoC), which requires continuous follow-up. This involves updating the patient status, cancer status, any recurrence, new cancer, or new treatments. To perform the follow-up, registrars continue searching and updating patients' information for life. When describing the follow-up required by CoC, one registrar stated:

Going through 3000 plus in the suspense file and only getting 300 or 50 in my case. That is a huge time-consuming part.

Technical Factors

Registrars collect information from diverse sources, which requires them to access different systems, paper records, or make phone calls. Being busy with one source will result in inactivity in the previous one, and most electronic systems will log the user out automatically if being inactive for certain period of time. One registrar commented:

My most time-consuming thing for me lately is getting the medical records to work...logging to the system, staying logged in, dealing with connection.

Other barriers were software-related. Some registrars indicated that open source software, such as Rocky Mountain, only provide the basic features and do not provide any of the additional functionalities that can promote an efficient workflow, especially for matching cases and case follow-up.

Workflow Recommendations

The redesign focused on the deviations that could have the highest impact on the reporting time (Textbox 3). On the basis of the respondents' feedback, time spent on cancer reporting comprises not only the time spent on tasks but also waiting time, which consumes most of the total reporting time (Textbox 1). Most of this waiting time occurs while patients await treatments and procedures. Respondents further indicated that the time cases reside in suspense files vary between facilities, but the same waiting time is applied to all cases within a given facility. Registrars agreed that procedures and treatments could be performed at different speeds, depending on many factors such as cancer type, cancer stage, and facility resources. This variation suggests that using a standard waiting time for all cases creates an unnecessary delay if treatments are delivered earlier than the anticipated time. We recommend using a notification system (described below) to target this phase of reporting due to its higher impact on timeliness relative to the other phases (Textbox 1). Moreover, cancer registrars reported that data exchange and access to external records was a major barrier during abstraction. On the basis of impact and pervasiveness, we recommend incorporating an electronic pathology reporting system (ePath) for case finding, access to HIE networks, and secure messaging systems (Textbox 3).

Textbox 3. Barriers addressed by recommendations.

<p>Recommendation: Electronic pathology reporting system</p> <ul style="list-style-type: none"> Barrier theme: Information processing <ul style="list-style-type: none"> Specific example: Over 90% of the cases identified during case finding are identified through pathology reports
<p>Recommendation: Notification system</p> <ul style="list-style-type: none"> Barrier theme: Not applicable <ul style="list-style-type: none"> Specific example: Waiting time in the suspense file: cases may take up to 6 months after case finding to abstracting
<p>Recommendation: Access to health information exchange</p> <ul style="list-style-type: none"> Barrier theme: Data exchange <ul style="list-style-type: none"> Specific example: Difficulty accessing information within facilities outside the hospital network Barrier theme: Information processing <ul style="list-style-type: none"> Specific examples: <ul style="list-style-type: none"> International Classification of Diseases codes are not sufficient for confirming the repeatability of the flagged cases Text reports using uncertain language such “probable,” “suspected,” “likely,” “questionable,” and “possible”
<p>Recommendation: Messaging system</p> <ul style="list-style-type: none"> Barrier theme: Data exchange <ul style="list-style-type: none"> Specific example: Difficulty accessing information within facilities outside the hospital network

Electronic Pathology Reporting System

About 90% to 95% of cases identified at the case finding stage are identified through pathology reports. Using an ePath system for case finding has been shown to improve reporting timeliness and increase reporting efficiency [32]. Many registrars stated that they had automated the process of case finding from pathology reports and adopted the Public Health Information Network Messaging System for sending Health Level Seven (HL7) messages [32-34].

Notification System

We propose adding a notification system between the hospital cancer data management system and the EHR system to notify registrars when new treatments are delivered. Using a notification system would enable registrars to abstract a given case as soon as new treatment data are added to the hospital EHR system instead of the current method, which applies the same waiting time for all cases. Notification systems for workflow optimization have been applied in other health care settings to promote the coordination of care [35]. System notification can be implemented using HL7 Clinical Document Architecture notification messages. Once a new treatment is added to the EHR system, an event can be triggered and the notification system will match it with patient lists in the suspense file. If a match is found, then registrars can be notified about the addition of the new treatment.

Access to Health Information Exchange

Indiana hospitals have participated in the Indiana HIE for more than a decade [36,37], yet the exchange does not currently facilitate access for cancer registrars. Utilizing the existing HIE network to facilitate access to information could reduce obstacles to obtaining details about cancer cases and outcomes. Moreover, accessing more information can also improve the accuracy of reporting. Several other states also have an HIE infrastructure that could be similarly utilized. Studies have shown the benefits of HIEs in improving access to clinical data [38-43].

Secure Messaging System

Our result shows that registrars encounter difficulties when asking clinicians at external facilities for patient information. As a result, they contact the registrars at the external facilities to access patient information. This relationship was perceived as more conducive to accessing the information needed, given their understanding of each other's job role and reporting requirements. In this workflow model, we propose the usage of a secure messaging system to facilitate communication among registrars so as to minimize the access barriers to the sharing of information. Studies have shown that the use of secure messaging in other clinical settings improves communication effectiveness among health professionals [44].

Table 1. Comparison of existing and proposed methods simulations.

Workflow design	Simulation time	
	1 year	2 years
Existing workflow		
Days (minimum, average, maximum)	102.2, 138.6, 177.8	102.2, 138.6, 180.6
Percentile (25%, 75%)	128.9, 149.1	128.9, 149.1
Standard deviation	10.8	10.7
Recommended workflow		
Days (minimum, average, maximum)	19.6, 51.8, 95.2	19.6, 51.8, 95.2
Percentile (25%, 75%)	39.5, 61.9	39.5, 61.9
Standard deviation	10.2	9.8
<i>P</i> value at 95% CI	.039	<.001

Recommended Workflow Steps

Figure 2 shows the flowchart for the redesigned workflow. The steps for the redesigned workflow are as follow:

1. Cancer cases are identified through pathology reports using the ePath system.
2. Registrars review and approve cancer cases identified by ePath.
3. Registrars perform case finding manually for the other data sources.
4. Cases identified as reportable are saved in the suspense file for abstraction. A copy of the identified cases is sent to the state registry and marked as incomplete.
5. EHR sends a notification to the cancer registry management system regarding the delivery of any new cancer-related treatment. If the notification matches any of the cases in the suspense file, then the case will be flagged.
6. The registrar will check the flagged case and start abstracting. If no new treatment is received within 6 months of the date of diagnosis, then the registrar will start abstracting and check the physician's notes and discharge summaries regarding whether treatment was provided elsewhere.
7. If treatment is received at an outside facility, then registrars will use the HIE to search for external information.
8. If more information is needed, then the reporting registrar can use the secure messaging system to contact other registrars at the outside facility.
9. Registrars save the completed abstracts in the local database to be reported at fixed intervals.

Simulation Output

The simulation results show that the redesigned workflow could potentially reduce the reporting time from an average of 138 days to 51 days (Table 1). Although the redesigned workflow added new tasks to minimize some of the barriers identified during interview, most of the reduction in reporting time was attributed to simulating the notification system. Although most tasks take an hour or less, waiting in the suspense file may take up to 6 months (Textbox 1). As seen in our simulation assumption (Multimedia Appendix 2), simulating the notification

system enables us to distinguish the time that cases reside in the suspense file among the three cancer types.

Discussion

Principal Findings

There is an increasing interest in leveraging cancer registry data to advance the quality of cancer care and bridge the gap between scientific discovery and existing practice [1-4]. Yet, the lengthy reporting time is a major challenge that inhibits the use of cancer registry data for actionable intervention [1-4]. Little is known about the cancer reporting process or the barriers encountered during reporting. In this study, we conducted key informant interviews to understand the details of the reporting process and workflow activities at the hospital level. We examined the time taken at each stage of reporting to target the most time-consuming activities and shorten the reporting process.

Prior research has applied data mining and machine learning techniques to simplify case finding activities and enable automated identification of cancer cases. Although this approach can minimize the time spent on these activities, we found that cancer reporting processes comprise not only active tasks performed by registrars but also inactive waiting times, during which registrars wait for new information about cancer cases to become available in the EHR. These waiting periods occur during the interval of time wherein patients receive diagnostic procedures and treatment. Our findings suggest that the waiting periods can consume more of the total time associated with cancer case reporting than those periods involving active tasks performed by registrars. Consequently, timeliness may be improved by changing the queuing method that is currently applied by registers across hospital types.

Cases generally reside in a suspense file at the hospital for a few months, during which time treatments and procedures are delivered by clinicians and subsequently entered into the hospital's EHR system. Thus, the first case entered into the suspense file will be the first case abstracted later when the registrar checks for updates. However, procedures and treatments are scheduled and performed at various speeds, depending upon factors such as the cancer type, stage, facility resources [31], as well as other social and clinical patient

characteristics. Using a standard waiting time for all cases creates an unnecessary delay if treatments are delivered earlier than anticipated. Adding automated EHR-based notification mechanisms, to inform registrars when new data are available, will enable cancer registrars to abstract case information as soon as it is available instead of waiting a fixed period of time for all cases.

Using EHR-based notification mechanisms could also be applied with two-phase reporting. Two-phase reporting could support the development of “Rapid Learning Systems” [45] where cases can be reported as an incomplete abstract after case finding and updated once treatment and outcome data become available. Technology-enhanced methods will further enable surveillance for timely and high-quality treatment by alerting registrars (or clinicians) when individuals diagnosed with cancer may be overdue for treatment or have been lost to follow-up.

Limitations

One methodological limitation of our study is the absence of field observations to complement the semistructured interview data, as well as a more quantitative assessment of the prevalence of various barriers through structured surveys. Yet, an advantage of the cancer registrar interviews was the ability to capture rich, in-depth descriptions of a broad range of processes involved in end-to-end cancer reporting. Self-reported interview data are subject to recall bias; however, this threat to validity is lessened by the fact that registrar descriptions generally agreed with one another. We also limited the interviews to experts who could provide insight into the process by focusing on certified registrars who currently report to the ISDH cancer registry. Moreover, we included both large and small hospitals, as well as urban and rural hospitals, to enhance the generalizability of our results.

A second limitation is the method for estimating the simulation input for the redesigned workflow. To conduct the simulation for the redesigned workflow, we needed an estimate of the expected time that cases reside in the suspense file. This is represented by the time from case finding to availability of treatment results. To estimate this time, we used a national study that measured the time from diagnosis to treatment [31].

Although this approach could underestimate the simulation input by disregarding the extra time needed to document the treatment result and add it to the EHR, it could also overestimate the simulation input by disregarding the shortened period for case finding likely to occur with implementation of the ePath system.

Currently, cancer registrars can begin abstraction at the start of the first course of treatment; however, registrars may decide to wait longer to have more complete treatment information to add. For future research, we recommend measuring the time from diagnosis to treatment using the treatment data available at the registry to estimate the minimum reporting time possible for a given rate of completion.

Moreover, our study was limited to cancer registrars within the state of Indiana. Although most state registries have similar reporting requirements and training, we believe evaluating the reporting process in other states will be important to assess the generalizability of our results and recommendations.

Conclusions

Key barriers to the rapid collection of cancer surveillance information in the existing reporting process include data residing at multiple institutions and the waiting period for the completion of treatment. Our results highlight how health information technologies could be leveraged to overcome these barriers, including ePath systems, HIE, and secure messaging. Understanding the time elapsing at each step within the process helps in prioritizing the needs and estimating the impact of future interventions.

In this study, we discovered that reporting speed cannot be entirely controlled by accelerating the case finding or the abstraction process. Pragmatically speaking, registrars need to wait for treatments and procedures to be performed and entered into the EHR before collecting the data. Appropriate waiting intervals could be better defined by further exploring how much the time from diagnosis to treatment varies for different cancer types. Understanding this variation could help determine the potential value of implementing a notification system, as well as setting reasonable expectations for reporting time by cancer type.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Interview script.

[\[PDF File \(Adobe PDF File\), 32KB - cancer_v4i1e4_app1.pdf \]](#)

Multimedia Appendix 2

Simulation input.

[PDF File (Adobe PDF File), 16KB - cancer_v4i1e4_app2.pdf]

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Abbreviations

- CDC:** Centers for Disease Control and Prevention
- CoC:** Commission on Cancer
- CTR:** certified tumor registrar
- EHR:** electronic health record
- HIE:** health information exchange
- HL7:** Health Level Seven
- ICD:** International Classification of Diseases
- ISDH:** Indiana State Department of Health
- NAM:** National Academy of Medicine

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Original Paper

Web-Based Communication Strategies Designed to Improve Intention to Minimize Risk for Colorectal Cancer: Randomized Controlled Trial

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Abstract

Background: People seek information on the Web for managing their colorectal cancer (CRC) risk but retrieve much personally irrelevant material. Targeting information pertinent to this cohort via a frequently asked question (FAQ) format could improve outcomes.

Objective: We identified and prioritized colorectal cancer information for men and women aged 35 to 74 years (study 1) and built a website containing FAQs ordered by age and gender. In study 2, we conducted a randomized controlled trial (RCT) to test whether targeted FAQs were more influential on intention to act on CRC risk than the same information accessed via a generic topic list. Secondary analyses compared preference for information delivery, usability, relevance, and likelihood of recommendation of FAQ and LIST websites.

Methods: Study 1 determined the colorectal cancer information needs of Australians (N=600) by sex and age group (35-49, 50-59, 60-74) through a Web-based survey. Free-text responses were categorized as FAQs: the top 5 issues within each of the 6 cohorts were identified. Study 2 (N=240) compared the impact of presentation as targeted FAQ links to information with links presented as a generic list (LIST) and a CONTROL (no information) condition. We also tested preference for presentation of access to information as FAQ or LIST by adding a CHOICE condition (a self-selected choice of FAQs or a list of information topics).

Results: Study 1 showed considerable consistency in information priorities among all 6 cohorts with 2 main concerns: treatment of CRC and risk factors. Some differences included a focus on general risk factors, excluding diet and lifestyle, in the younger cohort, and on the existence of a test for CRC in the older cohorts. Study 2 demonstrated that, although respondents preferred information access ordered by FAQs over a list, presentation in this format had limited impact on readiness to act on colorectal cancer risk compared with the list or a no-information control ($P=.06$). Both FAQ and LIST were evaluated as equally usable. Those aged 35 to 49 years rated the information less relevant to them and others in their age group, and information ordered by FAQs was rated, across all age groups and both sexes, as less relevant to people outside the age group targeted within the FAQs.

Conclusions: FAQs are preferred over a list as a strategy for presenting access to information about CRC. They may improve intention to act on risk, although further research is required. Future research should aim to identify better the characteristics of information content and presentation that optimize perceived relevance and fully engage the target audience.

Trial Registration: Australian New Zealand Clinical Trials Registry: ACTRN12618000137291; <https://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?id=374129> (Archived by WebCite at <http://www.webcitation.org/6x2Mr6rPC>)

(*JMIR Cancer* 2018;4(1):e2) doi:[10.2196/cancer.8250](https://doi.org/10.2196/cancer.8250)

KEYWORDS

internet; randomized controlled trial; information seeking behavior; consumer health information; health communication

Introduction

Background

Colorectal cancer is the third most common cancer in the world. Developing countries have the highest incidence, although only 46% of cases worldwide occur in developing countries [1]. Consequently, health providers need to develop engaging, efficacious, and cost-effective informational and educational communication strategies to decrease incidence through appropriate prevention and to assist patients, survivors, and their supporters. Developing an approach to providing the myriad of information materials that can address these needs, in a format that does not confuse the intended user, is challenging. Effective, acceptable, self-tailored engagement is likely to be best achieved by use of a well-designed, internet-delivered, interactive package targeted to the needs of different users.

Research suggests that Australians and health consumers in many other countries are happy to seek health information on the Web [2,3]. Although estimates of internet access vary, and accuracy can be questioned, estimates suggest that on July 1, 2016, approximately 3.4 billion people, or 46% of the population of the world, had access to the internet at home [4]; this is a 7.5% increase from 2015. In the Oceania region, which includes Australia, internet penetration was estimated at 73.2%, and, within Australia alone, it was estimated at 92.1% in June 2016 [5].

US data from a nationwide survey of more than 3000 people suggest that 72% of American internet users looked on the Web for health information in 2012 [6]. In 2010, a survey by the British United Provident Association (BUPA), a leading medical health insurance company, indicated that approximately 80% of Australians “sometimes” or “often” used the internet to “search for advice about health, medicines or medical conditions” [7]. This result compared with a high of approximately 95% of BUPA members in Russia and a low of 61% in France.

Consistent with these findings are results from a study in which we surveyed 8762 Australians aged 50 to 74 years about their health-related internet use [8]. Approximately 82% reported having internet access and 61% of this group reported actively seeking health-related information on the Web. Demographic variables influenced access and use; younger, more educated people had greater access and women were more likely to search the internet for health information.

These findings suggest that different demographic groups might respond differently to health information available on the internet. Optimizing presentation format and content so that they appeal to the needs of diverse groups is a challenge. Research in cognitive psychology highlights the importance of cognitive fit with, for example, differential effectiveness for tables and figures, although the differences are moderated by task difficulty (eg, [9]). Research in cognition also indicates that the ability to process different sorts of information varies with age and sex (eg, [10]).

These observations indicate the importance of careful consideration of webpage format in the development of Web-based health information sites so that these accommodate subgroup preferences for information provision. Yardley et al [11] assessed user reactions to an internet-delivered, health care intervention by asking participants (n=21) to “think aloud” while viewing paper versions of draft webpages and asked another group (n=26) to do the same while viewing the prototype website developed based on initial feedback. This feedback, and best practice principles, resulted in information being structured so that quantity of text on any one page was minimized, individuals were able to review information seen as personally relevant, and were able to choose what they viewed. The authors concluded as follows: “...our findings suggest that educational level may not be an insuperable barrier to appreciating web-based access to in-depth self-care information, *provided the users can feel they have sufficient choice and control and can quickly gain access to the specific information they value*” [11].

Strategies for achieving personalized health information provision on the Web require site developers to identify the information needs of those who will use the website before them accessing the site, and to create pages that are targeted to these needs and evaluated as usable and acceptable. The optimal structure for these pages remains to be determined, but there is some limited support for the use of frequently asked questions (FAQs). For example, Coleman et al [12] compared postings on a pancreatic cancer website maintained by Johns Hopkins Hospital before and after the addition of an FAQ module. Comparison of 597 postings recorded pre and post the upload of the FAQs module indicated that the upload was associated with a significant increase in the seeking of information.

If carefully constructed according to the information needs of different segments of the population, FAQs can offer targeting of information to cohorts based on broad demographic characteristics such as gender and age. Both of these variables

have been linked with differences in help-seeking and other health behaviors (eg, [13,14]) and highlight potential differences in information needs.

Project Aims

This paper describes results from 2 linked studies conducted in 2013. These describe, respectively, (1) the development and (2) the evaluation of a website for use as an information resource and decision support to reduce colorectal cancer incidence through strengthening of intention to engage in cancer-preventive behaviors.

The specific aims of the project were as follows:

- To identify and prioritize information needs relevant to colorectal cancer prevention in a sample of South Australian men and women aged between 35 and 74 years (study 1) and use this information to build a website, ordered by the most FAQs within each age and gender grouping.
- To conduct a randomized controlled, repeated measures study to compare the efficacy of an FAQ approach to information organization with a chronologically based list and a control condition not exposed to any information on improvements in intention to decrease personal risk for colorectal cancer through prevention activity (study 2).
- To compare preference for access to information presented via FAQs versus a general list and examine perceptions of usability and relevance of these websites and likelihood of recommendation.

The outcomes measured were as follows: (1) self-reported colorectal cancer information needs (study 1); (2) preferred format of access to information presentation on the Web; (3) readiness to reduce personal risk for colorectal cancer; and (4) ratings of website usability and intention to recommend (all determined in study 2).

Methods

Ethical Approval and Research Design

The two studies reported here were approved by the Commonwealth Scientific and Industrial Research Organization (CSIRO) Animal, Food and Nutritional Sciences Human Research Ethics Committee, proposals LR03/2013 and LR06/2013, and together they comprise a single research project. The project was not prospectively entered into a trial registry because it was designed as a pilot and feasibility study to inform the development of a larger, population-based, randomized trial to investigate the efficacy of a Web-based informational intervention to influence colorectal cancer-preventive behavior.

Study 1: What Do People Who Vary by Age and Gender Want to Know About Bowel Cancer?

The first study identified the colorectal cancer information needs of population subgroups distinguished by age and sex.

Study 1: Recruitment

A market research company was employed to recruit 600 men and women in South Australia who completed a Web-based survey in May 2013. The sample consisted of 300 males and females spread evenly between 3 age bands: 35 to 49 years, 50 to 59 years, and 60 to 74 years. Participants were paid an honorarium of AUD \$50. Informed consent was assumed by the fact that participants completed the survey.

Study 1: Procedure

The following question was asked to each participant. "If someone said to you that colorectal cancer (also known as bowel cancer) is a leading cause of death in Australia, what would be [up to] five things you would like to know more about?" We included the alternative term of "bowel cancer" to align with recommendations that presentation of health information materials should allow for potentially low levels of health literacy and use plain language [15,16] rather than scientific terminology associated with what might be an unfamiliar topic [17].

Study 1: Analysis

Responses to the question were extracted verbatim from the dataset. Where an item contained multiple concepts, they were separated and treated as individual responses. These were initially coded into 13 separate information categories. A second person reviewed the initial coding and indicated any disagreement. Disagreements were arbitrated by the second author. Coding agreement was high (98.3%). Questions within each category were totaled to enable comparison of frequency of each information need. Respondents were grouped by age band (35-49, 50-59, and 60-74 years) and sex for analysis.

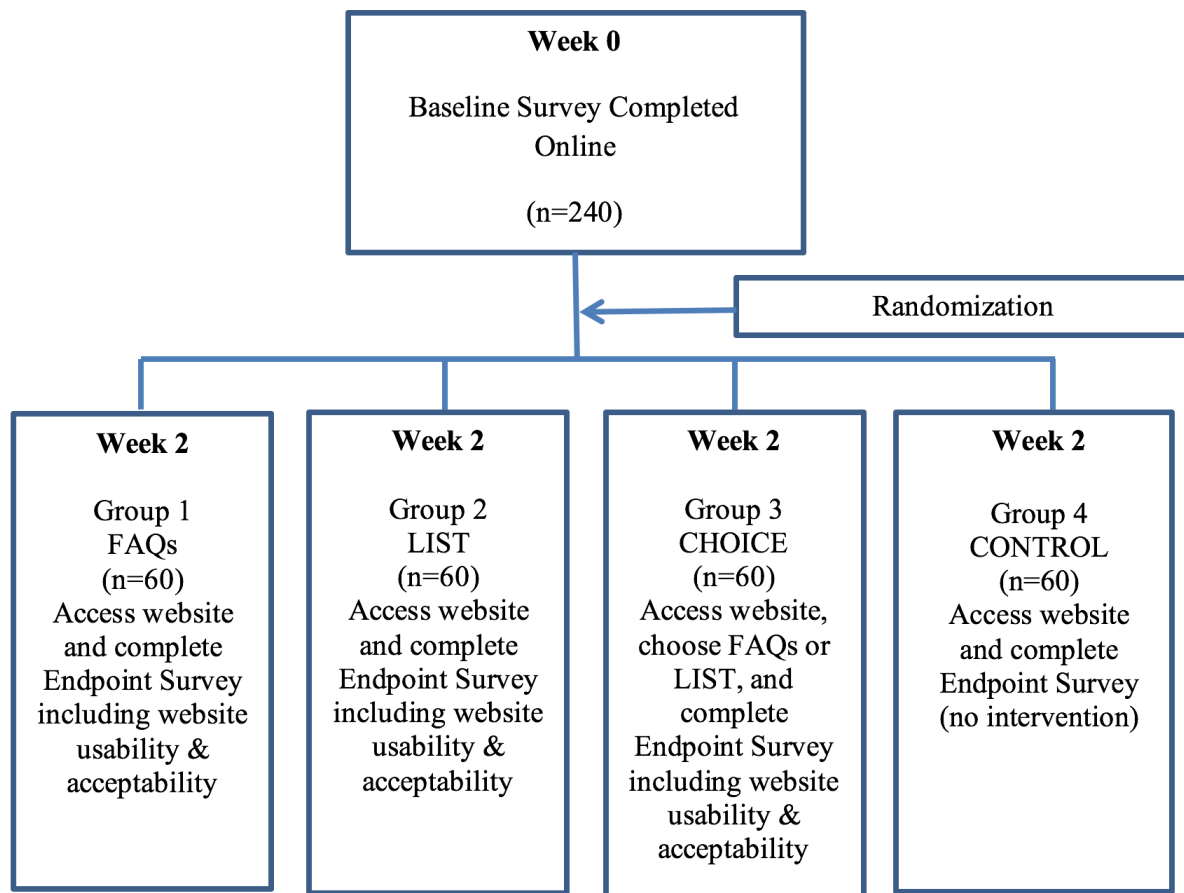
Study 2: Impact of the Organizational Structure of the Information on Intention to Act on Colorectal Cancer Risk and Ratings of Website Acceptability and Relevance

The second study was a randomized controlled trial (RCT) comparing reactions to information access presented as FAQs versus a simple list. Preference for one form of presentation over the other was tested within a condition that offered a choice between both. In the RCT, the primary dependent measure was intention to act on colorectal cancer risk. Figure 1 provides a summary of the experimental procedure. Data were also collected on perceived usability of the website and relevance of the information provided on the website and likelihood of recommendation.

Study 2: Recruitment

A second group of 240 participants was recruited through the same market research company used in study 1 utilizing a national database. The sample consisted of 120 men and women spread evenly between 3 age bands: 35 to 49 years, 50 to 59 years, and 60 to 74 years. Participants were paid an honorarium of AUD \$50. Informed consent was assumed by the fact that participants completed the survey.

Figure 1. Study 2: experimental flowchart. CHOICE: a self-selected choice of FAQs or a list of information topics; LIST: a list of information topics; FAQ: frequently asked question; CONTROL: a control group that received no information.



Study 2: Procedure

Preintervention

All participants logged on to a website using a personally allocated ID and completed a baseline survey 2 weeks before the intervention. The primary dependent measure collected was readiness to act on perceived personal colorectal cancer risk. Other measures collected are not reported here.

Intervention

Two weeks following completion of the baseline survey, participants logged in again on to the website. Participants were randomized into 4 groups (30 males and 30 females in each). Randomization was conducted using the preallocated ID numbers, which were block randomized by the market research company. Participants were allocated to groups according to the ID number entered when they logged in. They were blind to interventions other than that to which they were assigned. The 4 groups were defined by the format of access to colorectal cancer information provision: (1) FAQs; (2) a list of information topics (hereafter called LIST); (3) a self-selected choice of FAQs or LIST (hereafter referred to as CHOICE); and (4) a control group that received no information (CONTROL). Participants in the control group were directed to the postintervention survey. As for study 1, we used the more common vernacular of “bowel” rather than “colorectal” cancer [17].

The FAQs website opened with a page entitled “Prevention of Bowel Cancer” and provided 6 icons that could be clicked on to “Get answers to some of the most Frequently Asked Questions by people in certain age groups.” Each icon included a picture of a man or woman selected to be representative of the age group together with words identifying gender and age (eg, “I am a woman aged 35-49”). Clicking on the icon took the participant to a page that provided a further link to information to satisfy the top information needs of this group as identified in study 1. This page started with the “five most frequently asked questions” for the specified cohort and associated links to answers and was followed below by links to “OTHER questions asked...” This latter set of questions was also ordered by order of importance as identified in study 1.

The LIST website was also entitled “Prevention of Bowel Cancer.” It was followed by the statement, “The information I want about bowel cancer is...” and a list of 10 links ordered according to the chronology of cancer diagnosis and treatment, with the exception of prevention being included at the end.

The CHOICE website included both the LIST of information links and the FAQs icons on the initial page with the instruction “Get answers to some of the most Frequently Asked Questions by people in certain age-groups, or view a list of categories of information about bowel cancer” (Figure 2). The location of the icons and the list was balanced so that half ($n=30$) of group 3 (CHOICE) respondents ($n=60$) viewed the icons on the right

side of the screen and the list on the left, whereas the other half viewed the reverse order (subsequent analysis indicated that presentation of FAQs on the right or left of the screen had no impact on choice between LIST AND FAQs). Once a selection had been made, participants were treated as though they were assigned to the FAQs or LIST condition.

Hyperlinks to information displayed for each intervention group led to a single underlying library that contained material designed to address discrete topics as they were selected by the user. The selected material was displayed in an identical manner regardless of the intervention group.

Post Intervention

An endpoint survey followed the intervention immediately. Respondents were again asked about their readiness to act on their risk for colorectal cancer. Additionally, the intervention groups completed items measuring the perceived relevance of the information provided on the website and likelihood of recommendation and perceived usability and acceptability of the website.

Development of Materials

Frequently Asked Questions

Categories of information needs identified in study 1 were organized by frequency of responses within the 3 age groups (35-49, 50-59, and 60-74 years) and gender.

Information Topic LIST

The information topic LIST was general and not targeted by age or gender. It was organized according to the chronology of

the cancer care continuum [18], following the timeline from early detection and screening through treatment and palliation, with information for carers and prevention information at the end (Figure 2, ten items). The chronological list approach to information provision aimed to mimic the paradigm of a general topic information list, not weighted to group preferences, but organized in a sequential step-by-step manner [19], with “general” information included at the end.

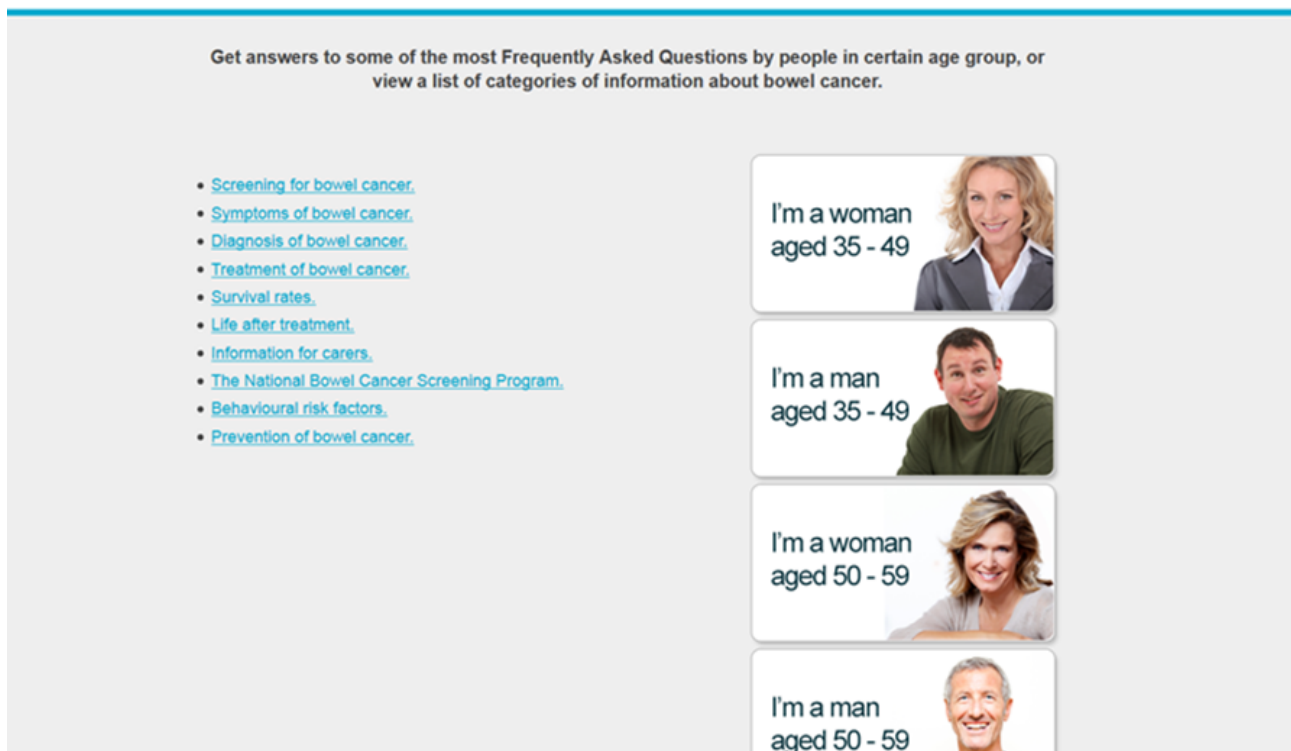
Information Library

Educational content was extracted from publicly available, Web-based resources with authoritative provenance and was reproduced verbatim on separate pages (with acknowledgment; information on HTML links used is available from the corresponding author).

Readiness to Decrease Perceived Personal Risk for Colorectal Cancer

Five stages of readiness to decrease personal risk of colorectal cancer were identified by asking the question “Which of the following best describes your thoughts about trying to reduce your risk for bowel cancer?” These were modified from Myers et al’s [20] study of screening decision stage. The stages used were as follows: (1) don’t want to (compared to decided against [20]); (2) never thought about my risk (compared to never heard of [20]); (3) aware but unconcerned (compared to not considering [20]); (4) undecided (same as [20]), and (5) want to try (compared to decided to do [20]).

Figure 2. Screenshot of the CHOICE (a self-selected choice of frequently asked questions [FAQs] or a list of information topics) website showing FAQ and LIST (a list of information topics) conditions.



Website Usability and Relevance and Likelihood of Recommendation

A 21-item questionnaire, adapted from a measure used by Lindblom et al [21] for a study on bowel cancer screening, was completed by the intervention groups to evaluate the perceived usability and acceptability of the website. Responses to all items were measured on a 4-point Likert scale from 1 “strongly disagree” to 4 “strongly agree.” The maximum score was 84, with a higher score representing higher perceived usability and acceptability. Examples of statements are as follows: “The website is a valuable resource” and “It was easy to find the information I was looking for.” Internal consistency, as measured by Cronbach alpha, was .913 (n=179; 1 data point missing).

Three items measured each user’s assessment of the relevance of the information provided on the website to (1) them personally, (2) to other people in their age group, and (3) to other people outside their age group. Responses were scored on a 3-point Likert scale, where 1 represented “not at all relevant,” 2 “somewhat relevant,” and 3 “relevant.” One item asked the participant “If this website became generally available, how likely would you be to recommend it?” with response options varying from 1 (very unlikely) to 4 (very likely).

Study 2: Analysis

Results were analyzed using nonparametric (chi-square) and parametric tests (independent samples *t* tests and one-way between-groups ANOVA), as appropriate. Clicky Web Analytics (Roxr Software Ltd, Portland, OR, USA) software was used to track the preference for information layout (FAQ or LIST) within group 3 (CHOICE condition). Change in decision stage for readiness to decrease risk for colorectal cancer from baseline to endpoint was measured as movement from any “lower” stage directly to “action” stage versus no movement to action. The independent variables for this analysis were study group (with respondents in the CHOICE group allocated to FAQ or LIST as they chose), age band (35-49, 50-59, and 60-74 years), and gender.

Results

Study 1: Results

A total of 2549 statements identifying “things about bowel cancer you would like to know” were provided by the 600 participants (mean=4.25 statements). These statements were coded into 13 separate information categories. The category names, a brief description of each, and the number of instances nominated are provided in [Multimedia Appendix 1](#). Among men and women combined, issues from the categories “treatment of bowel cancer” and “risk factors (excluding lifestyle)” were, respectively, the first (n=425) and second (n=394) most frequently identified information need. The others included in the top 5 categories were prevention, symptoms, and survival (see column 1 in [Multimedia Appendix 1](#)).

The information priorities identified through frequency of category selection within each and gender grouping are

summarized in [Table 1](#). As the table indicates, there was significant overlap in the areas of interest, with the interests of young men and women not differing much at all. Greater variability was observed in the older age groups, and there was a suggestion that interest in prevention lessened with older age. The information summarized in this table was used to order the FAQs in study 2.

The topic data were further examined using logistic regression. There was a significant association between gender and the need for general information; compared with women, men were 1.6 times more likely to nominate this category (OR 1.60, 95% CI 1.25-2.11, *P*=.001). Age was a significant predictor of wanting information about general risk factors (excluding diet and lifestyle) and, separately, the influence of diet and lifestyle. Compared with those aged 60 to 74 years, younger people were significantly more likely to want to know about general risk factors (OR 1.61, 95% CI 1.23-2.12, *P*=.001 and OR 1.77, 95% CI 1.34-2.34, *P*<.001 for the 50-59 year and 35-49 year age bands, respectively).

Paradoxically, younger people (35-49 years) were significantly less likely to require information about the influence of diet and lifestyle (OR 0.53, 95% CI 0.35-0.79, *P*=.002) compared with those aged 50 to 59 and 60 to 74 years.

Study 2: Results

Sample Characteristics

Demographic characteristics by allocated groups were compared. Mean age did not differ between groups, ranging from 52.83 years (SD 10.68) in the FAQs group to 55.53 (SD 10.41) for the CONTROL group ($F_{2,236}=0.649$, *P*=.58). The majority of participants (n=175) were from South Australia.

Preference for Information Access Presentation Format

A comparison of access to information format preference (FAQs vs LIST) through examination of the link selected by participants in group 3 (CHOICE) indicated a preference for FAQs. Data from 2 participants in group 3 were lost: of the 58 remaining participants, 44 (76%) selected FAQs, whereas 14 (24%) selected the LIST, with this result not impacted by location of each (right or left column) on the page.

Readiness to Decrease Personal Risk for Colorectal Cancer After Intervention

We analyzed movement in readiness from baseline to endpoint by determining readiness location after intervention exposure. At baseline, between the 3 groups there was no significant difference in numbers at the intention to act stage (FAQ, 53/104; LIST, 48/74; CONTROL, 37/60; $\chi^2_4=8.2$, *P*=.09). Post intervention, excluding those participants who were at the “action” stage at both baseline and endpoint (128/240), there was no statistically significant difference in movement directly to action from any “lower” decision stage by intervention group, age band, or gender, although there was a suggestion of a stronger association of willingness with exposure to FAQs, compared with LIST or CONTROL (*P*=.06). Results are shown in [Table 2](#).

Table 1. Top 5 frequently asked questions by gender and age band.

Gender, Age	Priority				
	1	2	3	4	5
Female, 35-49 years	Am I at risk for bowel cancer? ^a	What is the treatment for bowel cancer? ^b	What are the symptoms of bowel cancer? ^c	How can I prevent bowel cancer? ^d	What are the survival rates for bowel cancer? ^e
Male, 35-49 years	Am I at risk for bowel cancer? ^a	What is the treatment for bowel cancer? ^b	What is bowel cancer? ^f	How can I prevent bowel cancer? ^d	What are the survival rates for bowel cancer? ^e
Female, 50-59 years	Am I at risk for bowel cancer? ^a	What is the treatment for bowel cancer? ^b	How can I prevent bowel cancer? ^d	What are the symptoms of bowel cancer? ^c	What is bowel cancer? ^f
Male, 50-59 years	What is the treatment for bowel cancer? ^b	Am I at risk for bowel cancer? ^a	What is bowel cancer? ^f	How can I prevent bowel cancer? ^d	What are the symptoms of bowel cancer? ^c
Female, 60-74 years	What is the treatment for bowel cancer? ^b	What are the symptoms of bowel cancer? ^c	Am I at risk for bowel cancer? ^a	Are diet and lifestyle linked to bowel cancer? ^g	Is there a test for bowel cancer? ^h
Male, 60-74 years	What is the treatment for bowel cancer? ^b	What are the survival rates for bowel cancer? ^e	Is there a test for bowel cancer? ^h	Am I at risk for bowel cancer? ^a	What are the symptoms of bowel cancer? ^c

^{a-h}Items with same superscript letter indicate the same frequently asked question.

Table 2. Readiness to decrease personal risk for colorectal cancer after intervention exposure by group, age, and gender.

Variables	No indication of desire to reduce risk (1 to 4), n (%)	Indication of desire to reduce risk (5), n (%)	Chi-square (df) ^a	<i>P</i> value
Group^b				
Frequently asked question (n=55)	32 (58.2)	23 (41.8)	5.8 (2)	.06
LIST (n=32)	26 (81.2)	6 (18.8)		
CONTROL (n=25)	19 (76.0)	6 (24.0)		
Age band (in years)^c				
35-49 (n=52)	36 (69.2)	16 (30.8)	0.01 (2)	>.99
50-59 (n=38)	26 (68.4)	12 (31.6)		
60-74 (n=22)	15 (68.2)	7 (31.8)		
Gender^c				
Male (n=63)	46 (73.0)	17 (27.0)	0.8 (1) ^d	.37
Female (n=49)	31 (63.3)	18 (36.7)		

^adf: degrees of freedom.

^bTotal n=238 (2 participant choices not recorded); 126 participants who wanted to reduce risk at baseline and endpoint are excluded from analyses.

^cTotal n=240; 128 participants who were already wanting to reduce risk at baseline are excluded from analyses.

^dYates continuity correction.

Perceived Usability and Acceptability of the Websites

After participants in the CHOICE group had been assigned to FAQ or LIST as self-nominated, an independent samples *t* test was conducted to explore the impact of the FAQ and LIST presentations on perceived usability of the website. There was no significant difference in perceived usability and acceptability for the 2 websites (FAQs, n=104: mean 64.01 [SD 7.62]; LIST, n=73: mean 64.26 [SD 6.85]; $t_{175}=-0.224$, $P=.82$).

Perceived Relevance and Likelihood of Recommending Website

We compared responses on the 4 questions examining relevance and likelihood of website recommendation between the 2 website groups (FAQ and LIST, with CHOICE participants allocated as nominated), age bands, and gender using independent samples *t* tests and ANOVA as appropriate (see [Multimedia Appendix 2](#)). A Bonferroni adjustment for multiple comparisons was set at .0125.

Overall, both websites were seen as relevant (ie, returned mean scores of ≥ 2.5 from a maximum of 3 with a moderate SD of

between 0.3 and 0.6) and worthy of recommendation (ie, returned mean scores of ≥ 3.2 from a maximum of 4 with a moderate-to-high SD of between 0.7 and 0.8). There was a significant main effect for age on ratings of personal relevance ($P=.003$) and relevance for the same age group ($P \leq .001$); post hoc tests showed that the 35-49 year age group rated the information as less relevant to them and to others in their age group than the 50-59 year and 60-74 year groups, with medium-to-large effect sizes (partial $\eta^2=0.074$ and 0.249, respectively). There was no significant difference between the older groups. Females considered that the information would be more relevant to people outside their age group, compared with males ($P=.003$); however, the effect size was fairly small (partial $\eta^2=0.036$). People in the FAQ group considered the information to be significantly (although only marginally; $P=.009$; partial $\eta^2=0.029$) less relevant to people outside their age group than those in the LIST condition, a result consistent with the targeting of information by age and gender.

Discussion

Principal Findings

Identifying relevant information is a core component to information control: targeting of health information to the specific needs of subgroups within the broader population is likely to facilitate control and guard against information overload [22], a commonly identified problem with Web-based health information (eg, [3]). The critical task for effective information provision on the Web, thus, becomes identifying relevant and salient information to address the needs of diverse population groups and providing access to information in a structure and format that maximizes perceived relevance and likelihood of action.

Study 1 indicated significant consistency in areas of interest about colorectal cancer, regardless of sex and age. Treatment and risk factors were of interest to more than 50% of the study sample (54.3% (326/600) and 50.3% (302/600), respectively), regardless of sex and age, with resources for survivors and carers least frequently identified. Additionally, a large number of participants indicated an interest in survival statistics, an information topic not generally highlighted on websites. Our own review of information available to those impacted by cancer confirms that the focus is usually on the initial diagnosis and treatment stage of the cancer survivorship continuum, with a paucity of information relating to the later stages [23].

Comparison of the top 5 categories between groups suggested that prevention was of least interest to the oldest cohort (Table 1). Conversely, interest in a test for bowel cancer was most frequently expressed by those in the oldest cohort. Furthermore, comparison between groups of their evaluation of the personal (and age-group) relevance of the websites confirmed least perceived relevance in the youngest cohort, although this group could see the relevance for others outside their age group. Together, these findings are consistent with an interpretation that suggests personal relevance is likely dictated by personal experience and life-stage. This result warrants further consideration, but it suggests that young people need to be

encouraged to prioritize an understanding of cancer and cancer prevention early in life. Similarly, an interest in symptom identification was endorsed by all groups as a priority, with the exception of the younger male cohort. Other research has highlighted the less frequent participation in passive detection of cancer symptoms among young men (eg, [24,25]).

As noted, these findings are consistent with the well-documented gender and age differences in ratings of likelihood of using health services, for both psychological (eg, [26,27]) and physical problems (eg, [14]). Additionally, stronger commitment to health by women is consistent with a stronger, documented utilization of the Web for health and a more positive assessment of that information by women [28].

Analysis of preference for access to information targeted by gender and age (FAQs) versus nontargeted information provision (LIST) provided some support for the potential utility of targeted FAQs, with those in the CHOICE group overwhelmingly more likely to self-select the FAQ format than a general list. This may be because the FAQ “buttons” were more visually appealing—further work is required to deconstruct how people respond to information presented on a webpage and the relative importance of visual appeal, perceived relevance, and amount of information. Comparison of total scores on a measure of perceived usability and acceptability indicated that both FAQs and LIST information access routes were viewed as highly useable and acceptable. Subsequent analysis of ratings of relevance and likelihood of recommendation indicated that group, age, and gender had only a minor influence on these ratings; women rated the information they were exposed to as more relevant to people outside their age group than men, and younger people saw the information as less relevant to them and their peers.

Although there was no statistically significant difference between FAQ, LIST, or CONTROL groups on readiness to act on colorectal cancer risk at study end, a difference approaching significance ($P=.06$) suggests the need for further research. When viewed together with the data on preference for FAQs over LIST displayed by those responding to the choice condition, these findings suggest that FAQs may hold some promise as a strategy to facilitate interaction with information on the Web. Given the seeming ubiquity of their use on the Web, further identifying their impact on both intention to act and health behavior is important.

The importance of identifying optimum ways to provide credible and authentic cancer prevention and support advice on the Web is great, given the seeming ubiquity of internet use in the proactive search for information [3]. This has resulted in an argument for increased involvement of health professionals in the design, dissemination, and evaluation of information posted on websites [29]. Notwithstanding the importance of this aim, the impact of health messages identified by consumers on the Web will be impacted by their internet media literacy [30] and the strategies they use to interact with the information available on a website [31]. Findings from studies that have explored these strategies confirm the importance of user control of information flow [31].

Limitations

The study has several limitations. Participants were self-selected insofar that they had registered with a market research company as willing to be approached to complete surveys, and so may not be representative of the general population. Intention to reduce risk of colorectal cancer, rather than actual behavior, was measured and, because this information was captured immediately following the intervention, we were unable to ascertain whether the effect was maintained over time and translated to action. Further research could usefully investigate whether the intervention resonated with participants if the survey was administered 1 month following the intervention and actual behavior was captured.

Conclusions

In summary, few studies have examined whether the way in which access to health information is organized on the Web influences intended behavior or ratings of perceived relevance. Our results show some promising support for an organizational structure for cancer information access that uses age and gender as the organizing principle. These data are based on a small sample and reflect cross-sectional associations. Future research should examine how organization of access to information on the Web impacts on future health behavior as well as on endorsement and recommendation of a website to others. Further simplification of content and more complex and nuanced strategies for targeting (eg, by family health history, current health status, and other demographic variables) might achieve better outcomes.

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Conflicts of Interest

None declared.

Editorial notice: This randomized study was only retrospectively registered, which the authors stated was "because it was designed as a pilot and feasibility study to inform the development of a larger, population-based, randomized trial to investigate the efficacy of a Web-based informational intervention to influence colorectal cancer-preventive behavior." The editor granted an exception of ICMJE rules for prospective registration of randomized trials because the risk of bias appears low and the study was considered formative. However, readers are advised to carefully assess the validity of any potential explicit or implicit claims related to primary outcomes or effectiveness, as retrospective registration does not prevent authors from changing their outcome measures retrospectively.

Multimedia Appendix 1

Categorization and frequencies of self-generated information needs by gender and age group.

[\[PDF File \(Adobe PDF File\), 54KB - cancer_v4i1e2_app1.pdf \]](#)

Multimedia Appendix 2

Effect of intervention group, age, and gender on ratings of website relevance and likelihood of recommendation. Percentages have been rounded.

[\[PDF File \(Adobe PDF File\), 85KB - cancer_v4i1e2_app2.pdf \]](#)

Multimedia Appendix 4

CONSORT - EHEALTH checklist (V 1.6.1).

[\[PDF File \(Adobe PDF File\), 460KB - cancer_v4i1e2_app3.pdf \]](#)

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Abbreviations

BUPA: British United Provident Association

CHOICE: a self-selected choice of FAQs or a list of information topics

CONTROL: a control group that received no information

df: degrees of freedom

FAQ: frequently asked question

LIST: a list of information topics

RCT: randomized controlled trial

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Original Paper

Implications of Patient Portal Transparency in Oncology: Qualitative Interview Study on the Experiences of Patients, Oncologists, and Medical Informaticists

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Abstract

Background: Providing patients with unrestricted access to their electronic medical records through patient portals has impacted patient-provider communication and patients' personal health knowledge. However, little is known about how patient portals are used in oncology.

Objective: The aim of this study was to understand attitudes of the portal's adoption for oncology and to identify the advantages and disadvantages of using the portal to communicate and view medical information.

Methods: In-depth semistructured interviews were conducted with 60 participants: 35 patients, 13 oncologists, and 12 medical informaticists. Interviews were recorded, transcribed, and thematically analyzed to identify critical incidents and general attitudes encountered by participants.

Results: Two primary themes were discovered: (1) implementation practices influence attitudes, in which the decision-making and execution process of introducing portals throughout the hospital did not include the input of oncologists. Lack of oncologists' involvement led to a lack of knowledge about portal functionality, such as not knowing the time period when test results would be disclosed to patients; (2) perceptions of portals as communication tools varies by user type, meaning that each participant group (patients, oncologists, and medical informaticists) had varied opinions about how the portal should be used to transmit and receive information. Oncologists and medical informaticists had difficulty understanding one another's culture and communication processes in their fields, while patients had preferences for how they would like to receive communication, but it largely depended upon the type of test being disclosed.

Conclusions: The majority of patients (54%, 19/35) who participated in this study viewed lab results or scan reports via the portal before being contacted by a clinician. Most were relatively comfortable with this manner of disclosure but still preferred face-to-face or telephone communication. Findings from this study indicate that portal education is needed for both patients and oncologists, especially when portals are implemented across entire health systems since highly specialized areas of medicine may have unique needs and uses. Patient portals in oncology can potentially alter the way diagnoses are delivered and how patients and oncologists communicate. Therefore, communication about the portal should be established during initial consultations so patients can decide whether they want to be informed in such a manner.

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KEYWORDS

qualitative research; electronic health record; patient portals; physician patient relationship; health communication

Introduction

The uptake of patient portals by health systems is growing across the United States due to recommendations by the Institute of Medicine [1] and positive patient responses from accessing their electronic medical records through portals [2]. However, some providers remain skeptical about patient's unrestricted access to such medical information and have expressed concerns about the legal and ethical ramifications of patient portal usage [3]. In addition, studies analyzing physician's attitudes toward patients viewing medical information through portals found that there was concern that patients who were largely untrained and unprepared to view abnormal medical results [4,5] may be confused [5] and highly anxious [6] about their health condition.

Patient portals are relatively new applications, yet they are increasingly being offered to patients despite a limited number of studies that provide detail on successful implementation practices [7]. Moreover, the majority of research exploring experiences of patients using portals has focused on the primary care setting [8-13]. Primary care patients predominantly use patient portals to view doctor's notes, understand their condition, and to check for errors in their record [14]. Primary care patients have reported high levels of satisfaction when viewing lab results online [9]. However, patients favored office visits over Web portals for learning about abnormal cancer tests [15]. Face-to-face disclosures of cancer diagnoses and prognoses allow patients to express concerns, resulting in lower anxiety and depression [16-19].

The use of patient portals is growing in the oncology setting [20]. Cancer patients desire test results in the most rapid manner possible [21] and also rate the importance of electronic access to retrieve their medical records higher than patients without cancer [22]. However, in contrast to typical primary care patients, cancer patients who view results on patient portals may potentially discover that their cancer has grown or metastasized. This is particularly concerning as many cancer patients do not fully understand their prognosis [23]. Moreover, patients are viewing this information at a time of heightened emotional distress, characterized by fear and uncertainty, exacerbated by the complexity of the information [24]. Thus, distress levels of cancer patients may be compounded by unfettered access to their medical record through patient portals.

To illuminate our knowledge of the potential advantages and disadvantages of portal usage by cancer patients, we obtained the perspectives of key stakeholders—patients, oncologists, and medical informaticists. Since little is known about how cancer patients and other stakeholders utilize the portal, the goals of this study were (1) to understand attitudes about the adoption of the patient portal for oncology and (2) to explore the potential implications of patient portal usage as a method of communication in oncology.

Methods

Study Setting

This study took place at a National Cancer Institute designated cancer center in central Virginia. In June 2015, patient portals began displaying pathology results, doctor's notes, and after a 4-day delay, radiology reports. Over 70,000 patients across the entire health system are connected to the patient portal. Recruitment for this study occurred between May and September 2016. This study was approved by the local Institutional Review Board of Virginia Commonwealth University.

Participants

Oncologists

Members of the research team presented an overview of the study at hematology, radiation and surgical oncology service meetings. Out of the 46 oncologists present during the meetings, all agreed to be contacted in the future for potential study participation. Almost half (22/46, 48%) of the oncologists were randomly selected and then recruited through an email invitation to participate in the study. Informed consent was reviewed with willing participants, and written consent was obtained before the face-to-face interview.

Medical Informaticists

In total, 5 medical informaticists were recruited from the local health system. Among the 5 informaticists, 3 were members of the original patient portal committee that recommended its adoption, and 2 were involved in decisions regarding portal usage at the same institution. All 5 informaticists were contacted by email to participate in a face-to-face interview and written consent was obtained from them. To gain a broader perspective of opinions about portal transparency beyond the local health system, we sought viewpoints from external informaticists to either validate or provide alternative claims using purposeful snowball sampling [25]. Local medical informaticists referred 7 medical informaticists and chief medical information officers (CMIOs) at 5 health systems across the country utilizing similar information technology systems. An email invitation was sent that mentioned the referring medical informaticist and a description of the study. Informed consent was reviewed with potential participants who responded to the email, and verbal consent was given over the phone before interviews commenced.

Patients

Research staff identified potential patient participants using clinic schedules. Patients were eligible if they were (1) registered and enrolled in the portal, (2) fluent in English, (3) able to provide informed consent, (4) at least 21 years of age, and (5) had attended an appointment with a participating oncologist within the previous 4 weeks from patient identification.

From clinic schedules of oncologists, 72 eligible patients were randomly selected. In addition, purposive sampling [26] was used to recruit 6 patients, who were referred by participating oncologists since they reported a negative experience with the

portal. All 78 patients were mailed a letter explaining the study's purpose, with a form to opt-out of further contact coupled with a self-addressed stamped envelope. If no opt-out form was received until 2 weeks of the letter being mailed, a member of the research team contacted the patient by telephone to discuss study requirements, obtain verbal assent to participate, and to set up a time for the phone interview. Patients received a US \$25 gift card as appreciation for their participation.

Procedure

This study employed qualitative in-depth respondent interviews [27,28]. A semistructured interview guide was developed using the critical incident technique (CIT) [29], which is a qualitative research approach to collect information about significant incidents related to an event [30]. CIT has been used to analyze quality of care [31] and the applications of health care services [32]. CIT was employed by asking open-ended questions to elicit specific, in-depth details about respondent's encounters with patient portals. The semistructured interview guides were modified to enable use in each stakeholder group (oncologists, medical informaticists, and patients) and were designed to prompt their personal and professional experiences. For instance, patients were asked neutral questions about their experiences of using the portal to view their medical information, while oncologists were asked about their experiences with respect to patients using the portal. Similarly, all 3 groups were asked variations of the question, "how has viewing/inputting health information on the portal changed the way you interact with oncologists/patients?" The questionnaire was designed to have participants describe a situation, explain its significance, and specify the eventual outcome [33]. Interviews were audio-recorded, and ATLAS.ti (version 7.5, Scientific Software Development GmbH [34]) was used to manage the verbatim transcripts and coding process.

Data Analysis

The research team analyzed the transcripts verbatim using an iterative, thematic text analysis approach to best describe different stakeholder perspectives [35]. In the beginning, 2 members of the research team individually read 9 transcripts, 3 from each group, and began to develop preliminary codes [28]. They met weekly to compare coded transcripts, discuss discrepancies, and define codes that were compiled into a shared code book used by each coder on subsequent transcripts [36]. Subsequently, the entire research team gathered to synthesize, describe, and systematically group codes into larger-order thematic classifications. As part of this process, themes were compared across stakeholder groups to identify similarities and dissimilarities in experiences and attitudes. The authors confirm that all participant identifiers have been removed or disguised, so the participants described are not identifiable and cannot be identified through the details of their quotes.

Results

Demographics

Of the 60 participants enrolled, the enrollment rate was 59% (13/22) for oncologists, 92% (12/13) for medical informaticists, and 45% (35/78) for patients. Table 1 contains detailed

recruitment information. Of the 13 oncologists enrolled, 8 specialized in hematology/oncology, 4 in radiation oncology, and 1 in surgical oncology. The average age of the oncologists was 47 years, 54% (7/13) were women, and 77% (10/13) were white. Oncologists had an average clinical practice of 14 years, ranging from 3 to 33 years.

Half of the 12 medical informaticists were the CMIO at their institution, and the rest were clinicians trained as informaticists. The average age was 54 years with 24 years of medical practice, ranging from 11 to 34 years. Among the informaticists, 58% (7/12) were men, and 92% (11/12) white. All were physicians, except for 2 nurses. On average, patients were 54 years old, 60% (21/35) were women, and 24% (8/35) were reviewing information regarding breast cancer. A majority (25/35, 71%) underwent initial tests or was diagnosed at least 6 months before being contacted for this study. The status of cancer in patients included 43% (15/35) with metastatic cancer and 34% (11/35) with stage 2 cancer or further progressions. Compared with participants enrolled in the study, those who refused participation were slightly younger and mostly men. A full demographic summary is provided in Table 2.

Themes

We identified two primary themes (1) implementation practices influence attitudes, which describes how involvement, or lack thereof, during the decision-making and execution process of employing portals can impact the sentiment of the oncologists toward them and (2) perceptions of portals as communication tools varies by user type. This theme describes the lens of each stakeholder about how the patient portal is used to transmit and receive information, and contains several subthemes. Textboxes 1 and 2 provide a summary of the themes, subthemes, and representative quotes.

Theme 1: Implementation Practices Influence Attitudes

Opinions of oncologists about the portal were shaped by their lack of inclusion and consultation before the portal's implementation. Unable to voice their concerns about the potential of patients experiencing anxiety by viewing reports on their own, oncologists at the institution, where the study took place, were hesitant to embrace the portal. The portal's sudden implementation came as a surprise, as stated by the member of the medical informatics committee recalled about the decision to implement portals:

It was pretty uniform amongst all of us [on the committee] that we should...adopt [open access]...and there was not even a ruffle of any discussion about it. We just sort of sneaked it in on people. [Member of Informatics Committee]

During the initial rollout, sensitive tests such as pregnancy, HIV, scans and pathology were not visible to patients. However, the more medical informaticists used the system for less sensitive information, the more they believed that transparency was positively transforming patient engagement. After including test results such as scans and pathology, an embargo period of 14 days was established. Shortly thereafter, the embargo was reduced to 4 days. Medical informaticists were aware that physicians in other specialties would be concerned by the

shortened embargo, yet they did not receive any resistance nor were concerns voiced after the implementation.

According to oncologists, concerns were not raised because they were largely unaware of the embargo having been reduced to 4 days. A medical informaticist at the location of this study acknowledged this and said:

I don't think [oncologists] know about it [the reduction in embargo to 4 days].

Indeed, oncologists had limited knowledge of the patient portal's functionality which is exemplified below,

Provider training [is necessary]. I'd like to know like what patients can see and what the timeline is. [Radiation Oncologist]

Among external health systems, where medical informaticists sought buy-in from oncologists, better acceptability was reported. For example, a CMIO in the Western USA first acquired the endorsement of oncologists:

I worked with the chair and we went through all the different reports...He then went back to his group, explained it to the group. The group felt supportive of it as well and we moved on. [CMIO, Western United States]

However, the decision-making processes were unique to each institution. Some hospitals in the Western and Eastern United States did not make pathology reports accessible via the portal; a Midwestern hospital authorized a 7-day moratorium on scan reports; and a hospital in the Eastern United States unilaterally decided to implement based on the instructions of the CMIO.

Table 1. Recruitment summary and organization.

Participants	n (%)
Oncologists (N=46)	
Randomly selected to participate	22 (48)
Hematology	11 (24)
Radiation	10 (22)
Surgical	1 (2)
Enrolled in study	13 (59)
Hematology	8 (61)
Radiation	4 (31)
Surgical	1 (8)
Informaticists (N=13)	
Randomly selected to participate	13 (100)
Internal	7 (54)
External	6 (46)
Enrolled in study	12 (92)
Internal	6 (50)
External	6 (50)
Patients (N=78)	
Randomly selected to participate	72 (92)
Hematology	45 (63)
Radiation	23 (32)
Surgical	4 (5)
Referred by physician	6 (8)
Hematology	6 (100)
Radiation	0 (0)
Surgical	0 (0)
Enrolled in study	35 (45)
Hematology	24 (69)
Radiation	8 (23)
Surgical	3 (9)

Table 2. Sociodemographic characteristics of patients (N=35).

Characteristics of the patients	Values
Sex, n (%)	
Female	21 (60)
Male	14 (40)
Age in years, mean (SD)	53.7 (10.8)
Race, n (%)	
White	21 (60)
Black	14 (40)
Asian	0 (0)
Household income in US \$, n (%)	
Under \$19K	7 (20)
\$20K-\$39K	4 (11)
\$40K-\$49K	1 (3)
\$50K-\$74K	8 (23)
\$75K-\$99K	4 (11)
\$100K+	4 (11)
Prefer not to say	7 (20)
Education, n (%)	
Some high school	1 (3)
High school graduate	2 (6)
Some college	7 (20)
Associate degree	2 (6)
Bachelor's degree	13 (37)
Master's degree	7 (20)
Professional degree	2 (6)
Doctorate	1 (3)
Area of test/diagnosis^a, n (%)	
Breast	9 (24)
Hematologic	6 (16)
Gastrointestinal	5 (13)
Genitourinary	4 (10)
Lung	3 (8)
Sarcoma	3 (8)
Skin	3 (8)
Gynecologic	2 (5)
Other	3 (8)
Cancer status, n (%)	
Metastasized	15 (43)
Stage 2	4 (33)
Stage 3	4 (33)
Stage 4	4 (33)

^aEach diagnosis/condition counted separately for patients with multiple diagnoses/conditions.

Textbox 1. Representative quotes of theme 1.

Implementation practices influence attitudes—Responses to question about unawareness of oncologists to the test release timing results:

- *It's confusing because we brought it down from 2 weeks to 4 days and at the same time we brought the test results down from 72 hours to zero. And it's hard to keep up with all of that for them. So that's probably why.* [Informaticist]
- *It's very confusing because I feel like the health care system just threw it out there and it's almost like they threw providers and nurses under the bus because you don't know what the patient is seeing and when and you're just like, okay.* [Medical Oncologist]

Textbox 2. Representative quotes of theme 2 and its subthemes.

Perceptions of portals as communication tools varies by user type

- Lack of acknowledgment of the culture and communication processes surrounding the patient-provider relationship in different medical fields
 - *So I know my side in primary pediatrics, I don't know if I have a full understanding of what oncologists is, their side of it. I think it's two different, it's medicine, it's still sensitive subjects, sensitive discussions.* [Informaticist and Pediatrician]
 - *So in primary care, for the most part we're talking about laboratory results that are of a routine screening nature...which is potentially a motivator to help them do better with their diet, make sure they take their medications, things like that...I think for cancer patients, it's different...the big concern is finding out they've got recurrent disease or progressive disease before the doctor finds out.* [Surgical Oncologist]
- Patient preferences for receiving information
 - *I do everything digitally so I love just being able to just pop on there and see immediate results and also gave me a history of tracking so if I wanted to be able to look back at something it was easy to do that and then also to communicate with the doctor and whenever I had questions I would post an email for him.* [Patient, Lymphoma]
 - *It is helpful to be able to go on and check it out. I had a CT scan, I know I can go on there in just a couple days and check it out and see what the radiologist wrote. And then I find that very comforting.* [Patient, Lung Cancer]
 - *The best way would be to go to the doctor direct about it...I think finding out from the doctor is the best way. Obviously.* [Patient, Stomach Cancer]
- Type of information disclosed
 - *I just got back from the doctor yesterday and I had to wait 2 or 3 weeks to find out the results of my CAT scan. Because they had thought that it might have been lung cancer. So I've been worried...[Using the portal] would have been very helpful.* [Patient, Sarcoma]
 - *There is established literature that says that the patient, physician discussion of breaking bad news, is an important role of a physician and that it's done compassionately in person, much better than on your own and over the phone.* [Medical Oncologist]
 - *I do not want to read on an MRI that my diagnosis is cancer. I would rather have a doctor discuss that with me before I have to review it online.* [Patient, Sarcoma]
 - *I had very difficult interactions in the past trying to break news over the phone for somebody who didn't want to wait for their appointment because they were expecting one outcome and they saw another. And there's no further counseling that can take place. They're in the middle of their own workplace environment. They don't have their family's support there, they're not braced for these types of things and it was a very negative experience.* [Medical Oncologist]

Uncertainty about patient access was shared by medical informaticists at other institutions, but the benefits of transparency outweighed concern. Benefits included greater patient engagement and patient vigilance. For instance, a CMIO lauded the capability of patients to easily share information with family members and being able to discover inconsistencies in their record. Speed was also important, as quoted below:

Patients are really eager to be able to have both rapid access and more complete access. [Medical Informaticist, Western United States]

Theme 2: Perceptions on Portals as Communication Tools Vary by User Type

Oncologists, medical informaticists, and patients—the three stakeholders—cited examples of portal usage and how the portal was incorporated into their daily lives. The following subthemes

emerged: (1) lack of acknowledgment of the culture and communication processes surrounding the patient-care-provider relationship in different medical fields, in which oncologists and medical informaticists explained the norms of communicating with patients in their fields and differences in the meaning of paternalism; (2) patient preferences for receiving information, including whether patients view the portal before communicating with their oncologist and the ideal setting to receive diagnostic results, and (3) type of information disclosed, wherein the patient's phase of diagnosis determined their comfort level while using the portal.

Subtheme 2.1: Different Culture and Communication Processes

A cultural divide was present between oncologists and medical informaticists: none of the informaticists involved in this study had a background in oncology. Most medical informaticists

specialized in internal or family medicine, but they recognized that viewing information about potential metastasis could be different from primary care issues. The apprehension of oncologists toward the patients accessing medical information via patient portals stemmed from their belief that tests for cancer were more sensitive than common laboratory results screened during primary care visits. However, medical informaticists downplayed potential risks by citing existing literature indicating that it was not a problem and the fact that they have not personally encountered such negative incidents. Ultimately, the purview of informaticists was championed by a CMIO and internist, who recommended:

[Oncologists must] Get out of their comfort zone and recognize this as a new era.

However, oncologists remained steadfast in their belief that the patient-provider relationship, as well as the utilization of patient portals would be unique in cases of cancer and differed from primary care.

The stakes in oncology are really high. In primary care, if you get an x-ray of someone's shoulder, you're looking for arthritis. If I get an x-ray...I'm looking for a bone metastasis. [Radiation Oncologist]

Due to the precariousness of cancer, oncologists purposefully scheduled face-to-face meetings. However, interviews revealed that the patient portal has increasingly driven oncologists to communicate over the phone. A medical oncologist recalled the importance of face-to-face interactions:

There are times when you need to be able to hold hands...You need to be able to see them...to help them understand what that news really means. [Medical Oncologist]

Despite the beliefs of the oncologists that in-person discussions were necessary, informaticists considered any delay in disclosing results as paternalism. A family physician and informaticist decried the process of patients returning to the hospital to learn diagnoses and wondered:

If this was my MRI, would I want to wait for 2 weeks? Hell no...If that's right for me, why isn't it right for my patients? [Family Physician]

Oncologists, who were concerned about patients viewing scans or pathology results on their own using the portal, suggested alternative solutions such as permitting a function that allows tests to be released after a physician views it, but that type of functionality was not technologically feasible at the time when this study was conducted. Medical informaticists did not have the technology modify the visibility of certain tests for certain departments.

Subtheme 2.2: Patient Preferences for Receiving Information

Oncologists and medical informaticists were ardent in their respective beliefs, but these beliefs were somewhat disconnected to the perceptions of patients on the role of portals. Patients being treated or screened for cancer displayed attitudes and behaviors suggesting that despite some hesitation, they were largely comfortable using the portal. More than half (19/35, 54%) of patients interviewed retrieved test results or scan reports

using the portal before speaking with a provider. None of the patients expressed shock or extreme distress. In fact, a patient with a rare blood cancer appreciated the ability to discover the diagnosis on her own and said:

I learned about this in the privacy of my home where it's quiet.

The lack of distressed patients was in accordance with the limited number of negative incidents as cited by oncologists. Most (7/13, 54%) oncologists did not experience a negative incident, but instead mentioned anticipated dangers or negative experiences of their colleagues. Among the (6/13, 46%) oncologists who cited specific instances, each described a patient who suffered anxiety believing that their cancer had reoccurred. Due to such cited examples, 3 patients participating in the study were referred. When asked to describe their incident, a woman said that she experienced “no stress,” while a breast cancer patient said that her anxiety levels were raised “a little bit.” In general, cancer patient responses to portal usage were influenced by their stated preferences for communication with their oncologist and the types of information being disclosed.

Although patients preferred swift results, most patients believed that in-person meetings or phone calls were ideal to receive a diagnosis. A woman with breast cancer remembered her consultation and said:

By meeting with her [the oncologist], it made it more personal that she actually cared about the outcome versus, the report will be up there, you can read if you have cancer. [Breast Cancer Patient]

However, the portal was a welcome alternative if either a phone call or in-person meeting caused any delay in receiving results. Another breast cancer patient said:

I would've liked to have had the oncologist call me and say it's not cancer or, just make the report available on the portal. Rather than having it held before I could view it...I would've liked to have had it as soon as it was available. [Breast Cancer Patient]

While oncologists were fearful that patients would experience distress, most patients appreciated the ability of advanced access to medical reports, because as a breast cancer patient said:

When I am in the doctors' office, I'm not blindsided by information...there's no surprises.

Armed with their medical information in advance, patients claimed that face-to-face appointments were more productive with oncologists. Oncologists agreed that advanced access can improve engagement during consultations, as well as assist patients after appointments by allowing them to review information that was discussed.

Subtheme 2.3: Types of Information Disclosed

Patients with a previous cancer diagnosis or in the survivorship phase spoke positively about using the patient portal during or after treatment. However, they expressed reservations about the prospect of learning a cancer diagnosis through the patient portal. A lung cancer patient imagined the difficulties in not being able to get immediate answers to her questions, while a breast cancer patient stated:

I guess if I had found out over the Internet instead of face-to-face with a doctor that I had cancer the first time, it might be a little daunting. [Breast Cancer Patient]

Patients also placed different values on different types of tests. A man with sarcoma said:

I don't mind reading my blood levels, but if we're talking about...worsening or getting better, those things should come from the physician. [Sarcoma Patient]

A surgical oncologist agreed that scans, pathology, and biopsy reports should be disclosed by the physician. He went on to say,

[Reports] require a fair amount of explanation, particularly to a layperson who doesn't understand them. [Physician]

Relatedly, a medical oncologist worried that a rift may form between the patient and oncologist because positive findings may be present on the report, even though they are insignificant. He wondered if patients would trust oncologists less because some patients may be skeptical of what their oncologist was telling them, after reading the report themselves.

Discussion

Principal Findings

Health care delivery increasingly relies on technology to manage aspects of patient care [37]. In oncology, technology (eg, patient portals) is still novel, but its introduction assures implications for both patients and clinicians. In our interviews about the perceptions and use of the patient portal in oncology, we discovered divergent views and no clear blueprint for properly implementing such a system. The introduction of electronic records and health information technology in general has been known to profoundly affect health systems, impacting health care delivery [38] and altering relationships among patient care providers [39]. We found that while informaticists advocated for full transparency, oncologists preferred more control over the delivery of information, even though their fears of patient distress were generally unrealized. One explanation for this divide could be that none of the informaticists specialized in oncology and were mainly primary care physicians. Although it is not atypical for primary care physicians to break bad news, oncologists frequently deal with high mortality rates and face highly stressful situations on a daily basis, commonly addressing topics such as death, dying, and palliative care [40].

When faced with complex, potentially life-threatening, medical information through the portal, patients in our study seldom expressed concern or felt that they experienced additional distress. In fact, some patients found solace in being able to review their results on their own terms. This is consistent with limited studies that have measured anxiety among cancer patients who accessed test results through patient portals and also experienced low levels of distress [41-44].

Patient's lack of concern may be explained by the fact that the majority of participants (25/35, 71%) had progressed more than 6 months from their initial diagnosis and 43% (15/35) had

developed metastasized cancers. These patients had been managing their disease with treatment over the course of several months or years, may have gained knowledge and experience, and thus may have become desensitized to viewing their medical information compared with the patients confronted with an initial diagnosis.

Our findings that the majority of patients who were interviewed reviewed test results or scan reports before speaking with a provider is noteworthy. Perhaps, during an initial oncology consultation, oncologists should note that potentially threatening risk information can be available by using the portal and identify whether the portal is the patient's preferred communication channel. Oncologists should also recognize that their own preferred method of delivering bad news via in-person disclosures [45,46] accompanied by emotional support, may need to be modified in the light of patient preferences for immediate delivery of results [47], even when they are abnormal [48]. Similar to previous studies examining use of the Internet by patients to manage their cancer care, computer-savvy patients may necessitate the need for providers to modify the way they interact with patients [49].

Limitations and Future Directions

Despite the attempt to broaden the sample with representatives from other health systems, our results may still not extend beyond the health system in which this study was conducted. Similarly, the sample may include a proportional bias, since only patients enrolled in the portal were eligible, and almost all informaticists who advocated for portals agreed to participate. In addition, the average age of our sample was 54 years. It is possible that inclusion of younger patients would produce additional perspectives. Moreover, we did not recruit patients with newly diagnosed disease or new evidence of metastatic disease. Although it was important to report differences of recollections between perceptions of oncologists and patients, all patients in the study had received their diagnosis before the study, which highlights the need for further research to examine real-time responses using larger samples instead of recollected responses. In addition, to further illuminate our knowledge, future work is warranted to explore the attitudes and perceptions of patients with a broader range of disease sites and stages and to include patients who are early in their cancer trajectory. We also plan to involve patient's family members and caregivers, who are often avid patient portal users [50]. Further research could also focus on measuring how other highly specialized medical departments use patient portals and whether training programs and targeted education about portal use is an effective way of ensuring that portals are being used to optimize the quality of patient care.

Conclusions

Our findings indicate that the complexity of communicating medical information related to oncology varies the utility of patient portals. Although most patients prefer in-person consultations to learn about their condition, the patient portal is rapidly being accepted and may force oncologists to alter their communication habits.

Most cancer patients who participated in the study checked their laboratory results or scan reports in the portal before being contacted by their provider. Although most were relatively comfortable with this manner of disclosure, few patients were checking an initial diagnosis, wherein the preferred disclosure method was phone or face-to-face. As informaticists and other high-ranking personnel within health systems make tests available to patients through the portal, it is necessary that in-depth discussions with specialized areas of medicine, such as oncology, must take place. The implementation process across the entire health system is unlikely to succeed if certain groups are not able to give their input about critical features of the portal. However, oncologists should understand that the delivery of medical information via patient portals is inevitable, and therefore, they must take efforts to discuss the portal with

patients. Although using the patient portal as a new channel to transmit medical information will require oncologists to alter their communication methods with patients in the short term, establishing best practices will allow oncologists to incorporate new techniques before portal adoption.

In summary, we sought the perspectives of patients, oncologists, and informaticists to understand the advantages and disadvantages of patient portals in the oncology setting. Results indicate that the portal may provide benefits, such as enabling more productive in-person appointments. However, education and training is necessary to inform patients and oncologists of the portal's advantages. We anticipate that this study helps generate additional insights that will help future research in using patient portal technology in oncology effectively.

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Conflicts of Interest

None declared.

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Abbreviations

CMIO: chief medical information officer

CIT: critical incident technique

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Original Paper

Internet-Based Group Intervention for Ovarian Cancer Survivors: Feasibility and Preliminary Results

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Abstract

Background: Development of psychosocial group interventions for ovarian cancer survivors has been limited. Drawing from elements of cognitive-behavioral stress management (CBSM), mindfulness-based stress reduction (MBSR), and acceptance and commitment therapy (ACT), we developed and conducted preliminary testing of an Internet-based group intervention tailored specifically to meet the needs of ovarian cancer survivors. The Internet-based platform facilitated home delivery of the psychosocial intervention to a group of cancer survivors for whom attending face-to-face programs could be difficult given their physical limitations and the small number of ovarian cancer survivors at any one treatment site.

Objective: The aim of this study was to develop, optimize, and assess the usability, acceptability, feasibility, and preliminary intended effects of an Internet-based group stress management intervention for ovarian cancer survivors delivered via a tablet or laptop.

Methods: In total, 9 ovarian cancer survivors provided feedback during usability testing. Subsequently, 19 survivors participated in 5 waves of field testing of the 10-week group intervention led by 2 psychologists. The group met weekly for 2 hours via an Internet-based videoconference platform. Structured interviews and weekly evaluations were used to elicit feedback on the website and intervention content. Before and after the intervention, measures of mood, quality of life (QOL), perceived stress, sleep, and social support were administered. Paired *t* tests were used to examine changes in psychosocial measures over time.

Results: Usability results indicated that participants (*n*=9) performed basic tablet functions quickly with no errors and performed website functions easily with a low frequency of errors. In the field trial (*n*=19), across 5 groups, the 10-week intervention was well attended. Perceived stress (*P*=.03) and ovarian cancer-specific QOL (*P*=.01) both improved significantly during the course of the intervention. Trends toward decreased distress (*P*=.18) and greater physical (*P*=.05) and functional well-being (*P*=.06) were also observed. Qualitative interviews revealed that the most common obstacles participants experienced were technical issues and the time commitment for practicing the techniques taught in the program. Participants reported that the intervention helped them to overcome a sense of isolation and that they appreciated the ability to participate at home.

Conclusions: An Internet-based group intervention tailored specifically for ovarian cancer survivors is highly usable and acceptable with moderate levels of feasibility. Preliminary psychosocial outcomes indicate decreases in perceived stress and

improvements in ovarian cancer-specific QOL following the intervention. A randomized clinical trial is needed to demonstrate the efficacy of this promising intervention for ovarian cancer survivors.

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KEYWORDS

ovarian cancer; quality of life; feasibility studies; eHealth; psychological stress

Introduction

Due to difficulties in early detection, the majority of new cases of ovarian cancer (61%) each year in the United States are women diagnosed with advanced-stage cancer [1]. At present, 5-year survival rates for ovarian cancer are relatively low (46% overall) and drop to 29% for those with distant disease and 20% for those over the age of 75 years [1]. Although a significant percentage of patients respond well to initial chemotherapy, treatment efficacy is limited by the development of chemoresistance, and the majority of patients relapse and die from recurrent disease [2]. Thus, ovarian cancer survivors face a unique set of challenges related to late diagnosis, rigorous medical treatments, and poor prognosis.

Given these challenges, it is not surprising that most ovarian cancer survivors report high levels of distress at diagnosis, during treatment, and subsequent disease surveillance [3,4]. During the first year following primary treatment, patients report high levels of anxiety and depressive symptoms, sleep disturbance, fatigue, and treatment side effects (eg, peripheral neuropathy), which impacts their overall quality of life (QOL) [3,5]. Although QOL generally improves over time, patients utilizing avoidant or disengaged coping strategies are at risk for poor QOL [6,7]. Additionally, a greater number of life stressors at 1 year post surgery is associated with poorer concurrent QOL [8]. Numerous studies have identified links between psychological processes and biological pathways related to ovarian cancer progression [9,10]. Specifically, higher levels of perceived social connections with others are related to a more vigorous innate immune response, lower levels of biomarkers related to angiogenesis and invasion, lower levels of the stress hormone norepinephrine in tumor, and genomic changes in tumor indicative of a less aggressive phenotype [10]. Moreover, socially isolated ovarian cancer patients have been shown to have poorer survival [9]. These findings highlight the importance of psychosocial factors in both QOL and survival in ovarian cancer and identify psychosocial factors, particularly emotional social support, as potentially modifiable treatment targets.

A substantial amount of literature has documented the efficacy of psychosocial interventions in improving mood and QOL in cancer patients [11-13]. Although a variety of interventions have been developed for breast cancer survivors [14], development of psychosocial interventions that address ovarian cancer survivorship has been much more limited. Most existing trials have been pilot interventions utilizing small samples [15-20] or exercise- or symptom-based interventions [16,18,21,22]. Barriers to the development and implementation of interventions for ovarian cancer survivors include the relatively small number of ovarian cancer patients at any one treatment site, older age of patients, and physical limitations

(eg, neuropathy, fatigue, and cognitive problems), which make it difficult to attend an in-person intervention. A pilot study successfully addressed this difficulty with a 6-month exercise- and phone-based cognitive-behavioral therapy (CBT) intervention [16].

Given the significant problems of distress, social isolation, and poor QOL and the well-established links with biological pathways related to progression, there is a great need for the development of an easily accessible, group-based psychosocial intervention for ovarian cancer survivors. An Internet-based intervention is an ideal approach in this population and offers a number of advantages. First, an Internet-based intervention would provide the opportunity for the small number of ovarian cancer survivors from any treatment center to join with other survivors from around the country. Second, it would enhance accessibility for survivors in rural areas and those with physical limitations who would otherwise not be able to attend an in-person group. Internet-based group interventions have been found to be beneficial for women with breast cancer [23], men with prostate cancer [24,25], and posttreatment cancer survivors [26].

We have developed a 10-week, manualized Internet-based group intervention for ovarian cancer survivors entitled Living WELL: Web Enhanced Lessons for Living for Ovarian Cancer Survivors. The intervention incorporates elements of cognitive-behavioral stress management (CBSM) [27,28], mindfulness-based stress reduction (MBSR) [29,30], and acceptance and commitment therapy (ACT) [31]. It also incorporates topics specifically tailored to address the needs of ovarian cancer survivors such as finding meaning in the face of poor prognosis and managing fear of recurrence. Using a password-secured Web platform that can be used on any Internet-enabled device (eg, tablet, laptop), participants can access a link to the weekly videoconference as well as relaxation and meditation recordings, a journal to record daily gratitude or reflections, and content overviews. The aims of this study were to (1) develop and optimize the intervention and its Web platform and (2) examine the usability, feasibility, acceptability, and preliminary intended effects of an Internet-based group intervention for ovarian cancer survivors.

Methods

Study Design

Institutional review board approved all study procedures. Intervention development involved testing the usability, acceptability, and feasibility of the intervention's content and technological platform (eg, website, tablet, videoconference platform) as well as assessment of intended effects. This testing

was done in 3 stages: lab usability testing, field usability testing, and a one-arm field trial of the full 10-week group intervention.

Recruitment and Participants

Participants were recruited between May 2013 and October 2016. Participants for usability testing were recruited in-person at an oncology clinic at a large Midwestern medical center and by mailings to former participants in a longitudinal ovarian cancer study. Field trial recruitment additionally included listings on the Ovarian Cancer Research Fund Alliance website, flyers in oncology clinics in the Midwestern and Western United States, announcements in local gynecologic oncology newsletters, and referrals from oncology staff or previous participants. Individuals interested in participation called or emailed research staff to receive additional information about the study and participated in a brief eligibility screening. The study was open to English-speaking women with a histological diagnosis of any stage of primary ovarian epithelial cancer, primary peritoneal cancer, or cancer of the fallopian tube following completion of primary chemotherapy. Exclusion criteria included more than one recurrence of ovarian cancer, prior inpatient psychiatric treatment for severe mental illness, or overt signs of severe psychopathology (eg, psychosis) or dementia. Participants who recurred during the field trial and

began a new course of chemotherapy (n=2) were able to continue in the intervention; otherwise, participants on chemotherapy were excluded until treatment was completed. All participants provided verbal informed consent.

For the lab and field usability testing, 25 individuals were mailed a recruitment letter, and 19 individuals were reached by phone to discuss participation. In usability testing, 9 women enrolled and participated (6 lab usability; 5 field usability; 2 participated in both). Reasons for not participating included scheduling conflicts (n=2), being too busy (n=2), and lack of interest (n=6). For the field trials, 76 recruitment letters were sent, in addition to information posting as indicated above. Furthermore, 65 individuals emailed research staff requesting more information. A total of 31 women enrolled in the field trial; 3 withdrew before the intervention began for reasons such as being too busy (n=1) and lack of interest after receiving study materials (n=2). There were 9 participants who attended at least one session but did not complete the intervention; dropouts completed an average of 3 sessions (range 1-7). Reasons for dropout included recurrence with rapid disease progression (n=1), family illness (n=1), being too busy (n=4), and changed mind about participating in a group intervention (n=3). In total, 19 participants completed the intervention (Figure 1).

Figure 1. Participant recruitment and retention flowchart for field trial.

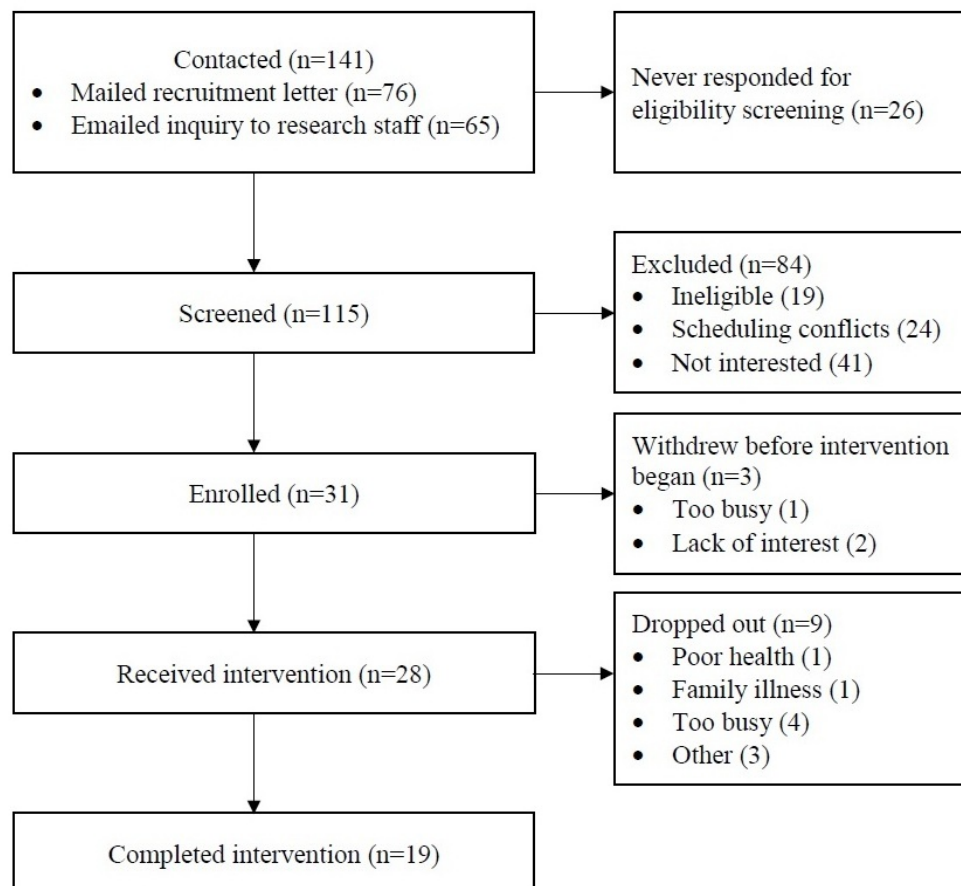


Figure 2. Intervention homepage.

Web Platform

The Web platform was developed so that participants could easily and securely connect to the group meetings and access intervention content outside of group (see Figure 2 for a screenshot of the Living WELL homepage). It included weekly content overviews, relaxation and meditation recordings, and a journal to record daily gratitude or reflections. It also included a link to the videoconference program, so that participants could connect to the group meetings. WebEx videoconference software (Cisco Systems, Inc., San Jose, CA) was used during the lab and field usability testing and the first 3 field trial groups. In the final 2 field trial groups, Zoom videoconference software (Zoom Video Communications, Inc., San Jose, CA) was used.

Development of the Web platform employed Northwestern University's (Chicago, IL) Behavioral Intervention Technology Core Facility Extensible Information and Communication Technology Intervention Platform. This platform uses a combination of open-source technologies including Linux, Python, and MySQL server technologies. It is designed for maximum flexibility in interfacing with other technologies while maintaining optimal security and full compliance with the US Health Insurance Portability and Accountability Act (HIPPA). A standardized interface exists to manage user experience as well as enable reports about site usage and data. The intervention's website was designed and optimized for deployment on tablets but could be accessed with any Internet browser on laptops, desktops, and smartphones.

Lab and Field Usability Testing

Lab usability testing consisted of a 90-minute session in a quiet room with research staff, in which participants were provided with a Samsung Galaxy 2 tablet as well as oral and written

instructions on how to use the device and access the intervention website. Participants were asked to perform a series of tasks involved in the operation of the device and website during which they completed a "think aloud" task where they provide a running commentary while executing tasks. They were also asked to give verbal feedback on obstacles they encountered as well as their overall experience with the technical components of the website.

Field usability testing was done from the participant's home with study staff available by phone. Upon enrollment, participants were mailed a tablet and user manual. If participants did not have wireless Internet, they received a tablet with 4G capability to provide Internet access. Headphones were supplied if participants needed additional assistance with sound quality. Tablets and headphones were returned upon study completion. In the first session, participants were asked to perform a series of tasks involved in the operation of the device and website. Participants were asked to describe aloud what they were doing to accomplish these tasks. If participants were not yet comfortable with connecting to the videoconference platform on their own, additional practice was offered. Once participants were comfortable connecting to the videoconference, a second and final session was scheduled in which participants were instructed to connect via videoconference with research staff at an appointed time. Before their final session, participants were asked to access the website and review its features at least two other times on their own. In this final session, participants were asked to report their experiences including obstacles with Web activities and evaluation of the website and user manual.

Field Trial Testing

Enrolled participants were given the option of using their own electronic device or a study-provided tablet. The intervention

was a structured 10-week group intervention that met weekly for 1.5 to 2 hour sessions via videoconferencing. Groups were made up of 4-6 ovarian cancer survivors and led by 2 clinical psychologists. In each session, the psychologists introduced a new meditation/relaxation exercise, reviewed homework from the previous week, presented new material, and directed discussion.

The intervention was adapted from a CBSM intervention manual in breast cancer [27,28]. Specific CBSM elements in the current intervention included relaxation training and developing stress management skills through in-session didactic material, experiential exercises, and home-based practice. Mindfulness and acceptance-based exercises from MBSR and ACT were incorporated to increase awareness of distressing thoughts and feelings without having to change or avoid them. ACT-based exercises were also used to help identify values and prioritize meaningful activities in one's life. The intervention consisted of 10 major themes, listed in Table 1, with accompanying relaxation and meditation exercises. A screenshot of the website's weekly overview page is shown in Figure 3.

Participants were asked to engage in intervention-related activities on their own, including brief homework assignments, daily journaling, and relaxation and meditation exercises. Participants received a printed workbook with the 10-week intervention content and a user manual with instructions on how to navigate the website and videoconference program.

Evaluation of Lab and Field Usability

All participants completed a survey including demographic and clinical information and ratings of their experience with various technologies (eg, computer, tablet, smartphone). Participants were classified as living in rural or urban location based on county residence using the 2013 US Department of Agriculture Rural-Urban Continuum Codes. For the purposes of this study, codes 7-9 were considered rural locations, a classification method used in previous research in cancer survivors [32,33].

Usability

Usability was assessed by completion of common usage tasks, including (1) performing basic tablet functions (eg, turning it on, charging it, entering the proper application); (2) accessing the website (eg, logging in with user id and password); (3) accessing the website features (eg, listening to relaxation recordings); and (4) asking for and utilizing technical support. Research staff recorded the amount of time it took participants to learn and execute tasks as well as their efficiency, frequency, and type of errors made, and ability to perform tasks again after a delay.

Qualitative interviews were used to explore experiences with the system and elicit feedback on the content. Consistent with principles of usability testing, an iterative process was used. Changes in the Web platform were made based on initial feedback. Then, a second group was tested and their feedback was used to further refine the Web interface and content [34,35].

Table 1. Weekly session topics and relaxation and meditation exercises.

Week	Session topic	Exercise
1	Introduction: Participants and group leaders introduce themselves. Didactics: Stress response and stress management. Discussion: developing an awareness of personal stressors and finding meaning and sources of personal strength	Deep breathing and progressive muscle relaxation
2	Automatic thoughts: Lecture and exercises to demonstrate the relationships between thoughts, emotions, and physical responses. Demonstration and discussion of appraisal process and cognitive distortions	Passive progressive muscle relaxation and guided imagery
3	Rational thoughts: Lecture and discussion on breaking the vicious cycle of irrational thoughts with rational thought replacement. Demonstration and discussion on alternative responses to negative self-talk	Autogenic relaxation
4	Acceptance: Introduction to mindfulness. Lecture and discussion of avoidance and control strategies and finding effective alternatives through personal values, acceptance, and gratitude	Guided mindful body scan
5	Coping strategies: Lecture and discussion on active problem-focused or emotion-focused coping strategies such as setting prioritizes, asking for help, and relaxation. Exercise on softening in response to painful feelings and emotions	Mindfulness meditation
6	Social support: Lecture on the benefits and types of social support. Exercise on identifying social support and disease-related challenges in communication (eg, fear, changes in intimacy). Discussion of strategies for enhancing support	Mindfulness meditation
7	Effective communication: Lecture on communication styles and effective communication. Exercises and discussion on effective communication and using a mindful moment to become aware of needs and communicate them effectively	Mindfulness meditation
8	Anger: Lecture and discussion on anger. Exercises on identifying patterns of anger expression and steps for dealing with anger such as appraising the situation	Loving kindness meditation
9	Meaning of life: Discussion of how personal values and spirituality help create meaning in life and can change because of cancer. Discussion of strategies to deepen spirituality and meaning such as personal reflection, prayer, and writing	Guided relaxation and visualization
10	Wrap up: Lecture and discussion reviewing material and assessing personal growth. Exercise helping participants develop a stress management maintenance plan	Guided relaxation and visualization

Figure 3. Intervention didactic content, weekly overview.

Acceptability

Acceptability was measured using a system usability questionnaire (SUQ) modified versions of the System Usability Questionnaire and After-Scenario Questionnaire [36,37] to evaluate user satisfaction and feedback. The questionnaire consisted of rating scales (1 being *strongly agree* to 7 being *strongly disagree*) and free form responses, which asked for general feedback on the overall system (ie, tablet, website, and videoconference platform).

Evaluation of Field Trial

For all self-report measures in field trial, participants were emailed a link to a Web-based survey tool using Qualtrics (Qualtrics, Provo, UT, USA). These surveys were in accordance with the Checklist for Reporting Results of Internet E-Surveys (CHERRIES; [Multimedia Appendix 1](#)) [38]. Structured interviews were conducted over the phone, and the information obtained was used to optimize the intervention manual content (eg, refining language, modifying content and changing the order of presentation, and changing language in relaxation scripts).

Acceptability

A 20-item survey, similar to that developed for usability testing, was used to assess acceptability and obtain user satisfaction ratings and feedback. This survey was administered after each group session. It consisted of 10-point Likert scales and free-form responses, requesting feedback on the overall system (eg, website, videoconference platform) and the relevance of that session's content (eg, topics, relaxation and meditation exercises). Higher scores reflected better ratings. Acceptability and user satisfaction were also assessed with a phone-based structured interview at the conclusion of each 10-week group.

Interview questions were separated into themes, including ease of access, usefulness of content, obstacles, and suggestions for improvement.

Feasibility

Feasibility was assessed in the field trial testing. It was demonstrated using study recruitment and study retention. Feasibility was also measured by the frequency of 3 intervention-related activities, including number of sessions attended, number of journal entries completed, and meditation/relaxation exercises completed. For each participant, a total for each activity was tallied on the website administrator page by research staff.

Preliminary Outcomes

Preliminary psychosocial outcomes of the 10-week intervention were evaluated by self-report measures at baseline and immediately following the last group session.

The Functional Assessment of Cancer Therapy-Ovarian Form (FACT-O) is a 51-item scale measuring QOL in patients with ovarian cancer [39,40]. This scale includes 4 subscales related to general dimensions of well-being, including physical, functional, social, and emotional. It also includes an ovarian cancer-specific subscale with items related to ovarian cancer and treatment-specific QOL issues. The Perceived Stress Scale (PSS) is a 14-item self-report measure used to assess current life stress [41]. Item responses are summed and higher scores indicate more perceived stress.

A total of 2 measures were used to assess mood. The Center for Epidemiologic Studies Depression (CESD) scale is a 20-item self-report measure used to assess depressive symptoms [42]. The Profile of Mood States short form is a 37-item inventory,

assessing 6 dimensions of mood, including anxiety, depression, anger, vigor, fatigue, and confusion [43]. A total mood disturbance score is calculated from the sum of all scales minus the vigor scale. Both scales are cued to mood over the last week.

The Pittsburgh Sleep Quality Index is a 19-item self-report measure assessing sleep quality and sleep disturbances over a 1-month period [44]. This measure includes 7 subscale scores that are summed to produce a global score with a score. The Social Provisions Scale is a 24-item self-report measure used to assess social support [45]. These subscales are summed to produce a total score.

Data Analysis

Data from weekly postsession evaluations, website usage, and self-report surveys were downloaded and stored in SPSS 23.0 (SPSS Inc., Chicago, IL, USA). Distributions were examined for normality and outliers. Paired *t* tests were used to examine changes in self-report psychosocial measures from baseline to follow-up. Level of significance was set at $P < .05$. Effect sizes were calculated as the standardized mean differences between the baseline and follow-up time points. The effect sizes and 95% CI reported here were calculated using Hedges's *g* because this method helps reduce positive bias in small samples [46].

The relationships between intervention-related activities and psychosocial outcomes were examined with those measures that showed statistically significant changes during the intervention. These relationships were examined with bivariate correlations using the number of intervention-related activities (ie, session attendance, journal entries, and relaxation and mediation exercises) and change (delta) scores. Delta scores were calculated by subtracting preintervention scores from postintervention scores to examine changes during the intervention in PSS and ovarian cancer-specific subscale of the FACT-O. A higher score on the PSS indicates greater disturbance; thus, a negative delta score indicates a decrease in perceived stress over time. Higher scores on the ovarian cancer-specific subscale indicate better QOL; thus, a positive delta score indicates improved QOL over time.

Results

Participant Characteristics

A total of 6 participants completed lab usability testing and 5 completed field usability testing; 2 of these participants completed both lab and field usability testing. As shown in Table 2, the sample was entirely white, non-Hispanic with an average age of 59.20 years (standard deviation [SD] 14.53). More than half of the sample (56%, 5/9) was college educated. Of the participants, 33% (3/9) lived in rural counties; 89% (8/9) reported an advanced-stage diagnosis (stage III or IV). The average time since diagnosis was 2.5 years (SD 2.12). All participants had completed their primary chemotherapy treatment, although 22% (2/9) were currently receiving additional chemotherapy. Approximately 89% of participants (8/9) had high-speed Internet access and a computer at home.

Moreover, 4 participants (44%) reported using videoconference services, and 7 participants (78%) reported using at least one social media service.

In the field trial, 19 participants completed the intervention during 5 successive groups. Group sizes ranged from 3 to 4 completers. As shown in Table 2, the sample was entirely white, non-Hispanic with an average age of 58.89 years (SD 6.87). Participants were located in 7 different states (from New York to Washington), and 4 participants (26%) lived in rural counties. The majority of the sample was college educated (14/19, 74%) and married (14/19, 74%). A total of 9 participants (48%) reported an advanced-stage diagnosis (stage III or IV) with an average time since diagnosis of 2.37 years (SD 1.67). Of these, 3 participants had a disease recurrence and received chemotherapy treatment at some time during the intervention. There were no significant differences in demographic or clinical characteristics between participants who completed the intervention and those who dropped out.

All participants had high-speed Internet access and a computer at home. However, due to poor video or audio quality during group sessions, tablets connected to cellular wireless networks were sent to 2 participants, which improved their connectivity and user experience. A total of 8 participants (42%) used a study-provided tablet to connect to group sessions, whereas 11 (58%) used their own electronic device. Before joining the study, participants reported using a Web-enabled device an average of 4.63 times per week (range 1-6); 6 participants (32%) reported use of videoconference services, and 11 participants (58%) reported use of at least one social media service.

Usability

There were no significant differences in usability assessments between the lab and field usability testing; therefore, results were combined (Multimedia Appendix 2). Most tasks took less than 10 seconds to learn. Logging into the intervention website (which required participants to type in a username and password) was the one task that took more time. Participants made relatively few errors with 73% (8 of 11 trials) making less than 2 errors. The most common errors were on tasks related to accessing website features for the first time and accessing the videoconference. Notably, most participants were able to correct errors quickly and with little to no instruction from research staff. Additionally, they were more efficient when performing learned tasks and were able to quickly execute tasks even after a delay. Overall, results indicated that participants performed basic tablet functions quickly with no errors, performed Web functions easily with a low frequency of errors, and were able to quickly recover from errors.

Acceptability

In usability testing, average responses to the SUQ were 1.43, indicating participants were satisfied with the system, felt it was easy to learn and operate, and felt comfortable using it. Themes from qualitative interviews regarding usability were organized into 2 categories: program strengths and program deficiencies.

Table 2. Demographic, clinical, and technology use characteristics for usability testing and field trial testing.

Characteristics	Usability testing, n=9	Field trial testing, n=19
Age, mean (SD ^a)	59.20 (14.53)	58.89 (6.87)
White, non-Hispanic, n (%)	9 (100)	19 (100)
Rural residence, n (%)	3 (33)	4 (21)
Highest level of education, n (%)		
High school	4 (44)	5 (26)
College graduate	5 (56)	7 (37)
Postgraduate	0 (0)	7 (37)
Marital status, n (%)		
Single	— ^b	3 (16)
Divorced	—	1 (5)
Married	—	14 (74)
Separated	—	1 (5)
Employment status, n (%)		
Full time	1 (11)	4 (21)
Part time	4 (44)	4 (21)
Not employed	1 (11)	1 (5)
Disability	0 (0)	3 (16)
Retired	3 (33)	7 (37)
Cancer stage, n (%)		
I	1 (11)	5 (26)
II	0 (0)	5 (26)
III	7 (89)	8 (42)
IV	1 (11)	1 (5)
Years since diagnosis, mean (SD ^a)	2.56 (2.24)	2.37 (1.67)
Current chemotherapy, n (%)	2 (22)	3 (16)
Technology at home (yes), n (%)		
Wireless Internet	8 (89)	19 (100)
Computer	8 (89)	19 (100)
Tablet	6 (67)	11 (58)
Smartphone	6 (67)	16 (84)

^aSD: standard deviation.

^bNot assessed in usability testing.

Program strengths included the appealing website layout, the ease of program access, and the relevance of information to ovarian cancer survivors. Most participants reported no difficulties navigating the website and were satisfied with its appearance and features, reporting that it was well organized, clear, and inviting. The program deficiency most commonly reported was the need for more of a focus on ovarian cancer survivors in the visual design. After using the system, 8 of the 9 enrolled participants reported that they would be further interested in the intervention. Taken together, these data indicate high levels of usability and acceptability.

Where usability testing revealed issues in the setup of the Web platform, tablet, or instructional materials, feedback was used to make changes in the visual design. These changes included increasing the size of buttons and font for greater readability, using “Teal,” the color associated with ovarian cancer awareness, and extending instructions in the user manual to include the videoconference program.

In field testing, acceptability was examined using the mean responses to questions (see [Multimedia Appendix 3](#)) regarding participants' satisfaction with the session, ability to implement strategies, and comfort with the videoconference platform on a Likert scale from 0 (*not at all*) to 10 (*completely*). The average

response to questions on satisfaction with the session and desire to return for the next session were 9.0 (SD 0.74) and 9.20 (SD 0.49), respectively. The average response to questions about session topics and ability to implement strategies discussed was 8.25 (SD 0.81). These results indicate participants were highly satisfied with the group sessions and felt able to implement intervention content. Connectivity issues were the most frequently reported obstacle; however, this varied by group with many participants from the first 3 cohorts reporting difficulties with the videoconference platform. Reported comfort with the videoconference platform increased from an average of 7.76 (SD 1.03) in the first 3 cohorts to 9.08 (SD 0.87) in the last 2 cohorts after the platform switch, indicating less frequent connectivity issues.

Receipt of a physical copy of the participant manual was reported as extremely helpful in promoting ease of access to information, particularly in reviewing past material and practicing concepts discussed in the intervention. Many participants indicated that they referred to the participant manual after the intervention ended to guide them in continued practice of concepts.

Overall, the intervention content was described as useful, well designed, and relevant to ovarian cancer survivors. Participants indicated that drawing examples from the group members' daily lives was an important aspect of the intervention. In addition, the progression of program material was reported as logical, clear, and relatable. One participant stated:

The progression you did was very helpful. Starting with awareness, then moving on to working with thoughts and tools for coping. It flowed well. Each step built on the ones before. You can't just say "love yourself," but by the time we got to self-gratitude, I was ready for it.

Participants reported the intervention had significant impacts on their lives. One participant declared:

This was a real game changer for me

Another stated:

Hands down the best thing I have done for myself since my diagnosis

Finally, many participants reported that a very meaningful aspect of the intervention was the opportunity to connect with other ovarian cancer survivors. In fact, one participant revealed she had:

never met another woman with ovarian cancer before this group

Another indicator of user satisfaction was that participants requested adding additional, monthly group booster sessions after the conclusion of the program to support the connection with other group members and continued practice of concepts learned.

Feasibility

Of the 96 eligible women screened, 31 enrolled in the study (32% enrollment rate). Scheduling conflicts were a common

reason for participant refusal. The retention rate for the field trial was 68% (19 participants completed the intervention out of the 28 who attended at least 1 session), and overall attendance was 88.9% (169/190 sessions) for participants who completed the intervention. The 19 completers attended an average of 8.79 (SD 1.08) group sessions. Notably, participants continued to attend sessions while traveling or on vacation. The average at-home relaxation and meditation practice was 2.78 times per week (range 0.22-7.33), and average journal use was 2.34 times per week (range 0.11-7.89).

Preliminary Outcomes

Changes in self-reported outcome measures from baseline to follow-up are shown in Table 3. At baseline, average FACT subscale scores were comparable with normative samples of ovarian cancer patients and mixed cancer patients, with higher scores indicating better QOL [39,40]. Following the intervention, there was a nonsignificant trend toward increased total QOL from baseline, 116.22 (SD 16.37), to follow-up, 122.09 (SD 12.52), $t_{17}=1.85$, $P=.08$. For FACT-G total scores, a 5-point difference indicates a clinically significant change; for FACT subscales, a 2-point increase indicates clinically significant QOL improvements [47]. Thus, the participant-reported increases related to total QOL scores would be considered clinically significant improvements. A statistically significant increase in ovarian cancer-specific QOL was also observed, with mean scores increasing from 37.11 (SD 4.42) to 39.67 (SD 3.56), $t_{17}=2.88$, $P=.01$, whereas increases in physical well-being ($P=.05$) and functional well-being ($P=.06$) approached statistical significance.

Significant decreases in levels of perceived stress were reported over the intervention, with mean PSS scores decreasing from 21.28 (SD 7.95) to 18.00 (SD 7.09), $t_{17}=-2.42$, $P=.03$. Nonsignificant decreases in depressive symptoms ($P=.18$) and negative mood states ($P=.17$) and increases in social support ($P=.18$) were also reported. No changes in sleep quality were reported.

Relationships Between Intervention-Related Activities and Outcomes

A final set of analyses examined the associations between the psychosocial outcomes that showed statistically significant changes and intervention-related activities. The number of relaxation exercises completed was significantly correlated with the number of journal entries, $r=.803$, $P<.001$, indicating a strong association between completion of these 2 activities. However, neither of these activities was significantly correlated with the number of sessions attended. The number of relaxation exercises completed was associated with significant decreases in PSS ($r=-.52$, $P=.03$), indicating participants who completed a greater number of relaxation practices reported a decrease in perceived stress over the course of the intervention. Similarly, the number of journal entries completed was also associated with decreases in perceived stress, but this was only marginally significant ($r=-.45$, $P=.059$). There were no significant correlations between any study activities and changes in ovarian cancer-specific QOL during the intervention.

Table 3. Changes in psychosocial outcomes from baseline to postintervention (n=18).

Outcome	Preintervention, mean (SD) ^a	Postintervention, mean (SD)	g (95% CI)	P
FACT ^b : Ovarian cancer QOL ^c	37.11 (4.42)	39.67 (3.56)	0.62 (–0.05 to 1.29)	.01
FACT: Total QOL	116.22 (16.37)	122.09 (12.52)	0.29 (–0.27 to 1.05)	.08
FACT: Physical QOL	22.26 (4.75)	24.18 (2.60)	0.49 (–0.17 to 1.15)	.05
FACT: Social QOL	18.80 (4.34)	17.46 (4.67)	–0.29 (–0.95 to 0.37)	.28
FACT: Emotional QOL	18.00 (3.14)	18.63 (3.63)	0.18 (–0.47 to 0.84)	.31
FACT: Functional QOL	20.06 (4.89)	22.17 (4.05)	0.46 (–0.20 to 1.12)	.06
PSS ^d	21.28 (7.95)	18.00 (7.09)	0.43 (–0.23 to 1.09)	.03
POMS ^e : Negative mood	11.94 (25.18)	5.78 (16.42)	0.28 (–0.37 to 0.94)	.17
CESD ^f : Depression	11.78 (8.95)	9.39 (7.65)	0.28 (–0.38 to 0.94)	.18
PSQI ^g : Sleep quality	7.17 (4.12)	6.78 (3.51)	0.10 (–0.55 to 0.75)	.53
SPS ^h : Social support	84.00 (8.44)	85.78 (8.66)	0.12 (–0.54 to 0.77)	.18

^aSD: standard deviation.

^bFACT: Functional Assessment of Cancer Therapy.

^cQOL: quality of life.

^dPSS: Perceived Stress Scale.

^ePOMS: Profile of Mood States.

^fCESD: Center for Epidemiologic Studies Depression.

^gPSQI: Pittsburgh Sleep Quality Index.

^hSPS: Social Provisions Scale.

Discussion

Principal Findings

This study describes the successful development and preliminary testing of a novel, Web-delivered intervention to address the unique needs of ovarian cancer survivors. The key findings were that an Internet-based intervention for ovarian cancer survivors had high levels of usability and acceptability, moderate feasibility, and preliminary indications suggesting psychosocial effects. In lab and field usability testing, participants were able to operate and navigate tablet and website functions easily with a low frequency of errors and were especially positive about the website's content and ease of use. These findings demonstrate high levels of usability and acceptability of the intervention's content and Web platform. Next, in the one-armed field trial of the intervention, participant feedback was especially positive regarding the intervention content and its relevance to ovarian cancer survivors. Preliminary outcome data from the field trial demonstrated statistically significant reductions in perceived stress and improvements in ovarian cancer-specific QOL. Trends toward improved QOL and reduced depressive symptoms were also observed, with medium effect sizes, but did not reach statistical significance.

These preliminary results mirror improvements in QOL and mood from randomized controlled trials of CBSM interventions in women with breast cancer [11,48] and men with early-stage prostate cancer [25]. Notably, the trends toward improved QOL and reduced depressive symptoms in this study align with the preliminary findings of a Web-based CBSM intervention for

men with advanced prostate cancer [24]. Adherence to home relaxation practice was relatively low, with participants completing an average of 2.78 at-home practices per week in contrast to the recommendation that participants practice daily. However, this frequency of practice was consistent with levels of home practice reported in similar studies [49]. Notably, participants who used the website's relaxation and meditation recording feature more often during the intervention reported a decrease in perceived stress after the intervention. This is consistent with findings of similar interventions with human immunodeficiency virus (HIV)-positive men [49], men with prostate cancer [25], women at risk for breast cancer [50], and women with breast cancer [48,51]. Each of these studies reported that the frequency of at-home practice or improvements in perceived ability to relax was associated with psychological and physiological benefits. This highlights the importance of developing approaches to increase at-home practice.

Overall, participants reported positive experiences with the intervention and described it as useful and relevant. Such feedback highlights the advantages of an Internet-based group intervention for ovarian cancer, which provides the opportunity for survivors to connect to one another, transcending the limitations of their treatment setting and physical limitations. Connectivity issues (eg, difficulty hearing or seeing other group members) were commonly reported in early groups, and these were largely addressed by switching videoconferencing platforms. Other obstacles were the time commitment to attending sessions and completing activities outside of the sessions (eg, homework, meditation practices). These obstacles can be addressed in future work by providing participants with

an opportunity to set goals for themselves each week. Feedback from participants can help illuminate possible changes that could be made as well as provide group leaders with real-world examples of how participants successfully implement activities into their own lives.

Limitations

Despite these strengths, it is important to note that the recruitment rate (31 enrolled/96 eligible=32%) for the field trial is a limitation. Although comparable rates are seen in similar research with cancer survivors with advanced disease [22,24,52], participants who completed the intervention may differ from those who chose not to participate or could not be contacted. Notably, scheduling conflicts made up approximately one-third (n=24) of the cited reasons why individuals eligible for the study did not participate. Therefore, providing more flexibility in scheduling group sessions may contribute to improved recruitment rates in the future. Another limitation is the overall retention rate (19 completed/28 attended at least one session=68%) for the field trial. Reasons for participant dropout were disease-related issues or competing priorities, such as family or work, which are similar to the reasons cited for dropout in other interventions with postsurgical ovarian cancer survivors [16,21]. The reasons for dropout underscore the challenges many ovarian cancer survivors face, including noncancer-related stressors and a disease with a high risk of recurrence. Attendance was high among those who completed the intervention, exemplified by attendance even while traveling overseas. Future work should aim to improve retention rates by including clearer expectations during the screening process and providing reminders.

Another limitation is the lack of overall diversity in the sample, which limits generalizability of the study. The sample of completers was entirely white, non-Hispanic women and most were college-educated. Despite these limitations in generalizability to all ovarian cancer survivors, this sample included a few participants who lived in rural areas. Therefore, the results of this study lend some insight into the impact that interventions can have on survivors from rural locations. A fourth limitation is the small sample size in the field trial that limited power of statistical analyses. Finally, without a control group, factors other than the intervention could have influenced the preliminary outcome results. Therefore, future work will need to include a randomized controlled trial with an active control group as well as longitudinal follow-up after the intervention.

Conclusions

Our findings suggest that an Internet-based group intervention is highly usable and acceptable for ovarian cancer survivors with moderate levels of feasibility at this time. Preliminary data suggest decreases in perceived stress and improvements in QOL, following the intervention. An Internet-based group may be especially well suited for this population, given the small number of ovarian cancer patients at any one treatment site. Future research with this intervention should focus on a randomized controlled trial to evaluate its efficacy on clinically relevant cancer outcomes such as mood and QOL. Other areas of future research include determining at which points in the survivorship trajectory an intervention such as this is most helpful, as well as assessing the potential effects on outcomes over time and examining potential effects on biological mediators that are known to modulate cancer growth.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Checklist for Reporting Results of Internet E-Surveys.

[[PDF File \(Adobe PDF File\), 15KB - cancer_v4i1e1_app1.pdf](#)]

Multimedia Appendix 2

Results of the usability assessment results for laboratory and field usability.

[[PDF File \(Adobe PDF File\), 32KB - cancer_v4i1e1_app2.pdf](#)]

Multimedia Appendix 3

Weekly session evaluation scores averaged across 10 weeks.

[[PDF File \(Adobe PDF File\), 27KB - cancer_v4i1e1_app3.pdf](#)]

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Abbreviations

ACT: acceptance and commitment therapy
CBSM: cognitive-behavioral stress management
CBT: cognitive-behavioral therapy
CESD: Center for Epidemiologic Studies Depression
CHERRIES: Checklist for Reporting Results of Internet E-Surveys
FACT-O: Functional Assessment of Cancer Therapy—Ovarian Form
MBSR: mindfulness-based stress reduction
QOL: quality of life
PSS: perceived stress scale
SUQ: system usability questionnaire

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Original Paper

A Web-Based Intervention to Reduce Distress After Prostate Cancer Treatment: Development and Feasibility of the Getting Down to Coping Program in Two Different Clinical Settings

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Abstract

Background: Distress after prostate cancer treatment is a substantial burden for up to one-third of men diagnosed. Physical and emotional symptoms and health service use can intensify, yet men are reticent to accept support. To provide accessible support that can be cost effectively integrated into care pathways, we developed a unique, Web-based, self-guided, cognitive-behavior program incorporating filmed and interactive peer support.

Objective: To assess feasibility of the intervention among men experiencing distress after prostate cancer treatment. Demand, acceptability, change in distress and self-efficacy, and challenges for implementation in clinical practice were measured.

Methods: A pre-post, within-participant comparison, mixed-methods research design was followed. Phase I and II were conducted in primary care psychological service and secondary care cancer service, respectively. Men received clinician-generated postal invitations: phase I, 432 men diagnosed <5 years; phase II, 606 men diagnosed <3.5 years. Consent was Web-based. Men with mild and moderate distress were enrolled. Web-based assessment included demographic, disease, treatment characteristics; distress (General Health Questionnaire-28); depression (Patient Health Questionnaire-9); anxiety (General Anxiety Disorder Scale-7); self-efficacy (Self-Efficacy for Symptom Control Inventory); satisfaction (author-generated, Likert-type questionnaire). Uptake and adherence were assessed with reference to the persuasive systems design model. Telephone interviews explored participant experience (phase II, n=10); interviews with health care professionals (n=3) explored implementation issues.

Results: A total of 135 men consented (phase I, 61/432, 14.1%; phase II, 74/606, 12.2%); from 96 eligible men screened for distress, 32% (30/96) entered the intervention (phase I, n=10; phase II, n=20). Twenty-four completed the Web-based program and assessments (phase I, n=8; phase II, n=16). Adherence for phase I and II was module completion rate 63% (mean 2.5, SD 1.9) versus 92% (mean 3.7, SD 1.0); rate of completing cognitive behavior therapy exercises 77% (mean 16.1, SD 6.2) versus 88% (mean 18.6, SD 3.9). Chat room activity occurred among 63% (5/8) and 75% (12/16) of men, respectively. In phase I, 75% (6/8) of men viewed all the films; in phase II, the total number of unique views weekly was 16, 11, 11, and 10, respectively. The phase II mood diary was completed by 100% (16/16) of men. Satisfaction was high for the program and films. Limited efficacy testing indicated improvement in distress baseline to post intervention: phase I, $P=.03$, $r=-.55$; phase II, $P=.001$, $r=-.59$.

Self-efficacy improved for coping $P=.02$, $r=-.41$. Service assessment confirmed ease of assimilation into clinical practice and clarified health care practitioner roles.

Conclusions: The Web-based program is acceptable and innovative in clinical practice. It was endorsed by patients and has potential to positively impact the experience of men with distress after prostate cancer treatment. It can potentially be delivered in a stepped model of psychological support in primary or secondary care. Feasibility evidence is compelling, supporting further evaluative research to determine clinical and cost effectiveness.

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KEYWORDS

prostatic neoplasms; Internet; self-management; cognitive behavior therapy; primary health care; secondary care

Introduction

Need for Psychological Support

In developed regions of the world, men are more likely to be diagnosed with prostate cancer than any other cancer, and those diagnosed are more likely to develop distress or serious psychological problems than healthy men [1,2]. Over 60% of men with prostate cancer report unmet psychological needs and up to a third experience pronounced clinical distress [3-7]. They also have a higher risk of suicide than their healthy male counterparts [8]. A range of factors contribute to men's psychological comorbidity. Side effects of treatment such as urinary, sexual, bowel, and body-image problems can have a negative effect on cancer-related distress for as much as 2-3 years after diagnosis [9-11], and men's psychological well-being can be adversely affected by lack of support, the threat of cancer, and the perceived loss of masculine identity [12-14].

The numbers of men with prostate cancer living with and beyond diagnosis are predicted to grow. There are over 1.1 million new prostate cancer cases globally per year, accounting for some 15% of all cancer diagnoses in men [2]. Incidence varies but trends indicate increasing diagnoses and decreasing mortality rates, particularly in developed countries and where screening programs have been implemented [15]. Five-year survival rates now exceed 84% in Western Europe and approach 100% in the United States and Australia [16-18], and in the United Kingdom for instance, incidence rates are expected to rise by 12%, to over 77,000 new cases per year by 2035 [19]. The growing number surviving prostate cancer means there will be more men experiencing reduced psychological well-being and quality of life, resulting in increased care utilization and health service costs. Innovative, accessible, and low-cost care delivery solutions are required to meet this long-term challenge.

Providing early psychological support is vital to ensure men experiencing distress after prostate cancer treatment do not fall into a cycle of negative thinking and avoidance behaviors, which can escalate symptoms and lead to the need for more intensive, prolonged support [5,6]. However, men's engagement with psychological support is frequently restrained: reticence to communicate and delays in presenting to clinicians are underpinned by fears of stigmatization and the desire to normalize their illness experience by not *needing help* [20]. To support men's psychological needs, it is essential to develop interventions that address these barriers.

Web-Based Support

The effectiveness of cognitive behavior therapy (CBT) is well documented; it can offer an acceptable, brief intervention within mental health services for people experiencing emotional difficulties as a consequence of comorbid problem(s) [21,22]. More recently, Web-based CBT has proved as effective as CBT delivered face-to-face [23]. However, there is mixed evidence for the role of clinician guidance in Web-based interventions. Although clinician support has been considered important for beneficial outcomes, there is evidence to suggest that the level of training for those providing guidance may be of limited importance; in some cases therapist effect may be minimal, and support can equally come from nonclinicians [23,24]. Conversely, a recent review concluded that there is limited evidence to show that self-guided interventions, in any delivery mode, can reduce psychological distress after cancer, but the authors did consider that efficacy may be increased if interventions are targeted at people formally assessed as being distressed [25]. Notably, recent meta-synthesis of qualitative studies in long-term conditions established that building Web-based social ties with peers can support self-management and improve illness experiences in aspects that are hard for individuals to negotiate offline [26].

Web-based CBT for cancer patients, and prostate cancer in particular, is a less-developed area compared with other chronic physical conditions [27-31]. For men with prostate cancer, Web-based delivery of psychological support is promising, it can facilitate access and engagement by providing a faceless, perceptually private environment to ameliorate men's fears of stigmatization; it can also prove cost-effective for health services. A systematic review has shown that psychological interventions for prostate cancer survivors can improve mental health [32], but although 10 of the 21 effective patient-focused interventions identified were based on or contained components of CBT, only 2 were Web-based interventions. Both showed an improvement in depression [33] or distress [31], but neither of the interventions was carried out among a sample of men who had been formally assessed as being distressed nor were they delivered within a clinical setting. Outcomes from these studies are more relevant to *worried* prostate cancer patients than to a clinically distressed prostate cancer population requiring a therapeutic service.

Study Aim

In this study, we describe the development and feasibility of delivering a Web-based intervention in clinical practice for men

with mild and moderate distress after treatment for prostate cancer. The program offers self-guided CBT augmented with filmed peer support and low-level chat room facilitation to encourage self-management; it aims to offer men the ability to monitor their condition and to affect the cognitive, behavioral, and emotional responses necessary to maintain an acceptable level of psychological well-being [32,34,35]. The program is intended to provide a cost-effective, brief intervention that can be offered through health services with minimal practitioner input. Reflecting recommended foci for feasibility studies [36], we assessed (1) demand through uptake and attrition, (2) acceptability by adherence and participant satisfaction, (3) potential for improvement in distress (and self-efficacy phase II) through limited efficacy testing, and (4) potential challenges for implementation in clinical practice.

Methods

Study Design

We conducted 2 phases of feasibility research. Phase I assessed the program prototype in a low-intensity, primary care psychological service within which it was developed. Data from that phase informed further development, and phase II tested a slightly revised version in a secondary care cancer service.

The studies were approved by the UK NHS National Research Ethics Service, phase I reference 13/SC/0065; phase II reference 15/SC/0690.

In accordance with the Medical Research Council framework for developing and evaluating complex interventions [37], we used a pre-post, within-participant comparison, mixed-methods design in both phases. In phase II, sequential qualitative interviews were conducted after the final assessments to provide complementary context to the data [38]. In phase I, the intervention ran in February and again in March 2015, with separate facilitators and participant cohorts. In phase II, the intervention ran once with a single cohort and facilitator in June 2016.

Participants, Setting, and Recruitment

Identification, eligibility, and screening are outlined in [Figure 1](#). Men diagnosed with prostate cancer, not receiving palliative care for metastatic disease, were invited. In phase I, 432 men diagnosed up to 5 years were invited by a letter from their primary care physician; in phase II, 606 men diagnosed up to 3.5 years were invited by a letter from a nurse consultant in a secondary care cancer service. The letter contained full participant information and a link to the study website where all further contact took place. Interested men visited the website and gave informed consent. Consented men were then assessed for eligibility and those eligible were screened for distress. Men experiencing mild distress and men experiencing moderate distress were asked to complete the remainder of baseline assessments and were offered the intervention. (All inclusion and exclusion criteria are summarized in [Table 1](#).) A risk-assessment protocol was administered throughout phases I and II (see [Multimedia Appendix 1](#)).

Figure 1. Identification, eligibility, and screening.

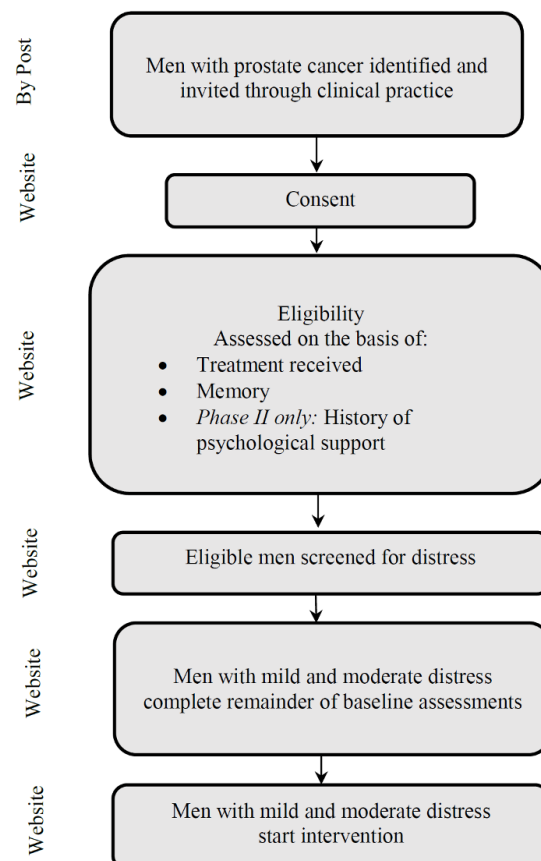


Table 1. Inclusion and exclusion criteria.

Inclusion and Exclusion	Phase I	Phase II
Inclusion	Men diagnosed with prostate cancer in last 5 years Received or receiving treatment: prostatectomy, radiotherapy, brachytherapy, hormone therapy, active surveillance, or watchful waiting Experiencing mild and moderate distress	Men diagnosed with prostate cancer in last 3.5 years Received or receiving treatment: prostatectomy, radiotherapy, brachytherapy, hormone therapy, active surveillance, or watchful waiting Experiencing mild and moderate distress
Exclusion	Palliative metastatic disease Referral or medication for memory loss Counseling or psychiatric referral since diagnosis Experiencing severe depression or suicidal thoughts	Palliative metastatic disease Referral or medication for memory loss (Men were not excluded on the basis of counseling or psychiatric referral) Experiencing severe depression or suicidal thoughts

Intervention

The program concept was developed from our previous research in urinary symptom self-management after prostate cancer treatment [39]. In response to a custom-made motivational peer support film used in the randomized controlled trial of that intervention, service users requested self-guided, easily accessible support to help manage their psychological distress. This need was confirmed in a scoping review of available psychological care, literature review of the status of cancer-related psychological interventions [40], and emerging policy initiatives to provide psychological support within primary care services for people struggling with a chronic condition.

The Web-based program, *Getting Down to Coping*, was produced in conjunction with a low-intensity psychological service that accepted general physician and self-referrals. The service was part of England's National Health Service, Improving Access to Psychological Therapies (IAPT) program, which offered low- or high-intensity therapy, or referral to specialist mental health services [41]. Particular features included the use of standardized and manualized evidence-based CBT and routine outcome monitoring at each clinical session. The low-intensity service typically offered brief courses for people with mild and moderate anxiety or depression, mostly by telephone, but face-to-face and computer-based support was available. Published evaluations have reported recovery rates in excess of 50%, supporting service objectives, and IAPT is now developing services to provide tailored support for people with mental health needs associated with a long-term physical condition [42,43].

The research team, in collaboration with a software engineer, senior mental health practitioners, urologist, psychosexual therapist, specialist nurse, and 3 user representatives, codeveloped the initial program prototype based on the manualized short course of CBT delivered by the service. The course was then tailored to reflect prostate cancer-related examples and concerns and supplemented with links to medical, physical, emotional, social, and financial prostate cancer information. The program website was styled with graphics and language to appeal to a male audience and to reduce connotations of mental health.

A fundamental component of the program was peer support, but providing this over the internet is complex. Active engagement with others through posting messages can mediate positive outcomes, but not all men are prepared to do this, and evidence shows that passively viewing messages is not associated with the same beneficial outcomes [31,44]. To support men, we embedded theory-driven peer support films [45], as well as a platform for interactive support via an asynchronous chat forum. A single chat forum thread ran weekly; each week the facilitator started the thread by posting a question relevant to the module topic. The program was beta-tested by service users and the films were evaluated in focus groups. Comments from users and research participants were incorporated to refine the program and films.

The program contained 4 weekly, consecutive CBT modules with an introduction at the beginning of Module 1 (see [Multimedia Appendix 2](#)). It was intended that men should spend up to an hour per week on each module, including chat room activity. Modules were available 1 each week and progress was sequential. A male narrator supported the text. Men were invited to create a profile that other men could view. All worksheets and materials were available to download.

The IAPT service used the Patient Health Questionnaire-9 (PHQ-9) [46] and the General Anxiety Disorder-7 scale (GAD-7) for outcome monitoring [47]. To mirror the service's practice, these were administered weekly within the program at the beginning of each module. Except in a situation of risk, it was intended that no formal feedback from these measures would be given to participants. In phase II, the measures were replaced with a noncompulsory weekly mood diary that invited participants to rate how they were feeling on 5 scales: down/cheerful, irritable/calm, vulnerable/in control, weary/active, and worried/relaxed; participants had the opportunity to review their previous scores. Phase II incorporated email notifications of chat room posts, chat room access from any page, easier navigation, and frequently asked questions for IT support. (screenshots in [Figure 2](#).)

The prototype was developed with hard-coded software, which limited functionality. For phase II, the program was redeveloped within a content management system to enable integration into clinical practice and facilitate further research.

Figure 2. Screenshots of the Getting Down to Coping Program.

The figure displays two screenshots of the 'Getting Down to Coping' program interface. The left screenshot shows a diagram titled 'THE VICIOUS CIRCLE IS A USEFUL WAY OF THINKING ABOUT HOW WE COPE AND WHAT WE CAN DO DIFFERENTLY'. The diagram illustrates the cycle between Situation, Thoughts, Feelings, and Behaviour, leading to Physical symptoms. The right screenshot shows a video player with the title 'STARTING TO MAKE A CHANGE' and a play button.

Facilitation

There were 3 chat room facilitators, each responsible for 1 cohort of men and all were trained by a subteam of researchers, clinicians, and user representatives. Training covered Web-based facilitation, prostate cancer issues, and/or CBT theory. In phase I, 2 low-intensity psychological practitioners from the collaborating service carried out facilitation. Each practitioner allotted 2, predesignated 2-h slots per week to facilitate the chat forum for their cohort. They also visited the website intermittently during office hours to assess risk. During these slots, the practitioners did not continue with their usual clinical caseload. In phase II, a specialist cancer nurse delivered facilitation and accessed and interacted with the program on an ad hoc basis during the time it was available to participants.

Data Collection

Uptake

Uptake was assessed as the proportion of men who took up the initial invitation, visited the website, and gave their consent.

Sample Characteristics

Demographic, disease, and treatment characteristics were collected in both phases from eligible participants before distress screening. Comorbidity was assessed separately at baseline in phase I and post intervention in phase II.

Screening and Outcome Assessment

Distress screening took place at baseline 2 weeks before the intervention; the remaining baseline assessments were completed 1 week before the intervention. Participants who entered the intervention were followed-up and assessed through the website in the week after intervention completion.

Attrition

Attrition was assessed by the number of men offered the intervention who dropped out before, during, or after the program and the proportion of core users who continued to use the program [48].

Adherence

Adherence is an important mediating variable for benefit in health-related Web-based interventions, yet it is a challenge to achieve and measure [49,50]. We assessed adherence using the persuasive system design (PSD) model [50,51], which proposes that the content of Web-based behavior-change programs is conveyed by a range of design features that can persuade and motivate the user without *deception, coercion or inducement* [52]. Design features can account for more than half the variance in adherence, but researchers have been slow to take account of this [50,52]. The PSD model advances 4 principles of design support through which an interactive system can persuade and enhance use: (1) support given to the primary *task* to communicate meaningful content, (2) support given to a *dialogue* between the program and the participant to help participants move toward their goal, (3) support provided through *social* features of the program to enhance participant motivation, and (4) *credibility* support that makes the system trustworthy and believable [51]. The Getting Down to Coping program contained elements of all 4 principles; in particular, quantifiable elements were located in *task support* and *social support* (Table 2). We also assessed static measures: time logged-in in phase I, time logged-in-and-active in phase II defined as follows: (1) any action within 10 min of a previous action would be considered to take place within the same session and (2) the user would be expected to look at the site for 1 min after their last action. We examined adherence among core users [48].

Table 2. Persuasive system design principles reflected in the Getting Down to Coping Program.

PSD ^a principles [51]	PSD elements ^a	Getting Down to Coping Program components
Supporting the primary task	Tunneling: Using the system to guide users through a process of experience provides opportunities to persuade along the way.	Content delivered in sequential modules that can only be accessed when the system releases the next module; Opportunities to self-assess and review progress.
	Tailoring: Information provided by the system will be more persuasive if it is tailored to the potential needs, interest, personality, usage context, or other factors relevant to a user group.	Program is prostate cancer focused throughout in respect of context, examples, and suggestions; Provides targeted links to Web-based information, education, and support services.
	Self-monitoring: A system that keeps track of a user's own performance or status supports the user in achieving goals.	In phase II, mood diary and CBT entries are available for back reference once completed.
Supporting the computer-human dialogue	Reminders: If a system reminds users of their target behavior, or that the system is ready to use, the users will more likely achieve their goals.	Emails from the system announce the imminent beginning of each module; In phase II, email notifications are sent to all chat room users when someone posts.
	Suggestions: Systems offering fitting suggestions will have greater persuasive powers.	Text and voice over provide suggestions for action.
	Similarity: People are more readily persuaded through systems that remind them of themselves in some meaningful way.	Graphics and layout are attractive and pertinent to men, films show men in similar situations, and language is inclusive and colloquial. Narrator (Robert) conveys familiarity.
	Social role: If a system adopts a social role, users will more likely use it for persuasive purposes.	Facilitator role to encourage peer support and self-management.
Supporting the credibility of the system	Trustworthiness and expertise: A system that is viewed as trustworthy and/or incorporating expertise will have increased powers of persuasion.	Badging via logos endorses clinical services and research team expertise. Narrator's voice (Robert) is reassuring.
	Surface credibility: People make initial assessment of the system credibility based on a first-hand inspection.	Ease of log-in, secure, simplicity of instructions, and clarity of format. Up-to-date, easily accessible information and downloadable resources. In phase II, wider device compatibility, addition of frequently asked questions, access to chat room from every page, easier navigation.
	Real world: A system that highlights people or organizations behind its content or services will have more credibility.	Optional voice over throughout; possibility of contacting facilitator for private email chat.
Social support	Social learning: A person will be more motivated to perform a target behavior if they can use a system to observe others performing the behavior	Chat forum provides opportunity to interact, to discuss self-assessment and progress, and to provide or receive support.
	Social comparison: System users will have a greater motivation to perform the target behavior if they can compare their performance with the performance of others.	Participants can compare their experiences with those of their peers in the films and in the chat forum.

^aPSD: persuasive system design. Part of table used with permission from Association for Information Systems, Atlanta, GA; 404-413-7444; All rights reserved.

Participant Satisfaction

Satisfaction with the program was assessed at post intervention via an author-generated questionnaire containing 4 Likert-type scales representing: (1) recruitment, (2) program, (3) chat room, and (4) films. In-depth telephone interviews were conducted by the study researcher with 10 phase II participants to understand personal experiences and contexts. Interviews were audio recorded, transcribed, and analyzed using framework analysis [53].

Distress

Screening for distress was measured by the General Health Questionnaire-28 (GHQ-28) [54]. Performance in cancer populations shows high reliability ($\rho \geq .80$, $\kappa \geq .60$, $r = .8$) and high validity ($\geq 80\%$) [55]. Mild and moderate distress was assessed as a score ≥ 4 .

The PHQ-9 [46] and GAD-7 [47] were administered at baseline and post intervention in both phases. In phase I, the program's week 1 data were used as baseline.

Self-Efficacy

In phase II, the Self-Efficacy for Symptom Control Inventory (SESCI) was administered at baseline and post intervention to assess participant self-belief to cope and manage prostate cancer-related symptoms. The SESCO contains 3 subscales: self-efficacy for physical function, self-efficacy for coping or tolerating symptoms, and self-efficacy for symptom management. Participants indicate how confident they feel on scales for each domain from 0 (not confident) to 100 (very confident). The measure is a modified version of a self-efficacy scale used in chronic pain and lung cancer symptoms [56,57]. For prostate cancer patients, reliability has been calculated with a Cronbach alpha for the total scale of .97, and for each subscale of .94 [58].

Service Implementation

Time spent by the facilitators in the program was assessed by log-in data. Issues related to delivery and integration in practice were explored after the intervention: in phase I, the study researcher conducted face-to-face interviews with the 2 facilitators; in phase II, a telephone interview was conducted with the facilitator. Issues relating to delivery and integration into current practice were explored. Interviews were audio recorded, transcribed, and analyzed with framework analysis [53].

Data Analysis

We assessed participant demographic, disease, treatment and satisfaction profiles, and uptake and adherence descriptively. We used descriptive statistics (mean, median, standard deviation [SD], interquartile range [IQR]) and box plots to examine the distribution of distress measured by the GHQ-28 and

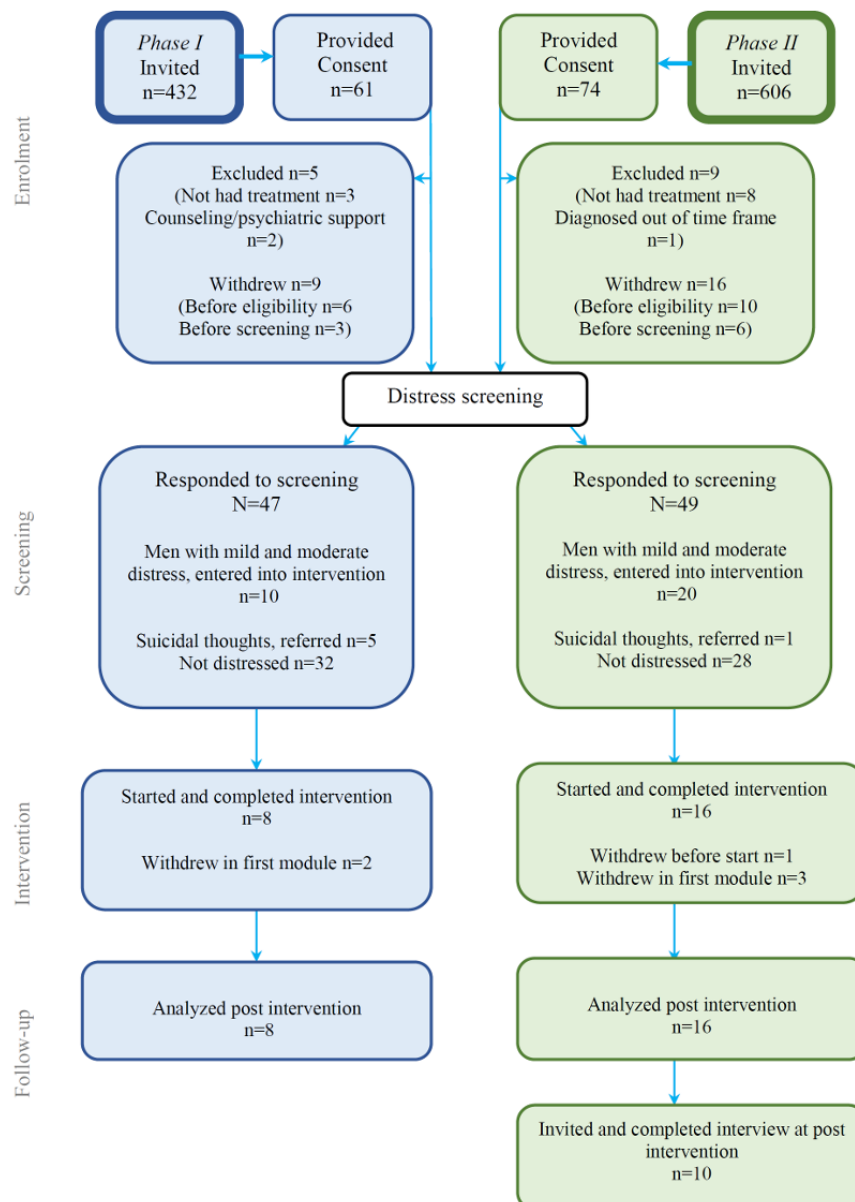
self-efficacy. The samples were not powered to detect significance in the outcome measures, nevertheless we present nonparametric data in relation to distress and self-efficacy to aid understanding of the potential effect of the program within these samples and provide data on which to base a power calculation for a larger study of efficacy. Statistical testing was performed on the 2 samples of core users, which for feasibility testing in this design provides a more useful measure of overall outcome [48].

Results

Uptake

A total of 14.1% (61/432) of invited men consented to the take part in phase I, and 12.2% (74/606) of invited men consented to take part in phase II (Figure 3).

Figure 3. Consolidated Standards of Reporting Trials (CONSORT) diagram of participant flow.



Participants

In phase I, 47 eligible men were screened, of whom 32% (15/47) were experiencing distress: 21% (10/47) indicated mild and moderate distress and were offered the intervention and 11% (5/47) indicated suicidal thoughts and were referred for clinical assessment.

In phase II, 49 eligible men were screened, of whom 43% (21/49) were experiencing distress, 41% (20/49) indicated mild and moderate distress and were offered the intervention, and 1 indicated a suicide risk and was referred for clinical assessment.

Attrition

In phase I, 10 participants were offered and started the intervention, and 2 withdrew in the first module (1 felt the program was not appropriate for his needs and 1 gave no reason). A total of 80% (8/10 across 2 cohorts) remained in the program for the 4 weeks and completed all assessments (Figure 3).

In phase II, 20 participants were offered the intervention, 1 did not start (no reason given), and 3 withdrew during the first module (1 declined because he had been recently bereaved and 2 gave no reason). A total of 80% (16/20 in 1 cohort) remained in the program for the 4 weeks and completed all assessments (Figure 3).

User Profiles

Baseline demographic, disease, and treatment characteristics for core users are reported in Table 3.

Demographics

In phase I, the median age was 68 years; typically, men were retired or working part-time, educated up to the age of 16 or 18 years without any higher education, and living in *least* deprived areas of the region. All were of white ethnicity, living with a partner, and reported co-existing health conditions.

In phase II, the median age was 62 years; men were typically living with a partner, retired, or working full-time; a fifth were on long-term sick leave. All were of white ethnicity, polarized between *most* and *least* deprived areas. All except one reported co-existing health conditions.

Disease and Treatment

The majority of men in both phases had been diagnosed under 2 years; locally confined disease at diagnosis was reported by less than half in phase I and by nearly 3 quarters in phase II. The majority in both phases recalled a PSA at diagnosis >10.

Most men in both phases were undergoing active treatment at the time of the intervention, either hormone treatment or hormone plus external beam radiotherapy.

All those who had completed treatment had done so within 1-2 years. In phase I, men had received hormone and or external

beam radiotherapy; in phase II, there was a broad range of treatment experience, including prostatectomy. A minority in each phase had experience of active surveillance; 1 man in phase II was undergoing active surveillance.

Adherence

Task Support

On the basis of page views, 50% (4/8) of men in phase I reached the end of all the modules. In phase II, 88% (14/16) of men reached the end of all the modules. This equates to overall module adherence rates of 63% (mean 2.5, SD 1.9) and 92%, (mean 3.7, SD 1.0) respectively.

On the basis of a possible 21 CBT entries, there was an adherence rate of 77% (mean 16.1, SD 6.2) in phase I, and 88% (mean 18.6, SD 3.9) in phase II. The mood diary in phase II was completed by 100% (16/16) of men.

Social Support

A total of 6 out of 8 men (75%) in phase I viewed all 4 peer support films, 1 (1/8) man watched 2 films, and 1 (1/8) man watched 3 films, equating to an adherence rate of 91% (mean 3.6 SD 0.7). Data available for the 4 weeks of phase II, indicated a total of 16, 11, 11 and 10 unique weekly views, respectively.

In phase I, 63% (5/8) of men posted in the chat room: median posts n=2 (range 1-6). In phase II, 75% (12/16) men posted: median posts n=5 (range 1-24).

Log-in Behavior

In phase I, median time logged in was 5 h 35 min (range 2 h 38 min to 11 h 31 min). In phase II, median time logged-in-and-active was 4 h 5 min (range 1 h 8 min to 8 h 33 min).

Participant Satisfaction

Questionnaire responses indicated that the Web-based recruitment and consent process was understood, appropriate in language and style, swift to respond, and easy to access (Table 4). Response to the program and the films was also positive, but there were some issues raised and clarified in open-ended and qualitative responses that will inform future development. Issues were related to the following: (1) length of sessions, the last module *Getting There* was shorter than the preceding modules, which was disappointing; (2) questions about suicide (at screening and assessment) were alarming for some; and (3) the need to enhance identification with the men in the films by providing details of what treatments they had received. In phase I, the chat room was poorly endorsed: it had been difficult to locate, there had been little activity and opportunity to chat, and the facilitation was not perceived as supportive. These issues were addressed in phase II and satisfaction improved: access and ease of use was enhanced, notifications of chat room activity were provided, and facilitator interaction was increased.

Table 3. Core user profiles.

Core user characteristics	Phase I (N=8)	Phase II (N=16)
Age in years, mean (SD)	69 (6.1)	64 (6.9)
Age in years, median (range)	68 (61-79)	62 (55-80)
Age groups, n (%)^a		
50-59	0 (0)	4 (25)
60-69	5 (63)	9 (56)
70-79	3 (37)	2 (13)
80-89	0 (0)	1 (6)
Living status, n (%)^a		
Alone	0 (0)	1 (6)
With partner	8 (100)	15 (94)
Working status, n (%)^a		
Full-time	1 (13)	5 (31)
Working part-time	3 (37)	0 (0)
Long-term sick	0 (0)	3 (19)
Retired	4 (50)	7 (44)
Other	0 (0)	1 (6)
Education, n (%)^a		
Up to 16 years	3 (37)	12 (75)
Up to 18 years	4 (50)	1 (6)
Post 18 years Diploma/certificate	0 (0)	2 (13)
Higher education	1 (13)	1 (6)
Residential area: EIMD^b; SMID^c quintiles, n (%)^a		
1 Most deprived	0 (0)	3 (19)
2	1 (13)	4 (25)
3	2 (25)	2 (13)
4	3 (37)	4 (25)
5 Least deprived	2 (25)	3 (19)
Ethnicity, n (%)^a		
White	8 (100)	16 (100)
Comorbidities, n (%)^a		
0	0 (0)	1 (6)
1	4 (50)	6 (38)
2	3 (37)	2 (13)
3	1 (13)	4 (25)
4	0 (0)	3 (19)
Time since diagnosis, n (%)^a		
Under 1 year	4 (50)	7 (44)
1-2 years	1 (13)	2 (25)
2-3 years	0 (0)	5 (31)
3-4 years	1 (13)	0 (0)

Core user characteristics	Phase I (N=8)	Phase II (N=16)
5 years +	2 (25)	0 (0)
Stage of disease at diagnosis, n (%)^a		
I	3 (38)	8 (50)
II	0 (0)	3 (19)
III	3 (38)	4 (25)
IV	1 (13)	1 (6)
Missing	1 (13)	0 (0)
PSA^d score, n (%)^a		
<4	0 (0)	0 (0)
4-10	1 (13)	2 (13)
>10	6 (75)	13 (81)
Missing	1 (13)	1 (6)
Gleason score (biopsy), n (%)^a		
6	1 (13)	2 (13)
7	3 (43)	4 (25)
8-9	3 (43)	4 (25)
Missing	1	6
Time since active treatment n (%)^a		
Current treatment	5 (63)	8 (50)
Under 1 year	0 (0)	5 (31)
1-2 years	3 (37)	2 (13)
Not had active treatment	0 (0)	1 (6)
Treatment received^e, n (%)^a		
Prostatectomy	0 (0)	9 (56)
External beam radiotherapy	4 (50)	7 (44)
Brachytherapy	0 (0)	1 (6)
Hormone therapy	7 (87)	10 (63)
Active surveillance	1 (13)	6 (38)
Watchful waiting	0 (0)	3 (19)
Current active treatment, n (%)^a		
Hormone therapy	5 (63)	8 (50)
External beam radiotherapy	2 (25)	2 (13)

^aPercentages rounded.

^bEMID: English Index of Multiple Deprivation (phase I).

^cSIMD: Scottish Index of Multiple Deprivation (phase II).

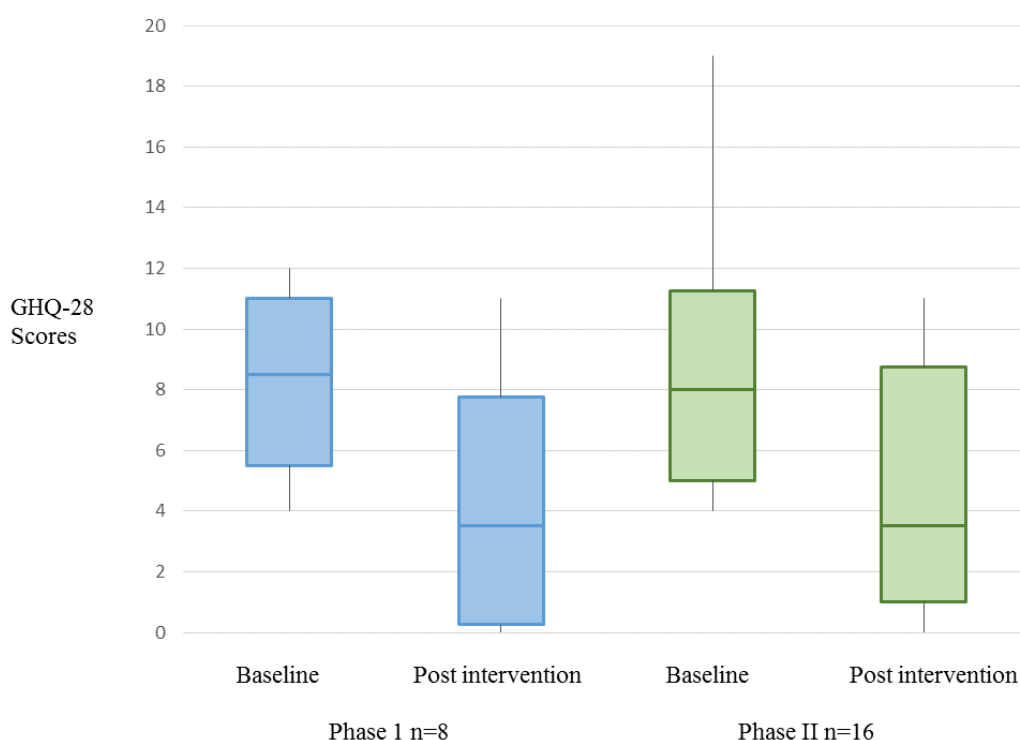
^dPSA: prostate-specific antigen.

^eParticipants may have had, or be having, more than 1 treatment.

Table 4. Participant satisfaction.

Program elements: Likert Scales	Phase I (N=8), n (%) ^a			Phase II (N=16), n (%) ^a		
	Agree ^b	Disagree ^c	Neutral ^d	Agree ^b	Disagree ^c	Neutral ^d
Recruitment pages						
Understood the process	8 (100)	0 (0)	0 (0)	16 (100)	0 (0)	0 (0)
Language appropriate	8 (100)	0 (0)	0 (0)	15 (94)	0 (0)	1 (6)
Look appropriate	8 (100)	0 (0)	0 (0)	14 (88)	0 (0)	2 (13)
Emails swift	7 (88)	0 (0)	1 (13)	16 (100)	0 (0)	0 (0)
Links easy to access	6 (75)	1 (13)	1 (13)	16 (100)	0 (0)	0 (0)
The program						
Language appropriate	8 (100)	0 (0)	0 (0)	15 (94)	0 (0)	1 (6)
Length of each step right	7 (88)	1 (13)	0 (0)	11 (69)	2 (13)	3 (19)
Week per session right	7 (88)	0 (0)	1 (13)	12 (75)	1 (6)	3 (19)
Questionnaires did not interfere ^e	7 (88)	0 (0)	1 (13)	N/A	N/A	N/A
Mood diary was helpful ^f	N/A	N/A	N/A	7 (44)	3 (19)	6 (38)
Worked through smoothly	6 (75)	1 (13)	1 (13)	15 (94)	0 (0)	1 (6)
Links easy to access	6 (75)	0 (0)	2 (25)	16 (100)	0 (0)	0 (0)
Information helpful	6 (75)	0 (0)	2 (25)	14 (88)	0 (0)	2 (13)
Understood diagrams	5 (63)	0 (0)	3 (38)	16 (100)	0 (0)	0 (0)
Worksheets useful	5 (63)	0 (0)	3 (38)	7 (44)	1 (6)	8 (50)
Robert's voice helped me	4 (50)	0 (0)	4 (50)	10 (63)	1 (6)	5 (31)
Chat forum						
Easy to locate	3 (38)	2 (25)	3 (38)	13 (81)	0 (0)	3 (19)
Facilitator was supportive	2 (25)	1 (13)	5 (63)	9 (56)	0 (0)	7 (44)
Opportunity for private chat was reassuring ^g	1 (13)	1 (13)	6 (75)	7 (44)	0 (0)	9 (56)
Learned a lot from other men	0 (0)	3 (38)	5 (63)	10 (63)	1 (6)	5 (31)
Films						
Range of experiences and stories	7 (88)	0 (0)	1 (13)	15 (94)	0 (0)	1 (6)
Made me feel not alone	7 (88)	0 (0)	1 (13)	10 (63)	0 (0)	6 (38)
Program benefited from films	6 (75)	0 (0)	2 (25)	12 (75)	0 (0)	4 (25)
Men were representative	5 (63)	0 (0)	3 (38)	14 (88)	1 (6)	1 (6)
Could relate to men	5 (63)	2 (25)	1 (13)	11 (69)	2 (13)	3 (19)
Reflected learning in modules	4 (50)	0 (0)	4 (50)	10 (63)	0 (0)	6 (38)
Gave me confidence ^h	4 (50)	0 (0)	4 (50)	9 (56)	0 (0)	7 (44)

^aPercentages rounded.^bAgree + agree strongly.^cDisagree + disagree strongly.^dNeither agree nor disagree.^ePhase I only.^fPhase II only.^gFull item *Opportunity to have private chat with facilitator was reassuring.*^hFull item *Gave me confidence to make a difference to how I feel.*

Figure 4. Change in distress. General Health Questionnaire-28 (GHQ-28).

Phase II interviews helped clarify the questionnaire responses. (Participant profiles: [Multimedia Appendix 3](#); verbatims: [Multimedia Appendix 4](#)). Acceptability of the program was high, even among those with low IT skills, and there was a readiness to improve skills. Men were comfortable using tablets, mobile phones, laptops, and desktop computers: they mainly found it effortless and flexible in comparison with other forms of support, even those who were finding concentration, or the availability of free time, a challenge. Some expectations were not met: disappointment with the length of modules noted in the assessment was attributed to less interaction time and *things to do* in the final module.

Men readily identified that the program targeted issues they found difficult to talk about. Learning about the link between the effects of treatment and mood and behavior was a fresh perspective, and they felt that the skills developed to manage now would be useful should things change in the future. Men referred more consistently, however, to other aspects of the program. The weekly provision of information via a range of links related to that week's learning was used enthusiastically because it provided access to immediate information that meant men could control when and how much they consumed. They identified that having the links was an improvement on their usual Internet use because they were direct and avoided lengthy searching and inappropriate or potentially scary information. The films provided discreet stories, preventing the unpredictable, which helped men feel connected and in control, particularly those with social and information needs.

For those who engaged in the chat room, it was a safe environment where they could be honest with each other without the inhibitions they often experienced with clinicians. It was also a source of quick answers to spontaneous questions, which

for some was very appealing; for others, it could be daunting if something was revealed that was incorrect or alarming. Despite the improved chat room satisfaction scores in phase II, some felt that the facilitator could have made more attempts to encourage men to open up and interact.

Distress

The samples were not powered to detect a significant change. Notwithstanding, we carried out nonparametric testing to determine potential for change in distress between baseline and post intervention; the samples performed similarly ([Figure 4](#)). A Wilcoxon signed-rank test indicated improvement in distress at the end of the intervention in both phases (phase I $z=-2.213$, $P=.03$, $r=-.55$; phase II $z=-3.342$, $P=.001$, $r=-.59$). In phase II, we also calculated change in domain scores. From baseline to post intervention, there was a positive change in somatic domain symptoms ($z=-2.588$, $P=.01$, $r=-.458$) and anxiety domain symptoms ($z=-3.466$, $P=.001$, $r=-.613$). Scores for social dysfunction domain symptoms were $z=-1.531$, $P=.13$, $r=-.27$ and for severe depression domain symptoms scores were $z=-1.283$, $P=.20$, $r=-.23$ (see [Multimedia Appendix 5](#)).

Clinical Caseness

A total of 17% (4/24) of participants overall registered scores on the PHQ-9 and GAD-7 that were above the clinical threshold for depression and anxiety and defined them as cases requiring clinical intervention in accordance with IAPT protocols. Of these 4, 3 scored over the threshold for depression on the PHQ-9, and 3 scored over the threshold for anxiety on the GAD-7 (see [Multimedia Appendix 6](#)).

Self-Efficacy Phase II

At baseline, men were most confident in performing daily activities (mean 69, median 80.0, SD 22.4, range 18-72), less-confident coping/tolerating symptoms (mean 52, median 53.5, SD 17.2, range 26-80), and least confident managing their symptoms (mean 31.6, median 31.50, SD 9.3, range 12-49; see [Multimedia Appendix 7](#)). A Wilcoxon signed-rank test performed on baseline and post scores showed an improvement in coping ($z=-2.329$, $P=.02$, $r=-.412$). Change was not indicated in managing symptoms ($P=.11$) or in performing daily activities ($P=.08$).

Service Implementation

Facilitator Time

Phase I facilitator clinical time was ring-fenced for 2, 2-h sessions per week, that is, 16 h over a 4-week program. To risk assess and monitor the program at other times, 1 facilitator spent 6 h 56 min in the program and the second spent 8 h 29 min, giving a total of 22 h 56 min and 24 h 29 min, respectively, per program. In phase II, the facilitator spent 15 h 45 min in total across 1 program.

Facilitator Feedback—Delivery

The psychological practitioners were reassured the program was consonant with their standard CBT practice. They emphasized that the lay approach did not overwhelm participants and encouraged active log-in and participant commitment. They indicated their clients generally found it difficult to differentiate the effects of physical and psychological symptoms on mood, and often there was little change on the service's standard outcome measures for clients with a physical long-term condition. In the cancer service, the opportunity to offer evidenced-based support for distress was welcomed as a practical and timely benefit for patients; this need was considered poorly covered in the nurse-patient interaction through a lack of competences and provision (Verbatims: [Multimedia Appendix 8](#)).

Facilitator Feedback—Implementation

The psychological practitioners found the self-management role difficult to integrate into their skill set, and they lamented the move away from their therapeutic expertise. They were supportive of being allocated time slots for facilitation as it was necessary for case management, but there had been little need for them to respond during these times as men's log-in preferences did not correspond to their availability. They felt this impeded the flow of conversation and highlighted the benefits of providing a rolling chat room rather than starting afresh each week. Integration into the nurse's current practice was challenging; the accepted nurse role of *fixer* was replaced in this context by an enablement approach which was unfamiliar and was considered to require a shift in practice values calling for bespoke training. Notwithstanding, the ad hoc facilitation had enabled a flexible response, and the role had been easily assimilated into the nurse's workload. In both services, the facilitator role was considered not to require the higher level skills associated with psychological practitioner and specialist nurse roles (Verbatims: [Multimedia Appendix 8](#)).

Discussion

Principal Findings

This is the first study, to our knowledge, to assess the feasibility of delivering Web-based CBT support in clinical settings among men screened with distress after treatment for prostate cancer. The Getting Down to Coping Program was embraced and acceptable to its target users. It can be delivered in a clinical service and has the potential to provide a therapeutic psychological service remotely.

Demand

Demand for the program was evident. Among men who were eligible and screened with mild and moderate distress, 29 of the 30 (96%) started the program. This exceeds reported rates in comparable cancer and prostate cancer Web-based studies for distress where enrolment after screening, which excluded distress, was between 31% and 41% [33,59]. Our retention rate of 80% meets the 70% criteria for feasible retention set by Yanez et al [33], and our 20% attrition rate is also at the lower end of rates found in randomized trials of Internet-based interventions for anxiety and depression, which range from 1% to 50% [60].

Initial uptake to our invitation of 12-14% among an unscreened sample, however, was low. Comparison with other Web-based, distress-related prostate cancer studies is problematic as they do not report the base numbers from which their screened samples were drawn [31,33]. Yet this level of uptake is not completely surprising. Across the spectrum of cancer, the profile of older age and male gender has been associated with lower uptake of Web-based psychological support [59]. Furthermore, mental health-related stigma can deter help-seeking behavior, particularly in men, and in a clinic environment, it has been reported that only 20% of unscreened cancer patients accept psychological help [61,62]. The remote recruitment process we used would also make it easier for reluctant men to avoid support [63].

Uptake may be enhanced if the nature and benefits of psychological support are conveyed so that accepting it is perceived as less *risky*. Our recruitment materials were intended to reduce perceptions of mental health and stigmatizing signals, but the research focus and length could have been burdensome for some. Information that is focused on the health problem rather than the trial process, and that is also brief and relatively simple, has been associated with enhanced recruitment rates [64-66]. To involve men, one approach may be to reflect the way they think and feel about receiving help. In the phase II interviews, men talked about how they were empowered rather than how they were supported by the program. This reflects work by Clover and colleagues who found in a survey among oncology outpatients the most common barrier to accepting psychological support was a preference for self-help [67]. The opportunity for men to increase control of their daily lives by self-help is a fundamental focus of the Getting Down to Coping Program and could be incorporated more explicitly into study communications. Framing the intervention in a self-management paradigm rather than a psychological one could help normalize men's engagement. Further ways to enhance uptake would be to provide the main component of participant information over

the internet with interactive elements so that men can choose what and how much to read. Clinician endorsement of the program as a self-help opportunity is another component that could encourage more men to take part [66,68]. The way in which we communicate psychological Web-based provision may be a crucial element in encouraging uptake of support and is an area for further examination [69].

Acceptance

Usage of the program and satisfaction of participants indicated that it is appropriate and acceptable to its core users. The adherence rates we achieved, from 63% to 100% across task and social support elements, illustrated that commitment was relatively high. In review of Web-based mental health programs, and in a trial among men with prostate cancer, rates of between 50% and 70% have been reported [31,60]. Men's satisfaction and involvement were borne out by their willingness to improve their IT skills to get the most out of participation. The program offered experiences that were consonant with masculine ideals, for instance, being connected, acquiring tools and information, and a focus on *the self*, which increased feelings of physical, social, and emotional control. This is consistent with the notion that support programs need to reflect masculine ideals to involve men and optimize benefit [70,71].

We found a larger proportion of men with mild and moderate distress in the second phase of our research (21% and 41%, respectively), and also higher adherence rates in this second phase. There was some previous experience of psychological support in phase II, and adherence would have been enhanced by improvements to the program between phases. However, the higher distress levels and adherence could also be evidence of a greater level of commitment to the program in men of lower socio-economic status who characterized the phase II sample. These men experience poorer access to support and higher-than-average psychological need, indicating that regional differences will be an important consideration in further research and clinical implementation [9,72,73].

Limited Efficacy Testing

We found improvement in distress with a medium-large effect size in each phase. Particular improvements were in the somatic and anxiety domains of the GHQ-28. The nature and definition of distress is complex in a cancer population [74,75], and there have been calls for a more realistic framework to identify cancer-related distress [76]. The change in somatic symptoms confirmed that this can be a factor in the etiology of distress in a prostate population and is important to include when assessing distress [77]. The finding that only 4 of our participants would have been offered standard psychological support on the basis of assessment with the PHQ-9 and GAD-7, which do not include somatic symptoms, further suggests that more tailored tools are required for this population.

We also found an improvement in confidence to cope with prostate cancer symptoms but not for confidence to perform daily activities or to manage symptoms. This can be expected; performing daily activities was at a high level at baseline, leaving little room for improvement, whereas physical symptoms related to the longer-term effects of prostate cancer treatment

can often be intractable [78]. Ongoing rehabilitation has to be focused on building resilience and fostering understanding and coping with symptoms. The program can offer this focus for men.

Implementation

Implementing the Getting Down to Coping Program has potential within both primary and secondary care settings. The intervention is a self-guided program, but some facilitation is optimal for risk monitoring and would be expected by a psychological service. However, the facilitation required calls for neither advanced psychotherapeutic skills nor high-level nursing skills, only the ability to perform the core skills necessary to motivate self-management and to monitor risk. In both settings, our facilitators were not practiced in communicating within Web-based support programs, and had no previous experience of supporting self-management. Our training contained elements of both, but all the facilitators still had difficulty performing the role; greater emphasis in training on facilitating self-management via Web-based interaction is required. Notwithstanding this, facilitation may be delivered in either setting by a lower band, health support role.

Although we were not able to assess cost-effectiveness in these studies, the time spent facilitating in each service suggests that the flexible model of intervention interaction may have the greatest potential: it did not disrupt the facilitators' standard caseload and, for the sample we had (n=16), amounted to 1 h per participant per 4-week program. This would be inversely related to the number of men in each program.

Limitations and Strengths

There are limitations to these studies. The sample sizes were small and were not powered to detect change, and participants were not randomized. Generalization of our findings must therefore be cautious. Where we found change we do not know what variables are responsible; natural recovery could play a role and so could extraneous events. Nevertheless, with feasibility testing in 2 clinical settings, we have developed our knowledge of both the intervention and research required to move to the next trial stage. The consistency across our 2 samples on a number of measures, and the effects found, indicate that larger scale, evaluative research is justifiable. Our further research will include a longer follow-up period to provide an indication of maintenance of change, as well as full cost-effectiveness analysis. Furthermore, we will analyze covariance in respect of facilitator and group effects.

A strength of our studies was that we incorporated the theoretical model of PSD [52], which can provide an objective understanding of adherence. We were able to measure *social* and *task* design elements, which we posited were the most important features in our intervention for effecting behavior change. Measuring *intended* use is reflective of assessing compliance in face-to-face therapy and has been proposed as the most realistic reference standard for adherence in Web-based interventions [50,60]. Analysis on this basis offers more robust comparability within and across studies than static measures of exposure, such as log-in data, which are inherently subject to system and participant ambiguity. For instance, *log-in time* in

phase I gave little indication of what interaction took place. In phase II, we measured *time logged-in-and-active*, which gave a clearer indication for adherence purposes, but we still had to make assumptions, that is, how long a log-in was deemed to contain *active* time. Such assumptions are often not reported in studies. More extensive application of the theoretical underpinnings of how design and system components can influence behavior change is called for [79].

Conclusions and Recommendations for Future Research

To integrate psychological services for cancer patients in the existing care pathways, interventions that fit with health provider parameters of care provision are required [75]. Without research sampling based on defined need, or analysis of implementation processes, many intervention studies do not provide sufficient evidence of viability or efficacy [75]. We have taken the first steps to address this with a Web-based intervention, by assessing feasibility among a population that requires clinical support and by providing that support within a clinical practice context.

The program has the potential to fit within a stepped model of care by providing psychological support for men who are mild or moderately distressed and who fall within the clinical parameters for low-intensity support. Addressing these men's needs will prevent escalation of symptoms and the need for higher-intensity therapy. Potentially, this would lead to service

cost savings in terms of reduced physical and mental health service use.

In a stepped model of therapeutic care, the program requires low-level facilitation for monitoring risk, which raises cost implications versus a completely automated system. However, within the clinical services we researched, risk surveillance was a mandatory requirement, and the true cost comparison would be versus a therapist-led, face-to-face, or telephone approach. The numbers of men who can be supported with the Web-based program at any one time is subject to economies of scale, and cost advantage can increase exponentially with the volume of patients taking part. Furthermore, facilitation need not be carried out by advanced practitioners, which contributes to delivery cost advantage. Assigning staff to the facilitator role who possess appropriate competencies, as well as ensuring their involvement with and commitment to the innovation, will be crucial to its success [80].

Clinical effectiveness, and cost-effectiveness in terms of clinical delivery and health service utilization, need to be tested in an evaluative research design. Future research should be underpinned by exploratory enquiry to establish the most relevant and engaging ways to communicate study and intervention characteristics for this prostate cancer population. In future, we hope to develop the Web-based program for men with other cancers.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Getting Down to Coping risk assessment.

[\[PDF File \(Adobe PDF File\), 22KB - cancer_v4i1e8_app1.pdf \]](#)

Multimedia Appendix 2

Getting Down to Coping program modules.

[\[PDF File \(Adobe PDF File\), 160KB - cancer_v4i1e8_app2.pdf \]](#)

Multimedia Appendix 3

Phase II interview participant profiles.

[[PDF File \(Adobe PDF File\), 89KB - cancer_v4i1e8_app3.pdf](#)]

Multimedia Appendix 4

Phase II participant verbatims.

[[PDF File \(Adobe PDF File\), 84KB - cancer_v4i1e8_app4.pdf](#)]

Multimedia Appendix 5

Distress total change scores in phase I and total and domain change scores in phase II.

[[PDF File \(Adobe PDF File\), 68KB - cancer_v4i1e8_app5.pdf](#)]

Multimedia Appendix 6

Patient Health Questionnaire-9 (PHQ-9) and General Anxiety Disorder Scale-7 (GAD-7): number of participants scoring in each diagnostic category in phase I and phase II.

[[PDF File \(Adobe PDF File\), 77KB - cancer_v4i1e8_app6.pdf](#)]

Multimedia Appendix 7

Self-Efficacy change scores in phase II.

[[PDF File \(Adobe PDF File\), 83KB - cancer_v4i1e8_app7.pdf](#)]

Multimedia Appendix 8

Phase I and phase II facilitator verbatims.

[[PDF File \(Adobe PDF File\), 154KB - cancer_v4i1e8_app8.pdf](#)]

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Abbreviations

CBT: cognitive behavior therapy
EMID: English Index of Multiple Deprivation (phase I)
GHQ-28: General Health Questionnaire 28
IAPT: Improving Access to Psychological Therapies
PSA: prostate-specific antigen
PSD: persuasive system design
PHQ-9: Patient Health Questionnaire 9
GAD-7: General Anxiety Disorder Scale 7
SESCI: Self-Efficacy for Symptom Control Inventory
SIMD: Scottish Index of Multiple Deprivation (phase II)

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Original Paper

Assessing Unmet Information Needs of Breast Cancer Survivors: Exploratory Study of Online Health Forums Using Text Classification and Retrieval

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Abstract

Background: Patient education materials given to breast cancer survivors may not be a good fit for their information needs. Needs may change over time, be forgotten, or be misreported, for a variety of reasons. An automated content analysis of survivors' postings to online health forums can identify expressed information needs over a span of time and be repeated regularly at low cost. Identifying these unmet needs can guide improvements to existing education materials and the creation of new resources.

Objective: The primary goals of this project are to assess the unmet information needs of breast cancer survivors from their own perspectives and to identify gaps between information needs and current education materials.

Methods: This approach employs computational methods for content modeling and supervised text classification to data from online health forums to identify explicit and implicit requests for health-related information. Potential gaps between needs and education materials are identified using techniques from information retrieval.

Results: We provide a new taxonomy for the classification of sentences in online health forum data. 260 postings from two online health forums were selected, yielding 4179 sentences for coding. After annotation of data and training alternative one-versus-others classifiers, a random forest-based approach achieved F1 scores from 66% (Other, dataset2) to 90% (Medical, dataset1) on the primary information types. 136 expressions of need were used to generate queries to indexed education materials. Upon examination of the best two pages retrieved for each query, 12% (17/136) of queries were found to have relevant content by all coders, and 33% (45/136) were judged to have relevant content by at least one.

Conclusions: Text from online health forums can be analyzed effectively using automated methods. Our analysis confirms that breast cancer survivors have many information needs that are not covered by the written documents they typically receive, as our results suggest that at most a third of breast cancer survivors' questions would be addressed by the materials currently provided to them.

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KEYWORDS

online health forum; automated content analysis; text retrieval; text classification

Introduction

Study Objectives

Health concerns are prevalent among breast cancer survivors both during and after their cancer treatments. These health concerns are ongoing and can include topics such as symptoms and side-effects, fear of cancer recurrence, and coordination of follow-up cancer screening. As a result, breast cancer survivors have a wide range of emotional and information needs that will vary over time. These issues can have an impact on both a survivor's quality of life and future decisions about health care. Medical providers need an accurate assessment of survivors' information needs, especially regarding any unmet needs, in order to provide appropriate educational resources to improve quality of care and to support patients' successful transition from treatment by an oncologist to care from a general physician and self-management.

The aim of this study is to assess the unmet information needs of breast cancer survivors [1-5] from the patient's perspective and to develop methods that can be used to improve the information resources provided to them. However, the problem and the methods are not specific to cancer. There are two subtasks to assessing the problem of unmet information needs. The first task is identifying what information the population of concern perceives as necessary, but they feel has been inadequately addressed. The second task is determining whether the perception is due to a true gap in the resources that are being provided to them or to ineffectiveness in how information is being provided.

Determining the nature of any perceived information gaps would assist in directing efforts to appropriately address them. Some gaps can be addressed by adding more content, as long as the right content is added, and it can be located easily. One might also want to consider creating more accessible means of providing content, so the relevant information can be easily found. Most existing resources for survivors, which include brochures, books, and care plans, are static paper documents or webpages. By design, static content must balance the goals of covering the most commonly needed topics, while remaining manageable in size. Finding the required information can be difficult even when a resource provides it, because the relevant knowledge may be surrounded by less relevant information or may not be expressed in the terminology that a person expects. Voice assistants and chatbots that support question-answering could target dynamically expressed information needs, to eliminate searching, but they also require very specific information about the topics of interest and how they might be expressed. Assessing patients' perspectives on their unmet information needs, in the most authentic means possible, will assist in the design of new tools to address these problems.

This study will consider postings to peer-to-peer online health forums as a relevant resource for learning about patients' unmet information needs because the very fact that a person posted an information-seeking question online is evidence of their perceived need. The postings also provide information about the language patients typically use to describe the information that they need. Using online forum data also allows for the

assessment of needs over a wide span of time and from a diverse population that resides and receives care across a wide geographic area. We envision that the selected health forums could be accessed periodically to obtain up-to-date information about the needs of breast cancer survivors, and this information could be shared with content experts to guide them in creating and refining educational resources. Because these forums might contain information (posts) unrelated to information-seeking, automatic methods would be applied to discriminate true expressions of information need from similar sentences, such as questions that are primarily social or intended to clarify a previous statement. To obtain more specific information, sentences would be classified into meaningful categories and keywords or concepts extracted and subject to further analysis.

Background

There have been several recent efforts to assess the unmet needs of cancer patients. Many use the Supportive Care Needs Survey [1-5]. This validated questionnaire covers 5 domains; namely psychological, health system and information, physical and daily living, patient care and support, and sexuality needs. The need for counseling to deal with psychological distress and the need for information about treatment, prognosis, wellness, and managing symptoms and side-effects have been the most commonly reported unmet needs in cancer patients. This survey and the results provide a useful starting point for an automated analysis.

Having multiple methods for assessing unmet information needs would be valuable, as relying only on survey results introduces bias that limits the reliability of the results. Bias can arise from how questions are worded, how subjects are recruited, and the beliefs and psychology of individual subjects when interacting with researchers or participating in a survey. The needs of an individual can also change over time. In our experience with developing a prototype phone-based question-answering tool, less than half the topics mentioned in surveys and focus groups of providers and clients were mentioned in the questions posed to the tool by subjects during an at-home user study and the subjects also asked many questions not previously identified [6].

Online health forums have been found to be a valuable resource for gaining the patients' perspective on their health concerns. As such, researchers have analyzed online forum data to learn about the experiences and needs of groups that might be difficult or sensitive to reach, including patients taking new medications [7] and people with eating disorders [8]. The results reveal evidence of unmet information needs including questions about indications and contraindications, proper use and storage, diet and drug restrictions, side effects, safety, and efficacy [7]. The importance of examining forum data is also supported by survey studies of health forum users, who report finding them to be valuable sources of health information and support, including both the active posters as well as "lurkers" (ie, those who read but do not post), which suggests that the forums are a place where participants return over time as new information needs arise [9].

The prior studies on health forums [7-9] all relied on a manual analysis of content that would be costly to replicate on a regular

basis. A more automated method of analysis would be beneficial, but typical postings to online health forums, as shown in [Textbox 1](#), have many characteristics that would present challenges to applying automatic approaches (for clarity, the sentences in the post have been separated and the general function of each sentence has been noted underneath in italics). A qualitative analysis of several forums for breast cancer survivors revealed a number of distinctive features. First, the vocabulary used to express information needs contains a mix of terminology from clinical medicine, consumer health, and daily living (including family, finances, and hygiene). Second, the style of interaction is often similar to semiformal written correspondence. For example, in addition to information exchange, the posts may include text that expresses social conventions, such as salutations and closings. However, sometimes the posts resemble text messages and forgo (or abbreviate) traditional conventions. The sequences of the posts are also similar to spoken conversations and involve turn-taking that shifts focus among the participants. Turns may address multiple functions including control of the dialogue (eg, to start a conversation or to invite the next person to give a response), to enhance a social relationship, or to provide or request specific information. The final feature found revealed that individual posts, and the sentences that comprise them, often vary greatly in length, possibly reflecting the variety of devices that people use to post online. In the longer posts, one often observes survivors sharing extensive information about their journeys, which both establishes a context for seeking information and creates a social connection to other survivors which encourages trust. Several sentences may be used to separately introduce a topic, provide context, and make an information request that includes references to the other sentences. The post shown in [Textbox 1](#) is the start of a much longer conversation that overall contained 23 separate posts by different participants, with a total of 110 sentences.

The characteristics found in forum postings represent challenges for automated text classification because classification

approaches generally work best when items in a class are similar to each other and each item of data has a unique class. To reduce the number of classes an item of data might represent, one can split posts into individual sentences. However, sometimes even short sentences can contain more than one class. Also, splitting the posts may make it necessary to later combine the results from separate sentences to fully understand a sentence. For example, in [Textbox 1](#), to understand the query, “Anyone else have this difficulty,” one must refer to previous sentences to identify that “this difficulty” refers to the previously mentioned problem with a prosthesis used after a mastectomy being “hot and uncomfortable.”

Approach

This study contributes both to the problem of identifying information needs survivors perceive as unmet and to the problem of identifying potential gaps in the knowledge commonly provided to them. This work involves four steps, namely (1) creating a taxonomy, (2) annotating sentences from two online health forums with categories from the taxonomy, (3) developing and evaluating classifiers using the annotated data, and (4) using an annotated corpus and information retrieval methods to measure the gap. Using any supervised classification approach requires having a corpus of annotated data and using two provides more generality. We developed a new taxonomy to annotate the data with categories related to the previously noted concerns of survivorship, including treatments and the physical and psychological problems afterwards, as well as categories related to the structure of posts, such as social or referential expressions.

Developing classifiers involves comparing several alternative algorithms and combinations of features for training classifiers using the annotated data. This step is necessary, because while there are a large number of different algorithms for building automated classifiers, there is no known method for predicting which algorithm, or which combination of possible input features, is best for a given problem.

Textbox 1. Example post to a health forum for breast cancer survivors. Each sentence in the post is presented on a separate line, with its general function as described in this study noted in italics below the sentence.

<p>Hi to all the women out there! I was diagnosed with breast cancer, stage 1, 11 months ago</p> <p><i>(Social greeting)</i></p> <p>I am 59 years old</p> <p><i>(Non-medical background)</i></p> <p>I had a right breast mastectomy and chose to not get breast reconstruction</p> <p><i>(Medical)</i></p> <p>The prosthesis I was given is hot and uncomfortable, so I am finding that I do not use it</p> <p><i>(Physical problem)</i></p> <p>Anyone else have this difficulty</p> <p><i>(Expresses an information need)</i></p> <p>I have recently moved and need to start all over with a new oncologist</p> <p><i>(Other problem)</i></p> <p>How do I choose one?</p> <p><i>(Expresses an information need)</i></p>
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To find the best approach, one must systematically evaluate several different classification methods and input features, starting with the most basic features (words or pairs of words), and then assessing more complex ones, such as features that would capture lexical semantics or local context. We assess using topic models and word embeddings as a way of introducing semantic information that sometimes generalizes better than a simple word or bigram model. We also assess using the categories associated with the immediately preceding and immediately following sentences to capture some of the local context.

To measure the potential knowledge gap, we apply commonly used methods from information retrieval. This step serves two functions. First, it gives a better understanding of unmet needs. It also provides a way of assessing the usefulness of the data that one could collect from social media. The technique uses survivors' own language as queries to an indexed set of commonly distributed documents. Annotators judged the relevance of the top-ranked results. If documents are retrieved that seem relevant, it would suggest that there is no knowledge gap, but there may be a problem with survivors not having the right document when they need it. If no document is retrieved that seems relevant, then there is likely a gap (but there could also be a difference in language that would make both search and understanding the document difficult.) Both problems would warrant further review.

Thus, the four steps of this work, together, will reveal the extent to which automatic approaches can identify expressions of unmet information need from online health forum text and provide new information about how resources might need to be improved.

Methods

Data collection

This study used data collected from two online health forums. We started by creating a data set from a MayoConnect (MC) forum for breast cancer survivors. This forum was selected primarily because of its local interest. It also included data spanning at least five years, had active postings, and (at the time) was a peer-to-peer forum. To create a data set, we extracted the complete set of conversations available at the time, each consisting of multiple posts from different authors, removed any metadata and split the sentences into sentence-type units using an automated procedure. This data set consists of 65 conversations which yielded 1943 items for coding. The average number of sentences in a post was 6.35 (SD 4.42), the average number of words per sentence was 14.04 (SD 6.30) and the average number of characters per word was 5.24 (SD 2.31).

Textbox 2. Iterative algorithm for building patterns of expressions of information need.

For each positive example of the training set
 If the example is not already matched by a pattern,
 then generate the smallest set of bigrams from V such that
 the positive training example has all the bigrams in the set
 and no negative training example has all the bigrams in the set

To better assess the generality of any findings, a second forum, the American Cancer Society Cancer Survivors Network on breast cancer (CSN), was selected. It also had active posts spanning at least five years and involved peer-to-peer interaction. This forum met the additional criterion that the forum is easily accessible for research. One can download archived posts using open-source software called curl [10]. From this site we created two data sets; one that contains complete conversations and is similar in size to the MC data set, which is henceforth referred to as "CSN," and another, smaller data set of randomly selected sentences, "CSN-R." To select conversations for the larger dataset from CSN, a simple rule-based classifier was created to identify sentences that might represent an expression of an information need and only used conversations that contained at least one such sentence. We used this strategy in the hopes of increasing the density of information-seeking examples in the data set, as the natural density appeared to be less than 5%, which might affect the coders.

To build the rule-based classifier, a training set was made from the complete annotated MC data set and a small sample (<200 sentences) from the CSN forum data which was labelled separately before extracting the complete CSN data set. This yielded about 150 positive examples of information needed. Additionally, a vocabulary (V) was defined which contained potential question cues or components of one, such as auxiliary verbs, pronouns, wh-words (when, where, why, and how), and verbs, nouns, and adjectives associated with direct and indirect requests for information (wondering, wanting, trouble, anyone, similar). The patterns for the rules were then created using the algorithm shown in [Textbox 2](#).

This simple classifier is helpful in building a data set but both false negatives and false positives will occur due to unseen examples and counter examples. To investigate whether this classifier would be more broadly useful, a test set, CSN-R, was created for evaluating both the rule-based classifier and the statistically trained classifier for expressions of information need which is planned for development. CSN-R (the test set) comprised a random sample of 1000 sentences extracted from the CSN forum for a time period that, importantly, did not overlap with the other larger sample.

For the main CSN dataset, 195 conversations were obtained which were then split into posts and then the posts were further separated into sentences. From this process 2246 items that could be coded were obtained. The average number of sentences per post was 11.52 (SD 5.29), the average number of words per sentence was 13.97 (SD 5.30), and the average number of characters per word was 6.12 (SD 3.21).

Taxonomy for Supervised Classification

Following a review of the literature related to past assessments of the needs of breast cancer survivors [1-5], and some prior taxonomies [11,12], a new taxonomy was iteratively developed. As mentioned above, prior survey work [1-5] revealed that the most commonly reported unmet needs in cancer survivors include psychological distress and the need for information, especially about treatment, prognosis, wellness, and managing symptoms and side-effects. Some categories included in the Supportive Care Needs Survey, such as relationships or sexuality, were considered but not included in our taxonomy because they did not occur in our data. In examining prior taxonomies, some relevant categories were found, such as expressing an information need, or providing medical background, but also many categories rarely mentioned by survivors, including anatomy, causes, complications, diagnoses, manifestations, and susceptibility. Prior taxonomies lacked categories for treatments and for physical or psychological problems associated with survivorship. Furthermore, it was found that the topics and information need were orthogonal types, suggesting it would be prudent to use separate categories that could be later combined.

The new taxonomy includes a single binary category “has information need” or “HASN” to indicate whether an entity expressed an information need. This category covers both direct questions as well as implicit questions expressed as statements, such as “I am concerned about...” or “I was wondering about...” It also includes 10 categories to indicate the primary type of information provided or requested, namely medical, resource, social, psychological, background, wellness, physical, previous, other, and multiple. These primary types of information correspond to medical events (“medical” eg, clinical observations, diagnoses, and interventions), educational resources (“resource” eg, books or websites), social interaction (“social” eg, greetings, invitations to talk, thanks, or good wishes), self-identified psychological problems (“psychological” eg, fear or sadness), non-medical personal information (“background” eg, age, family, or employment), wellness tips (“wellness” eg, diet, hygiene), and self-identified physical problems (“physical” eg, pain, hair loss). The other categories are used for exceptions where appropriate. “Previous” is used when the main topic of a sentence requires interpreting a referring expression to another sentence; “other” is used for information topics that fall outside the realm of any of the defined topics (such as travel); and “multiple,” used only for coding the MC data, is used to indicate when a sentence covered multiple categories. The category “multiple” does not apply to the CSN data as when coding the data, annotators were allowed to specify up to two information categories and did not explicitly label data as “multiple.” The complete annotation guideline, along with examples, is given in [Multimedia Appendix 1](#).

Data Annotation

Four people performed the data annotation tasks. The team included 2 experts from the research team who had expertise in computer science and 2 nurse abstractors with experience in data abstraction for health sciences research. The 2 experts developed the written guidelines for annotation. The nurse

abstractors were trained to conduct data annotation using a small sample set (approximately 200 items). For the MC data set, one expert and one trained abstractor independently annotated the data, and another expert adjudicated the results. For the CSN data set, one trained abstractor and one expert independently coded the data, and another trained abstractor adjudicated the results. For the CSN-R dataset, two experts annotated the data and one trained abstractor adjudicated the results. For rating the relevance of retrieved educational documents, the same 2 trained abstractors acted as independent judges.

Inter-annotator agreement was assessed for each class separately using both simple counts and the percentage of the final calculated quantity of the class captured by the agreed items. This measure was used as the sample sizes were quite variable and often small. Using this measure, for the information classes (eg, “medical,” “resource,” “social,” and “psychological”) the agreed items for the MC data set covered from 11% (16/147, “previous”) to 96% (541/597, “medical”) of the total number of items determined to be in each class. For the CSN data set, the agreed items covered from 62% (454/728, “other”) to 100% (32/32, “resource”) of the final items in each class. Using this same measure, the agreement for the class “has information need” covered 20% (22/110) of the final items for the MC data set, 69% (135/196) for the CSN data set and 66% (23/35) for the CSN-R data set. The agreement counts for all categories across all data sets are provided in [Multimedia Appendix 2](#). After the annotation of the MC data set, the guidelines were revised so that annotators could assign multiple categories to each sentence and therefore the category “multiple” was no longer used. Additionally, the description of the protocol for coding “has information need” was improved to better capture indirect expressions of information need, which had been frequently missed.

Assessment of Information Needs and Content Expressed in Social Media

To assess how well these automatic approaches to analyzing social media text can identify expressions of unmet information needs and help to identify the nature of the need, we performed 3 studies using the annotated data sets, exploring several alternative forms of semantic and statistical analysis. The first two studies consider the distribution of sentences across categories of the taxonomy and the types of semantic information expressed in the sentences. The third involved experiments training classifiers with different algorithms and features using the annotated data.

Analysis of Distribution of Sentences across Categories of Taxonomy

After annotation of the complete MC data set, inter-annotator agreement was assessed and any differences between the annotations were adjudicated using an additional annotator and some discussion. The distribution of sentences across each of the categories of the taxonomy and the distribution of categories for sentences marked as indicating having a need was calculated.

Content Analysis of Social Media

Using the MC and CSN data sets described above, we identified the concepts most closely associated with each of the annotated

and adjudicated categories, using MetaMap [13]. The concepts were selected by counting the number of occurrences of each concept in the sentences associated with each category and ranking them based on the size of those counts.

Assessment of Information Needs Using Text Classification

We trained and tested Naïve Bayes, linear Support Vector Machines, and Random Forest (RF) classifiers for each of the information classes (“medical,” “social,” “psychological,” “background,” “wellness,” “physical,” “previous,” and “other”) as one-versus-the-others using 10-fold cross-validation as implemented in Weka (machine learning software) [14]. Thus, if uniform distribution of the categories across the folds is assumed, in each iteration, the number of positive examples for each class ranges from approximately 55-535 from a total of 1750, depending on the class. We evaluated the following input features: words and bigrams alone, words and bigrams along with features derived from topic modelling, words and bigrams along with features derived from word embeddings, and words and bigrams along with features to represent the local context. For each combination, the precision, recall and F-measure using the functions that Weka provides were computed.

For the topic-modelling features, latent Dirichlet allocation [15] was used to generate sets of words corresponding to different topics appearing in the sentences of the posting. We used the MC data set, which contains 1943 sentences, with an average length of approximately 14 words. For each topic, a feature corresponding to the probability that the sentence contained that topic was added. This is calculated as the percentage of the tokens in the sentence generated by a topic. We used 50 topics, each of which corresponded to 15 words. To determine the number and size of topics to use, we experimented with different numbers of topics (5, 10, 50, and 100) and different numbers of words (5, 15, 20, and 50) per topic, with the goal of creating topics, that upon manual inspection, appeared most coherent. For our data, 50 topics with 15 words per topics appeared best. Some examples of these topics are shown in [Textbox 3](#). The topics shown appear to correspond to medical treatments and tests, family and friends, and parts of social greetings.

For word embeddings, pretrained word vectors generated by the GloVe algorithm were used [16]. The training corpus contains Wikipedia and Gigaword (newswire) text. To use word embeddings as features, the deepLearning4Java library and GloVe pre-trained word vectors corpus with 50 dimensions

were used. We generated vectors for all words in each sentence of a forum posting, calculated the average of the vectors and used the average vector to add features for the classifier, such that each element of the average vector adds one feature in the classifier for each sentence.

For the local context features, we added binary values for each of the information types using the values determined from the hand-labelled results for the immediately preceding and the immediately following sentences.

After determining the best classifier (RF) and best set of features (words, bigrams, and local context) using the MC data set, we trained and tested on the annotated CSN dataset using 10-fold cross validation with the same combination of features and analyzed the results using standard measures of precision, recall and F-measure. The feasibility of training on data from one forum and using it to classify data from another forum was also assessed.

Finally, potential classifiers for identifying sentences that express an information need were evaluated using a small test set of randomly selected and hand-annotated sentences, CSN-R, that had not been used for any other purpose. Both the rule-based classifier and three different statistical learning models (Naïve Bayes, linear Support Vector Machines, and RF) were evaluated. The statistical classifiers were trained with the combined hand-annotated data from the MC and the CSN data sets using only words and bigrams as features and the precision, recall, and F-measure were computed.

Assessment of Knowledge Coverage using Text Retrieval

To review the adequacy of current patient education materials, we performed the following steps:

Electronic copies of brochures typically given to breast cancer patients at the Mayo Clinic Breast Center were obtained and each page was indexed separately using Elasticsearch [17], an enterprise search engine. Complete pages, rather than sentences or subsections, were indexed because we did not want to overestimate a gap if the query terms spanned multiple such units.

A set of 136 queries, based on our hand-coded results from the CSN dataset, was created. Hand-annotated data was used so that we would not over-estimate the gap; however, the ultimate goal would be to perform similar reviews using sentences that had been classified using an automated process.

Textbox 3. Sample topics derived by latent Dirichlet allocation processing (w: word).

```
topic:23
w1:chemo w2:treatment w3:surgery w4:pain w5:mastectomy w6:treatments w7:rads w8:lumpectomy w9:results w10:reconstruction w11:tumor
w12:scan w13:bone w14:test w15:biopsy

topic:41
w1:family w2:someone w3:husband w4:friend w5:friends w6:talk w7:mom w8:sister w9:daughter w10:sisters w11:small w12:couple w13:together
w14:mother w15:kids

topic:42
w1:hugs w2:thank w3:read w4:thoughts w5:wish w6:lots w7:sending w8:questions w9:enjoy w10:welcome w11:wishes w12:question w13:answer
w14:send w15:sent
```


We started with all the sentences marked as “has information need.” Then, we manually removed any duplicates, where a sentence was defined as a duplicate if it had been marked as “previous” and immediately followed another sentence marked as “has information need.” For example, in the sentence pair “*I am concerned about whether insurance companies cover this like they do taxol. Any answers out there?*” the second sentence would have been removed. For the remaining sentences classified with an information category (not “previous”), stop-words were removed, the tf-idf score for each remaining content term was computed, and up to ten of the highest-scoring terms were selected. For sentences classified as referential (“previous”) but not considered duplicates, we obtained, scored, and selected up to ten content terms from the nearest sentence with a nonsocial information category. For each query, we then used the search engine to obtain a ranked list of documents. The ranking was based on the standard similarity algorithm provided by Elasticsearch, Okapi BM25, which accounts for term frequency and inverse document frequency.

A formatted file was created to show the complete posting, the (highlighted) query and the two top-ranked, retrieved documents with matched portions also highlighted. More than two were not provided, because an examination of preliminary results did not reveal any cases where lower-ranked documents appeared relevant. Multiple raters were asked to specify, for each document, whether or not they felt that it satisfies the information need.

Simple agreement among judgements, not adjusted for chance, were computed and assessed overall coverage.

Results

Distribution of Sentences Across Categories

In the MC data, there were 65 conversations, which yielded 1943 sentences (Table 1). Among the sentences, 5.7% (110/1943) were identified as having an expression of an information need (HASN). In the CSN data set, there were 195 conversations, yielding 2246 sentences (Table 1). Among these sentences, 8.7% (196/2246) were identified as expressing an information need. In a smaller, randomly selected set of 1000 sentences from the CSN (CSN-R), 3.5% (35/1000) were information seeking questions.

The distribution of sentences among the categories identified above in both the MC and CSN data sets is shown in Table 1. In the MC data set, the distribution of sentences among the categories ranged from 3% to 31%, with the “medical” category being the most common (597/1943, 30.7%) and the “social” category being the second most common (353/1943, 18.2%). Mentions of “psychological” and “physical” problems together accounted for a combined 11.7% (228/1943) of the sentences. Sentences most likely to discuss solutions (eg, “wellness” and “resource”) accounted for a combined 9% (175/1943) of sentences. In the CSN data set, the distribution of sentences among the categories ranged from 1% to 32% with the “other” category being the most common (728/2246, 32.4%), followed by the “medical” (473/2246, 21.5%), and “social” (443/2246, 19.7%). Mentions of psychological and physical problems

accounted for a combined 11.4% (256/2246) of the sentences. Sentences potentially discussing a solution (“wellness” and “resource”) accounted for a combined 4.9% (110/2246) of the sentences.

The distribution of categories in the subset of sentences expressing information need is shown in Table 1. The most common information type for the identified information needs in MC data was “medical” (34/110, 31%). Upon manual inspection, we found sentences desiring information about interventions such as chemotherapy, radiation, reconstruction, or double mastectomy (17 sentences); information about outcomes such as chance of recurrence, spread of cancer, or general prognoses (9 sentences); information about diagnoses, such as being Stage 3, triple negative, or metastatic (6 sentences) and information about tests, such as value of biopsy, mammograms, and other tests (3 sentences). The second most common information needs involved physical problems, including soreness, (being) tired, or (having) hair loss, swelling, trouble swallowing, blood pressure spikes, breast pain, or bowel issues. “Resource” requests accounted for 8.2% (9/110) of information needs, “wellness” accounted for 2.7% (3/110), and “other” accounted for 7.3% (8/110). The remaining 34.5% (38/110) were marked as “previous,” indicating they contained references that needed context outside the sentence for their interpretation.

In the CSN data, “medical” was again the most common information type among the sentences expressing an information need (48/196, 24.5%), followed by physical problems. “Resource” requests accounted for 4.6% (9/196) of information needs and information about “wellness” and psychological problems accounted for 2.6% (5/196) each. Twelve percent (24/196) were marked as “other” and 41.3% (81/196) were marked as needing context outside the sentence for their interpretation.

Content Analysis Across Categories

Content analysis presents an automated method for analyzing the content. The analyses of concepts detected by MetaMap are shown in Table 2, where the concepts are listed in decreasing order of frequency from most frequent to least. In the sentences expressing an information need in the MC data, the most frequently mentioned topics include “*side effects*,” “*surgery*,” and “*chemo*” and in the CSN data the most common topics included “*chemo*,” “*treatment*,” and “*normal*.” Across both, the general concepts “*Help*,” “*Look*,” and “*Experience*,” were also commonly mentioned, but these likely reflect the expression of need itself (eg, “*Looking for...*” or “*anyone with that experience*”) In non-need sentences, the most commonly mentioned MetaMap concepts included “*cancer*,” “*breast cancer*,” and “*chemo*,” and many more general words, such as “*years*,” “*now*,” “*take*,” “*good*,” and “*feel*.”

The concepts determined by MetaMap to be associated with the information categories in the MC and CSN data sets are also shown in Table 2. Overall, the most common concepts found in the “medical” category included the diagnoses (*cancer*; *breast cancer*; *diagnosed*) and interventions (*chemo*, *radiation*, *Taxol*, *treatment*). The most common concepts in the category for physical problems include *hair (loss)*, *pain*, and *back (pain)*, as

well as language to express their concern (*side-effects, issue, feel*). The most common concepts found in the category for psychological problems include *depressed, scared, and cry* and language to express the concern (*feel*). Overall, none of these concepts seem surprising and one might expect that typical educational materials might cover them well.

Classifier Training Across Categories

After training and testing multiple classifiers and combinations of features, it was found that the best configuration used RF classifiers using words, bigrams, and local context-based features corresponding to the information labels of adjacent sentences. Table 3 shows the performance of the RF algorithm trained with and without local context features for the MC and CSN data sets, where the classifiers within each data set were trained and tested using 10-fold cross-validation. The performance of alternative classifier training algorithms (ie,

Naïve Bayes and linear Support Vector Machines) and the addition of features from topic modelling and word embedding were also assessed but they were found to not be helpful and impaired the performance of classifiers across every category (Multimedia Appendix 3). When RF classifiers using local context features and trained on data from one forum but tested on another were considered, it was found that the performance was impaired for all categories, although this reduction was somewhat less for the medical and social categories (Table 4).

The results of evaluating the developed rule-based classifier and different learning models for a binary statistical classifier to identify sentences that express an information need using the CSN-R data set showed that a classifier trained using the RF algorithm was the most successful. The results for the statistical classifiers are shown in Table 5. The RF algorithm achieved a precision of .62, recall of .65, and F-measure of .63.

Table 1. Distribution of expressions of information need (HASN) and categories in the MayoConnect (MC) and Cancer Survivor's Network (CSN) data sets.

Category	MC total, n (%)	MC HASN, n (%)	CSN total, n (%)	CSN HASN, n (%)
Any	1943	110 (6%)	2246	196 (8%)
Medical	597 (31%)	34 (31%)	473 (21%)	48 (24%)
Resource	87 (4%)	9 (8%)	32 (1%)	9 (4%)
Social	353 (18%)	0 (0%)	443 (20%)	9 (4%)
Psychological	61 (3%)	0 (0%)	63 (2%)	5 (2%)
Background	69 (4%)	0 (0%)	38 (1%)	0 (0%)
Wellness	88 (5%)	3 (3%)	78 (3%)	5 (2%)
Physical	167 (9%)	18 (16%)	193 (8%)	15 (7%)
Previous	147 (8%)	38 (35%)	425 (18%)	81 (41%)
Other	313 (16%)	8 (7%)	728 (32%)	24 (12%)
Multiple	60 (3%)	0 (0%)	N/A ^a	N/A

^aN/A: not applicable. This category was not used when annotating the CSN data set.

Table 2. Five most frequent concepts for each information and topic category

Category	Top 5 MC ^a concepts	Top 5 CSN ^b concepts
Information need	experience, side effects, look, surgery, chemo	help, chemo, treatment, normal, experience
No information need	cancer, breast cancer, chemo, years, now	now, take, good, chemo, feel
Medical	chemo, cancer, radiation, breast cancer, diagnosed	chemo, radiation, now, taxol, treatment
Social	thank, hope, good, luck, best	Hi, thank, good, love, take
Psychological	feel, make, right, better, depressed	scared, go, feel, cry, thing
Background	live, years, breast cancer, now, old	years, old breast cancer, diagnosed, age
Wellness	help, shampoo, started, make, work	exercise, eat, help, diet, keep
Physical	hair, pain, back, side effect, issue	pain, back, hair, feel, Taxol
Previous	help, need, experience, make see	one, help, think, out, now
Resource	website, research, mayo, cancer, breast cancer	book, breast cancer, insurance, groups, site
Other	one, out, need, go, cancer	make, think, thing, out, feel

^aMC: MayoConnect.

^bCSN: Cancer Survivor's Network.

Table 3. The performance of Random Forest classifiers for each category for MayoConnect (MC) and Cancer Survivor's Network (CSN) data.

Category	MC data						CSN data					
	Without local context features			With local context features			Without local context features			With local context features		
	Prec ^a	Recall	F-measure	Prec	Recall	F-measure	Prec	Recall	F-measure	Prec	Recall	F-measure
Medical	.74	.73	.73	.90	0.91	.90	.65	.64	.64	.78	.75	.76
Social	.78	.78	.78	.85	.85	.85	.71	.70	.70	.83	.82	.82
Psychological	.73	.72	.72	.77	.76	.76	.69	.68	.68	.73	.74	.73
Background	.77	.77	.77	.77	.77	.77	.73	.73	.73	.74	.74	.74
Wellness	.76	.75	.75	.80	.79	.79	.67	.66	.66	.70	.71	.70
Physical	.80	.79	.79	.82	.83	.83	.64	.64	.64	.70	.70	.70
Previous	.61	.61	.61	.58	.58	.58	.70	.70	.70	.71	.71	.71
Other	.59	.59	.59	.84	.86	.85	.61	.60	.60	.67	.66	.66

^aPrec: precision.

Table 4. The performance of Random Forest classifiers for each category tested on MayoConnect (MC) and Cancer Survivor's Network (CSN) data and trained on either MC or CSN data, using local context features.

Category	Test MC data						Test CSN data					
	Train MC data			Train CSN data			Train CSN data			Train MC data		
	Prec ^a	Recall	F-measure	Prec	Recall	F-measure	Prec	Recall	F-measure	Prec	Recall	F-measure
Medical	.90	.91	.90	.71	.71	.71	.78	.75	.76	.71	.67	.68
Social	.85	.85	.85	.61	.69	.66	.83	.82	.82	.75	.77	.76
Psychological	.77	.76	.76	.51	.55	.51	.73	.74	.73	.50	.54	.52
Background	.77	.77	.77	.51	.53	.51	.74	.74	.74	.50	.52	.51
Wellness	.80	.79	.79	.55	.59	.56	.70	.71	.70	.51	.60	.55
Physical	.82	.83	.83	.56	.54	.55	.70	.70	.70	.60	.66	.63
Previous	.58	.58	.58	.54	.60	.57	.71	.71	.71	.55	.58	.56
Other	.84	.86	.85	.65	.56	.60	.67	.66	.66	.61	.63	.62

^aPrec: precision.

Table 5. Results of classifier training to identify sentences expressing information need in CSN-R (data set of randomly selected sentences from the Cancer Survivor's Network data set).

Learning model	Precision	Recall	F-measure
Naïve Bayes	.57	.75	.59
Random forest	.62	.65	.63
Support Vector Machines	.58	.71	.61

By contrast, the rule-based classifier achieved a precision of .43, recall of .26, and F-measure of .33. Upon closer inspection, it was determined that most false negatives (24/25) represented entirely new patterns (one was due to a misspelling of a word) and the false positives mostly represented unseen counter examples (eg, the bigram *how long* used adverbially rather than as a question cue).

Assessment of Potential Knowledge Gaps

The two most highly ranked documents (N=272) for each of the 136 queries were assessed by two raters. Of the 136 queries, 33.1% (45/136) were found to have relevant content by at least

one rater and 12.5% (17/136) were found to have relevant content by all raters. The agreement, calculated over documents, was 86.8% (236/272). One rater found that 10.3% (28/272) of the documents were relevant, while another rater found that 13.2% (36/272) were relevant. On the agreed items, 15 were annotated as relevant by both and 221 were marked as irrelevant by both. On 36 items, one annotator marked an item as relevant while the other marked it as irrelevant. In [Multimedia Appendix 4](#), several example queries, as well as the page that was returned and how it was rated, are provided to illustrate cases where there is no gap and where there is likely a gap.

Discussion

Principal Findings

This study investigates methods to automatically identify the information needs of breast cancer survivors based on their postings to online health forums. We found that an automated content analysis using MetaMap provided information very similar to what we had observed and counted manually.

The classifier results were also promising and suggest that such an approach should incorporate some discourse-level analysis because many conversations in online forums cannot fully be understood without it. In the MC data set, it was determined that 34.5% (38/110) of the sentences that expressed an information need had a discourse-dependent aspect and, in the CSN, there was an even higher proportion of information needs expressed that depended on other sentences (81/196, 41.3%). Although this study focuses on the problem primarily from an individual sentence perspective, the results illustrate the potential value of adding information features from nearby sentences. When using only the words or bigrams as features, the F-measure did not exceed 75%. However, when features corresponding to the immediately preceding and following categories were added, F₁ scores of 90% on “medical” and 83% on “physical” for MC and 82% on the “social” category in CSN (with 75% on the “medical” and 69% on the “physical”) were achieved.

The value of adding additional semantic features is less certain. When additional features based on topic modelling and word embeddings were added for training classifiers of information topics, it was found that instead of improving the analysis, it reduced the overall accuracy. We suspect that the sentences in online forums are too short, and the vocabulary is too heterogeneous, to benefit from topics or embeddings pretrained from more homogeneous corpora such as Wikipedia or newswire text. Indeed, when classifiers were trained on data from one health forum and tested on the other, it was found that the F₁ values were uniformly lower than when data was trained and tested within the same forum.

We found that classifiers could also be used for identifying sentences that express an information need. The most successful approach in this study involved training a RF classifier, for which a precision of .62, recall of .65, and F₁ of .63 on unseen test data was obtained. For comparison, a simple rule-based classifier was created for filtering, and it did much worse. This result is promising, and one might improve it by incorporating local context information.

The assessment of the gap between the expressed information needs and typical educational literature was revealing. Considering the results from our content analysis, none of the concepts mentioned in sentences expressing information need seemed surprising. Typical tests, procedures, and medications were mentioned, however, the results from our experiment using standard information retrieval techniques suggest that, at best, only a third of breast cancer survivors’ questions would be addressed by the materials currently provided to them, and at worst only one in eight.

In many of the matches found, the query sentence includes specific clinical language and the topic is somewhat expected (eg, mentioning a specific drug and whether it is normal to have a known side effect). There also tended to be a match when a general word was used in a very predictable way, for example support for survivors. Many failures to match seem like true gaps. Mismatches tended to occur when a question mentions clinical but common terms associated with breast cancer treatment (surgery, chemotherapy, or oncologists) but asks something uncommon or perhaps is considered too dependent on medical history (such as the prognosis after treatment). In this case, the raters felt the retrieved document, which provided only general information about going to see an oncologist for follow-up care, was not sufficiently relevant. Another gap was revealed when the information need query was about abnormal sensations after surgery and the retrieved information document discussed breast MRIs and what happens if the results are abnormal; this type of partial match is typical of an information retrieval approach. One interesting example of a query that was nearly matched mentions the terms *chemotherapy*, *Taxol*, and *hair* and asks when hair might regrow; however, the information page returned explains that hair loss is a common side-effect, but it only suggests how to cope with the side effect and no information on how long the problem might persist is provided. These results suggest that it would be valuable for information providers and health educators to know more about the specific questions cancer survivors or their friends and family are asking.

Limitations

One limitation of this study is that the taxonomy for categorizing the forum sentences was generated based on a manual process. In addition, some of the annotation was done by people who helped develop the taxonomy, creating a possibility for bias. To reduce this risk, when the sentences were annotated, there was always one annotator or adjudicator involved who had not been involved in creating the taxonomy.

The accuracy for categories with fewer examples is lower than for those with more, which is typical for this approach. The accuracy achieved for the CSN data set was also generally slightly lower than for the MC data set. We suspect that this difference reflects the broader scope of nonmedical, physical, and psychological topics present in the CSN data set (with many more marked as “other”) and a higher degree of complexity in the posts. In fact, it was found that the individual posts in the CSN data were nearly twice as long as in the MC data. We also note that the CSN sentences also included more referring expressions. In this case, additional features, if carefully chosen, might improve classification accuracy. Here, the focus was on word-based features (unigrams and bigrams) and the information categories of nearby sentences. Experiments using topic models as features did not reveal them to be helpful, however the training set used for generating the topics was fairly small, which may have negatively affected the quality and effects of the topic features. We did not perform named entity recognition, such as for names of specific drugs or treatments for cancer, but we suspect that might have been helpful to improve accuracy.

A rule-based classifier was created with the goal of helping to select conversations for annotation, with the aim that it might have broader utility. Currently this approach performs poorly compared to using hand-labelled data to train a statistical classifier. Having a rule-based classifier, however, was useful before enough data is obtained to train a statistical classifier. The classifier increased the frequency of sentences expressing information need in our data from the expected rate of approximately 3% occurring in a random sample to approximately 6%. Furthermore, the increased concentration of sentences expressing information need may have been helpful in improving data quality, as we found that with a very low density in our random sample, the annotators seemed to miss more positive examples than in the earlier, larger data set. However, this result may also be explained as by selecting random sentences, background information was lost, and this was crucial in helping them recognize a need.

While the hand-labelled data was used for the local context features for classifiers, in a production system this would not be feasible. Instead, one could classify sentences sequentially (and just use the immediately preceding class) or one could train a sequence-based classifier, such as one based on Linear-Chain Conditional Random Fields [18,19].

During the assessment of knowledge gaps in the educational literature, we used the words from the expressions of need and, when a sentence was classified as referential, we added words from nearby sentences. This approach is reasonable for document retrieval, but not sufficient for question answering. We did not augment any queries with synonyms, as our raters (and the general public) would not necessarily know when two specialized medical terms, or a medical and a consumer term, are synonyms. As a result, the approach used may overestimate knowledge gaps because the desired content might exist but use a different term than the one in the query. Nevertheless, this approach is valuable as it provides a good indicator of the difficulty that people would experience in trying to address their information needs with the available educational literature. A domain expert, familiar with the literature distributed to patients, could take the information we provide to either verify the information need to create new resources, or to revise the existing resources so that needed information would be easier to find.

Comparisons with Prior Work

Other researchers have explored methods to classify sentences in various online forums and other online short texts. Most past studies of online health communities [7-9] have used social scientific approaches that involve examining relatively small samples of data and identifying themes by manual coding. These studies, while they provide valuable insights, cannot easily be repeated for different forums or different points in time. These studies also use the entire message as the unit of analysis, which makes the coded data created unsuitable for automated methods of text analysis. Automated methods work best when units of analysis can be assigned a single or small number of labels. However, postings to Web-based health forums and internet email discussion groups, which are asynchronous and do not significantly limit the length of postings, tend to combine social

communication with “technical information about treatments, side effects, clinical trials, empathic comments, requests for information, (and) meta-comments about group processes [20],” each of which will naturally involve a distinct sublanguage.

Zhang et al reports the use of automated classification methods for health forum posts [21]. In this study supervised machine learning methods are used to label the posts with the writer's (broad) intent. Two key differences between this work and our own have been identified, namely (1) they classify groups of sentences as a unit, ignoring their internal structure and (2) the classes seem more pertinent to new diagnoses than to survivorship. Specifically, the classifications are “Manage” (prevention, treatment options, and management of chronic illness), “Cause” (diagnosis of physical findings and test results), “Adverse” (negative side effects of treatments), “Combo” (multiple intents), and “Story” (social narrative and personal story-telling). They found that a simple word-based classifier performed poorly, with a precision at most of 62%, but that by defining and using new pattern-based features, a precision of 75% could be achieved. The new features included short sequences of lower cased and stemmed words, part-of-speech tags, and semantic groups from the Unified Medical Language System.

There have been four efforts to develop automated methods to assess the content of online health question-answering and health-related search data [11-12,22-23]. The data used in these studies differs from online health forums in that they do not include on-going dialogs (instead they are isolated attempts to receive an answer or search result) and they do not involve communication among peers, and thus lack many of the social aspects found in health forums (such as self-introductions or offers of support). This work, however, demonstrates the feasibility and some of the challenges of using automated methods for complex questions, which can be indirect (eg, *I would like to learn more about this condition*) or involve coordination (eg, *I would like to learn more about this condition and what the prognosis is for a baby born with it*). McRoy et al [11] examined questions sampled from several community question-answering Web sites. They developed a more fine-grained taxonomy than the one used here and methods to classify the specific type of information being requested, such as “definition”, “entity”, “explanation”, “property value”, “reference”, “diagnosis”, “outcome”, or “recommendation”, which would be useful for formulating a response, but is not needed for information retrieval. Roberts et al [12,23] have developed methods related to understanding consumer health questions submitted to the Genetic and Rare Diseases Information Center (GARD) website. For example, they have developed a taxonomy of different types of medical questions about a wide range of diseases [12] and methods for decomposing multi-sentence, multifaceted questions by classifying sentences as either a “question,” “background,” “coordination,” “exemplification,” or “ignore.” They also developed methods for identifying the disease of central concern, which might occur in any part of the question [23]. Phan et al [22] explored the use of topic modelling as a feature for the classification of short texts where the topics were obtained from a combination of short coded data (eg, Web search snippets)

and a larger body of uncoded text, such as Wikipedia and Ohsumed or Medline. They saw benefits when the classification tasks were to classify search snippets into different domains (eg, Business, Computers, or Health) and to classify medical abstracts into a small set of disease types (eg, neoplasms, digestive disorders, etc). However, both types of text are relatively homogeneous and do not include dialog or social discourse.

There have also been attempts to classify the dialog acts in online (non-health related) chats. This type of data has some characteristics similar to the breast survivor forums used in this study as the interactions involve peers and ongoing interactions. The main difference between these studies and our work is that the classification of dialog acts addresses the communicative function of an utterance (such as being a greeting, statement, question, or answer), rather than the content; see [24] for a discussion. Annotations based on dialog acts are potentially useful for finding the topic of an information need when the statement of the topic and the expression of need occur in separate sentences or postings. Classification of dialog acts commonly uses a rule-based approach. For example, Wu et al [25] used a search-based procedure to instantiate a set of classification rules, an approach similar to the one we have taken for finding conversations that express a need prior to coding them. In the study reported by Forsyth et al [26], a neural network approach was used. This approach relies on many of the same features as the study reported by Wu et al [25] and achieved an accuracy of 83.2%.

Conclusions

This research considers the task of identifying the information needs of breast cancer survivors from their postings to online

health forums. This approach allows one to assess a broad range of people over a span of years, and to observe true information-seeking rather than self-reports, which can be faulty. We used a supervised classification approach, which is easily repeatable. The sentences within the postings to forums were classified, rather than the posting as a whole, so that we could discriminate among social information, background, and expressions of information need and subsequently identify the general type of the need (such as “medical” or “physical”). Our results show that automatic methods can be an effective method of assessing information needs. One could also perform further processing on the sentences to reveal more specific information, such as names of medications or side-effects.

We also examined whether using expressions of information need to help assess a set of commonly provided education materials was a viable approach. We used well-known methods from information retrieval, mapping sentences onto queries for a search engine with an index of the most frequently provided documents given to patients at the Mayo Breast Clinic. It was found that only a small percentage of information needs are addressed by the provided materials. This finding would explain the use of health forums by breast cancer survivors to seek information as most of their information needs are not easily findable within the brochures they likely received. Further investigation of these unmet needs is warranted to create better materials—and better means of dissemination—in the future. In addition to mobile devices, new opportunities exist for the creation of content that could be delivered by interactive voice assistant products, like Amazon Echo or Alexa or Google Home. It is crucial, however, that to be effective for breast cancer survivors, they must closely target their true information needs.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Annotation Guideline.

[\[PDF File \(Adobe PDF File\), 53KB - cancer_v4i1e10_app1.pdf\]](#)

Multimedia Appendix 2

Inter-Annotator Agreement.

[\[PDF File \(Adobe PDF File\), 32KB - cancer_v4i1e10_app2.pdf\]](#)

Multimedia Appendix 3

Comparisons of Classifier Algorithms.

[PDF File (Adobe PDF File), 47KB - [cancer_v4i1e10_app3.pdf](#)]

Multimedia Appendix 4

Study of Knowledge Gap Examples.

[PDF File (Adobe PDF File), 41KB - [cancer_v4i1e10_app4.pdf](#)]

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Abbreviations

CSN: Cancer Survivor's Network

CSN-R: data set of randomly selected sentences from the CSN data set

HASN: has information need

MC: MayoConnect

RF: random forest

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Original Paper

Quality of Web-Based Educational Interventions for Clinicians on Human Papillomavirus Vaccine: Content and Usability Assessment

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Abstract

Background: Human papillomavirus (HPV) vaccination rates fall far short of Healthy People 2020 objectives. A leading reason is that clinicians do not recommend the vaccine consistently and strongly to girls and boys in the age group recommended for vaccination. Although Web-based HPV vaccine educational interventions for clinicians have been created to promote vaccination recommendations, rigorous evaluations of these interventions have not been conducted. Such evaluations are important to maximize the efficacy of educational interventions in promoting clinician recommendations for HPV vaccination.

Objective: The objectives of our study were (1) to expand previous research by systematically identifying HPV vaccine Web-based educational interventions developed for clinicians and (2) to evaluate the quality of these Web-based educational interventions as defined by access, content, design, user evaluation, interactivity, and use of theory or models to create the interventions.

Methods: Current HPV vaccine Web-based educational interventions were identified from general search engines (ie, Google), continuing medical education search engines, health department websites, and professional organization websites. Web-based educational interventions were included if they were created for clinicians (defined as individuals qualified to deliver health care services, such as physicians, clinical nurses, and school nurses, to patients aged 9 to 26 years), delivered information about the HPV vaccine and how to increase vaccination rates, and provided continuing education credits. The interventions' content and usability were analyzed using 6 key indicators: access, content, design, evaluation, interactivity, and use of theory or models.

Results: A total of 21 interventions were identified, out of which 7 (33%) were webinars, 7 (33%) were videos or lectures, and 7 (33%) were other (eg, text articles, website modules). Of the 21 interventions, 17 (81%) identified the purpose of the intervention, 12 (57%) provided the date that the information had been updated (7 of these were updated within the last 6 months), 14 (67%) provided the participants with the opportunity to provide feedback on the intervention, and 5 (24%) provided an interactive component. None of the educational interventions explicitly stated that a theory or model was used to develop the intervention.

Conclusions: This analysis demonstrates that a substantial proportion of Web-based HPV vaccine educational interventions has not been developed using established health education and design principles. Interventions designed using these principles may increase strong and consistent HPV vaccination recommendations by clinicians.

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KEYWORDS

papillomavirus vaccines; internet; program evaluation; health personnel

Introduction

The human papillomavirus (HPV) causes almost all cervical cancers, 50% of vulvar cancers, 65% of vaginal cancers, 90% of anal cancers, and 35% of penile cancers [1]. Recent studies have shown that the incidence of oral cancers caused by HPV is increasing [2-4]. The 9-valent HPV vaccine (9vHPV) is nearly 100% effective in preventing precancerous lesions caused by 7 genotypes [5], accounting for 81% of cervical cancer cases [6]. Despite ample evidence that licensed HPV vaccines are safe to use and effective in preventing certain anogenital cancers, only 42% of adolescent females and 28% of adolescent males have completed the HPV vaccine series [7]. These HPV vaccination rates fall short of Healthy People 2020's objective of 80% coverage for girls and boys aged between 13 and 15 years [8].

Missed opportunities for clinicians to recommend and administer the vaccine, as well as a lack of strong and consistent recommendations by clinicians who do recommend the vaccine, are primary reasons for low HPV vaccination rates in the United States [9]. Factors contributing to missed clinical recommendation opportunities and insufficiently strong and consistent recommendations include providers' limited knowledge of HPV and the vaccine, discomfort discussing a topic related to sexual behavior, concerns about vaccine safety, parental resistance, preference for vaccinating older adolescents, and lack of time or incentive to educate parents about the vaccine [10-19]. While improving communication between health care providers and parents is considered a critical component to increasing vaccination rates [20-26], health care providers report they do not feel well-prepared to provide strong vaccination recommendations [15,27,28]. Additionally, 75% of clinicians expressed they would benefit from continuing education about recommending the HPV vaccine [29].

To improve clinicians' HPV vaccine recommendations, numerous Web-based HPV vaccine educational interventions for clinicians have been created. Web-based educational interventions have become a popular delivery method for health care professionals to obtain continuing education (CE) [30], as Web-based interventions provide an opportunity to quickly update and address health education topics at low cost [31]. With rapid proliferation of Web-based health education programs, there is a potential risk of neglecting fundamental health communication and education design principles in these programs that are important to ensure their efficacy [32-34].

Web-based CE interventions created using strategic health communication design principles—communicating effectively with intended users and taking into account audience factors such as culture, race, ethnicity, language, access, functional needs (ie, disabilities), and expectations [35,36]—are likely to increase clinicians' knowledge, perceptions, attitudes, and practice behaviors [37-42]. Numerous Web-based HPV vaccine educational interventions have been introduced to accommodate clinicians' educational needs [43]. However, an extensive and comprehensive review (of CINAHL, MEDLINE, ERIC, and Ebsco Academic Complete databases, using variations and Boolean connectors with the following terms: “online intervention,” “online program,” “HPV vaccine,” “clinicians,”

“physicians,” “nurses and evaluation”) demonstrated that there has been no rigorous evaluation of the design, content, and usability levels of these programs. Without such evaluation data, it is unknown whether such interventions are achieving their intended outcomes, and which aspects of the interventions should be refined [44,45].

Evaluation of the leading Web-based HPV vaccine educational interventions is important in guiding efforts to promote clinician recommendations for the HPV vaccine [44,46]. Evaluation of Web-based interventions, using established health communication and education design principles can (1) identify strengths and weaknesses of educational interventions from the users' perspective; (2) determine whether interventions are worth the time, resources, and expense for continued implementation; and (3) provide the evidence for designing optimally effective interventions [47]. Additionally, evaluation data can provide insights into any negative unintended consequences of the interventions, such as boomerang and iatrogenic effects [48,49] and ensures that interventions address audiences' unique needs, culture, and expectations [35]. Evaluation research is vital not only to improve health outcomes but also to ensure that interventions are cost-effective [50]. Estimated health care cost in the United States was \$2.7 trillion (18% of the gross domestic product) in 2011 [51], leading policy makers to prioritize identifying effective, evidence-based methods to prevent disease and manage rising health costs [50].

Rigorous evaluation is a central component of developing successful health education interventions [45,52] and essential for understanding clinicians' educational needs and assessing outcomes [50]. However, current Web-based HPV vaccine interventions developed for clinicians have not been evaluated using health education and design principles. Therefore, the objectives of the study were to: (1) systematically identify HPV vaccine Web-based educational interventions developed for clinicians, and (2) evaluate the quality of Web-based educational interventions as defined by access, content, design, evaluation, interactivity, and use of theory or models to create the interventions.

Methods

Sample

We systematically identified current HPV vaccine Web-based educational interventions by examining general search engines (eg, Google), continuing medical education search engines (eg, PedsUniversity, MedScape), health department websites, and professional organization websites. The following search terms and variations of search terms were used within each of the search engines and websites: “clinicians,” “healthcare providers,” “HPV webinars,” “HPV vaccination webinars,” “HPV online education,” and “HPV continuing medical education.” Web-based educational interventions were included if they were (1) created for clinicians (defined as individuals qualified to deliver health care services, such as physicians, clinical nurses, and school nurses, to patients aged between 9 and 26 years); (2) delivered information about the HPV vaccine and how to increase vaccination rates; and (3) provided continuing education credits. Interventions were excluded if

they were created for patients, parents, or adolescents, or if they focused on vaccines other than the HPV vaccine. We conducted the search from April 2016 to August 2017 and identified a total of 178 interventions. Of these, 21 interventions met all 3 research criteria for this study.

Instrument

The study team developed a quality evaluation framework based on criteria established in the literature for evaluating health-related websites [53-56]. The quality evaluation framework assessed Web-based interventions using 6 key indicators: access, content, design, evaluation, interactivity, and theory or models [53-56]. Each key indicator was scored using various subindicators: higher scores for the indicators designated higher quality interventions.

Internal reliability of the subindicators was calculated using the Krippendorff's alpha coefficient (K-alpha; for additional information please see De Swert, 2012) [57]. This coefficient was selected because it provides information on the reliability of variables, not coders, and its robust calculations are not impacted by sample size, multiple coders, or missing data [58]. After calculating Krippendorff's alpha coefficient for 2 rounds of samples with 2 independent coders (Dr Rosen, a PhD trainer faculty member with expertise in HPV vaccination uptake, and a doctoral graduate research assistant in health education), the evaluation tool was considered to be internally reliable given that all indicator scores were above .80, which is considered the norm for acceptable reliability [57].

Access

To examine access of the educational interventions [53,54], 2 subindicators were used to measure different components of access. These subindicators included whether registration was required to access the intervention (score ranging from 0-1) and the cost of the intervention (score ranging from 0-1).

Content

Content was evaluated using 7 subindicators [53,55]: identification of purpose (score ranging from 0-1), date on which the information was updated (score ranging from 0-1), presentation of clear references (score ranging from 0-1), and links to other sources (score ranging from 0-1). Additionally, reliable sources (score ranging from 0-1) were assessed and whether the intervention included reliable sources, the type of source (eg, Centers for Disease Control and Prevention, National Institutes of Health, published peer-reviewed literature) was included in the scoring metric. The final 2 subindicators included a statement indicating that content was developed or reviewed by experts (score ranging from 0-1) and a statement of disclosure of authors, sponsors, or developers (score ranging from 0-1).

Design

The design components of the interventions were evaluated by layout and graphics [53]. The layout of the intervention was assessed by examining font and line spacing. Specifically, font was assessed by whether the style was easy to read (score ranging from 0-1), size was easy to read (score ranging from 0-1), text color and page color contrast were easy to read (score ranging from 0-1), and line spacing was easy to read (score

ranging from 0-1). Graphics were assessed to determine if they were clearly labeled, and scores ranged from 0 to 3 with 0 indicating 0% of graphics were labeled, 1 indicating a minimum of 25% of the graphics were labeled, 2 indicating a minimum of 50% of the graphics were labeled, and 3 indicating a minimum of 75% of the graphics were labeled.

Evaluation

Evaluation was assessed using 3 subindicators [53-55]: whether participant outcomes were evaluated (eg, knowledge and attitudes; score ranging from 0-1), the level of that evaluation (score ranging from 0-2; 0 indicating no evaluation, 1 indicating an evaluation of HPV or HPV vaccine knowledge, and 2 indicating an evaluation of HPV or HPV vaccine attitudes) and whether the participant was provided an opportunity to evaluate the intervention (score ranging from 0-1).

Interactivity

The indicator for interactivity included 2 subindicators [54,55]. The first subindicator assessed whether there was a location for participants to direct questions during the educational intervention (score ranging from 0-1). The second subindicator assessed whether the intervention included any interactive components (score ranging from 0-1). If the intervention included any interactive component, the interactive component was recorded in the scoring metric. The interactive components included discussion boards, "ask the expert" bulletin boards, sign up for email reminders, sign up for newsletters, and other interactive components.

Theory and Models

The theory and models indicator was assessed by examining whether there was an explicit statement that a theory or model was used to develop the intervention (score ranging from 0-1) [54-56]. If a theory or model was used to develop the intervention, the theory or model was recorded in the scoring metric.

Procedure

Once interrater reliability was established for the evaluation tool with all indicator scores above .80, 2 independent coders (Mr Bishop and Ms McDonald) utilized the tool to evaluate the educational interventions identified. One of the coders, Mr Bishop is a health education doctoral student with expertise in sexuality education and evaluated the first 11 interventions. The other coder, Ms McDonald is a health education doctoral student with expertise in school health and evaluated the remaining 10 interventions. Frequency distributions were calculated for each of the subindicators to determine specific strength and weaknesses of the interventions. Because this study assessed access, content, and design aspects of interventions and did not include human subjects; this study is considered nonhuman subjects research and hence institutional review board approval was not required.

Results

Intervention Characteristics

A total of 21 interventions were identified out of which, 7 (33%) were webinars; 7 (33%) documentary, TV series, or videos; and 7 (33%) other (eg, text article, modules). Medscape, a health information website, provided 10 (48%) interventions, Continuing Nursing Education University provided 2 (10%), CDC provided 3 (14%), professional organizations (eg, American Academy of Pediatrics and Texas Medical Association) provided 3 (14%), nonprofit organizations (eg, Indiana Immunization Coalition) provided 1 (5%), a federally-authorized regional organization (The Suwannee River Area Health Education Center) provided 1 (5%), and a university (Boston University School of Medicine Continuing Medical Education and Continuing Nursing Education) provided 1 (5%). [Multimedia Appendix 1](#) includes the characteristics of the interventions.

Quality Evaluation

On the basis of the evaluation indicators, 13 (62%) interventions required registration, but all interventions were accessible without cost to the participant (K-alpha=1.0). Additionally, 17 (81%) educational interventions identified the purpose of the intervention (K-alpha=1.0), and 12 (57%) provided a date when the information had been updated: 7 (33%) were updated in the last 6 months (K-alpha=1.0). In assessing presentation of clear references, 18 (86%) interventions provided references (K-alpha=1.0), and 8 (38%) provided links to other sources (K-alpha=1.0). Most interventions (18/21, 85%) provided reliable references or sources (K-alpha=1.0). The references or

sources included information from the CDC (n=16), published peer-reviewed literature (n=16), American Cancer Society (n=5), National Cancer Institute (n=4), Institutes of Medicine (n=4), WHO (n=2), and American Academy of Pediatrics (n=1). Of the 21 interventions, 14 (67%) had a statement of disclosures from the authors, sponsors, or developers (K-alpha=1.0).

For the design subindicators, 2 interventions were documentary or videos that did not include text, and therefore, were not included in the total sample for these subindicators. All interventions (n=19) included easy-to-read font size, font style, color, and line spacing (K-alpha=1.0 for these 3 subindicators). For the subindicator "Graphics were clearly labeled," only 13 interventions included graphics; thus, the sample for this subindicator is 13 interventions. Out of the 13 interventions, there were 10 (77%) interventions with a minimum of 75% of graphics labeled, 2 (15%) with a minimum of 50% of graphics labeled, and 1 (8%) intervention with a minimum of 25% of graphics labeled. No intervention had 0% of graphics labeled (K-alpha=1.0).

Of the 21 interventions, 17 (81%) included an evaluation for participant outcomes: 17 (81%) assessed HPV and HPV vaccine knowledge, and none assessed attitudes toward HPV and the HPV vaccine. Furthermore, 14 (67%) interventions provided the participants the opportunity to evaluate or provide feedback (K-alpha=1.0). Five (24%) interventions included an interactive component (K-alpha=1.0). The most commonly used interactive component was a polling or knowledge check activity (n=4). No educational intervention explicitly stated a theory or model that was used to develop the intervention. [Table 1](#) provides additional results from the evaluation, and [Table 2](#) provides the quality summary score for each Web-based intervention.

Table 1. Web-based educational intervention quality evaluation results (n=21).

Indicator and subindicator	Scoring frequency	
	Yes	No
Access		
Registration required	13	8
Cost	0	21
Content		
Date information was updated	12	9
Identification of purpose	17	4
Presentation of clear references	18	3
Links to other sources	8	13
Reliable references and sources ^a	18	3
Statement indicating content was developed or reviewed by experts	20	14
Disclosure of authors, sponsors, or developers	14	7
Design		
Font style was easy to read ^b	19	0
Font size was easy to read ^b	19	0
Font color and page color contrast was easy to read ^b	19	0
Line spacing was easy to read ^b	19	0
Graphics were clearly labeled ^c	13	0
Evaluation		
Evaluation for participant outcomes ^d	17	4
Participant provided opportunity to evaluate intervention	14	7
Interactivity		
Location to direct participant questions	6	15
Included interactive component ^e	5	16
Theory or model(s)		
Theory or model was used to develop intervention	0	21

^aThe Centers for Disease Control and Prevention (n=16) and published peer reviewed literature (n=16) were the most common frequency cited sources, followed by American Cancer Society (n=5), National Institutes of Health (n=4), Institute of Medicine (n=4), World Health Organization (n=2), Food and Drug Administration (n=1), and the American Academy of Pediatrics (n=1).

^bTwo interventions were a documentary or TV series that did not include any type of font or graphics for informational purposes. Therefore, for the Design subindicators font style, font size, font color, and line spacing, the sample size was n=19.

^cFor the graphic subindicator, eight interventions did not include graphics for informational purpose. Therefore, the sample size was n=13. There were 10 interventions with a minimum of 75% of graphics labeled, 2 interventions with a minimum of 50% of graphics labeled, 1 intervention with a minimum of 25% of graphics labeled.

^dSpecific levels of evaluation for participant outcomes include 17 interventions assessing HPV and HPV vaccine knowledge, and no intervention assessing attitudes toward HPV and the HPV vaccine.

^eFive interventions provided participant interactivity. Four interventions included an interactive knowledge check, and 1 intervention included directions to email reminders and newsletters.

Table 2. Quality summary scores for Web-based interventions.

Intervention title ^a	Summary score (out of 25)
HPV Vaccine Safety and Efficacy	20
HPV Vaccines: Updates and Clinical Perspective	20
Increasing Adolescent Immunization Coverage	20
Don't Wait Vaccinate! The Prevention of HPV Cancers (Part 2)	19
HPV Vaccination is Cancer Prevention (2017 Update)	19
Overcoming Gender and Socioeconomic Disparities in HPV Vaccination	19
You are the Key to HPV Cancer Prevention	18 ^b
Don't Wait Vaccinate! The Prevention of HPV Cancers	17
Immunization: You Call the Shots-Module Eight-HPV, 2016	17
Immunization: You Call the Shots-Module Eighteen—Vaccine Administration	17 ^c
You are the Key to HPV Cancer Prevention	17 ^d
ACIP Releases Pediatric Vaccine Schedule	16 ^c
Adolescent Immunizations: Strongly Recommending the HPV Vaccine	16
AAP Provides Guidance for Parents Who Refuse Vaccination	15 ^c
ACIP Releases Adult Vaccine Recommendations	15 ^c
CDC Updates Guideline Recommendations for HPV Vaccination	15 ^c
Human Papillomavirus (HPV) Vaccine Safety	15 ^c
The Story of HPV: Yesterday, Today, and Tomorrow	14
HPV Vaccines: Updates and Clinical Perspective	13
Putting HPV Vaccine Knowledge Into Practice	7 ^e
HPV Documentary—Division of Continuing Medical Education	2 ^e

^aHPV: Human Papillomavirus; ACIP: Advisory Committee on Immunization Practices; AAP: American Academy of Pediatrics; CDC: Centers for Disease Control and Prevention.

^bYou are the key to HPV Cancer Prevention intervention published 9/2/2015 and expires 9/7/2017.

^cThese interventions did not include any type of graphics for informational purpose. Therefore, the total score is out of 24.

^dYou are the key to HPV Cancer Prevention intervention published 4/21/2016 and expires 4/21/2018.

^eThese interventions were documentaries and did not include any type of font or graphics for informational purposes. Therefore, the total score is out of 20.

Discussion

Principal Findings

This study provides a systematic, evidence-based assessment of the strengths and weaknesses of current HPV vaccine Web-based educational interventions. Strengths of the assessed Web-based educational interventions include: (1) being developed by experts in the field; (2) providing reliable references or sources; (3) providing clinicians with access to CEs for no cost; (4) following basic design principles with easy-to-read fonts, colors, and graphics; and (5) consistently providing evaluation opportunities for participant knowledge outcomes. Weaknesses of the educational interventions included lack of: (1) evaluation of outcomes including participants' attitudes about HPV vaccination, intention to recommended vaccination, and recommendation of behaviors; (2) theory-based interventions; (3) opportunity for participants to provide

feedback or evaluation of the intervention; (4) links to other sources or resources; and (5) interactivity throughout the intervention.

HPV vaccination rates are well below the Healthy People 2020 objective [8], and clinicians report that they would benefit from CE regarding the HPV vaccine [29]. Because clinicians' HPV vaccine recommendation is one of the most important predictors of HPV vaccination uptake [59-62], ensuring that clinicians are equipped with current and accurate information is critical [63]. Clinicians, however, are continually challenged in providing parents and patients with evidence-based HPV vaccine information because of changing vaccine guidelines and the volume of information and sources available [64]. Thus, clinicians' report obtaining a large portion of HPV vaccine information from professional organizations [65] possibly because of lack of time needed to identify multiple sources of accurate information [66]. In this study, only 3 interventions

were provided by 2 professional organizations, including the American Academy of Pediatrics and the Texas Medical Association. Medscape, a health information website, provided almost half of the interventions. Given that professional organizations are cited by clinicians as an important and trusted source of HPV vaccine information, professional organizations need to increase efforts to collaborate with health information websites and other organizations and institutions to provide evidence- and theory-based interventions. A recent study demonstrated that organizations working on cancer research identified the ability to leverage resources, lower costs, increase organization reputation, and the development of new tools and methodology as benefits to interorganizational collaboration [67]. Therefore, interorganizational collaboration to provide clinicians with HPV vaccine Web-based interventions has the potential to improve outcomes related to HPV vaccination rates and cancer risk reduction.

We found that none of the interventions examined included a statement that a theory was used to create the intervention. To improve outcome behaviors and increase clinician HPV vaccine recommendation behaviors, intervention developers should utilize science and evidence that supports effective medical education and behavior change [54]. Theories can be used for quality assessment and improvement by identifying factors contributing to behavior change and which factors are ineffective. Overall, interventions based in theory provide an advantage in changing behavior by providing a logical and systematic approach to increasing clinicians' recommendation of the HPV vaccine [54].

None of the Web-based educational interventions included in this study evaluated HPV attitudes, intention to recommend vaccination, or actual recommendation behavior. This is concerning given that clinician attitudes are an important predictor of vaccine recommendations. Clinicians have reported concerns regarding HPV vaccine safety [68-70], a lack of self-confidence in providing strong vaccine recommendations [15,27,28], and belief that it is not important for adolescents to receive the HPV vaccine at the recommended age of 11 to 12 years [71]. Therefore, interventions should be designed with the goal of changing clinician attitudes and vaccine recommendations, and evaluation of these outcomes is a key component of successful interventions [45,52]. Evaluation of outcomes is also important for the translation of health communication research into efforts to promote clinician recommendations of the HPV vaccine [44,46]. Finally, evaluation is essential for understanding clinicians' educational needs and assessing program outcomes addressing important health issues [50].

Although face-to-face educational interventions have shown to improve clinicians' willingness to provide immunizations and routinely screen immunization records at visits [72], evaluations specifically assessing HPV-related Web-based educational interventions are limited [73]. Only 2 published studies provided evaluation results on webinars designed to increase adolescent vaccination rates. Results suggest webinars have the potential to increase clinician recommendation behaviors and adolescent Tdap, meningococcal, and HPV vaccination rates similar to in-person educational interventions [74,75]. Web-based

educational interventions create a unique platform to provide clinicians with the knowledge and skills needed to promote the HPV vaccine among adolescents. One important component of Web-based educational interventions is interactivity [54,55]. Interactive components encourage users to be actively involved in the intervention and have been linked to short-term behavioral improvements [76]. Furthermore, Kreps and Neuhauser pinpoint interactivity as a communication attribute with the ability to exponentially improve health promotion [76]. Even though interactivity can have a significant impact on participants, only 5 interventions from this study included an interactive component. Because Web-based educational interventions continue to gain popularity because of convenience and economic benefits [31], the lack of interactivity in the majority of HPV-related Web-based educational interventions is alarming given the research supporting the importance of interactive components. More research should be conducted to determine the impact of interactive components in HPV-related Web-based educational interventions on clinicians' HPV vaccination recommendation behaviors.

Limitations

While this study provides innovative insight into the quality of Web-based HPV vaccine educational interventions created for clinicians, there are limitations that should be considered. First, only Web-based educational interventions were evaluated, and these results cannot be generalized to other types of interventions such as face-to-face lectures, grand rounds, or seminars. There would be substantial benefit to conducting evaluations of face-to-face lectures and seminar materials to assess all venues of continuing education for clinicians regarding the HPV vaccine. Second, this quality evaluation did not assess participants' experience of the intervention and therefore, cannot identify every area for improvement. Data were not collected from participants themselves regarding usability: this study identified only 7 indicators of usability. Third, this study was a quality evaluation and did not evaluate participant outcomes (eg, knowledge, attitudes, recommendation behaviors) after completing the intervention. Fourth, the evaluation was conducted using only the materials that were accessible at the time of the study, and there is the potential that a component (such as, a follow-up emailed evaluation after the intervention to participants) was not included in this evaluation. Despite these limitations, these findings provide valuable information for those who develop Web-based continuing education interventions regarding HPV vaccines, by providing a quantitative approach to identifying the design and usability strengths and weaknesses of HPV vaccine Web-based educational interventions.

Future Work

The data resulting from this study have the potential to help shift current research practice paradigms. The findings suggest that those who develop Web-based educational interventions to promote HPV vaccine recommendations utilize design science principles, a powerful approach and process that includes participatory action research to iteratively develop and evaluate health education interventions [77]. Additional qualitative, multi-approach evaluation research is needed to further assess

the content (eg, the specific messages provided to clinicians about the HPV vaccine and recommendation behaviors) and usability of these interventions from the participants' perspective. Further evaluation research is needed to ensure that interventions are being developed using all design principles and are effective at increasing strong and consistent HPV vaccine recommendations from clinicians.

Conclusions

The quality evaluation of these interventions demonstrated that Web-based interventions were based on reliable sources,

developed by experts, and were created with critical design aspects (eg, font style, size, and color were easy to read, graphics were clearly labeled). However, there were limited outcome evaluations for users measuring attitudes, intentions, or behaviors, and lack of user interactivity. Results from this study suggest best practices for designing, refining, and implementing Web-based interventions to promote HPV vaccination within the clinician population.

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Authors' Contributions

BLR is the primary author, JMB conducted intervention evaluation and assisted in writing the manuscript, SLM conducted intervention evaluation and assisted in writing the manuscript, JK provided expert guidance for the evaluation and revised the manuscript, and GLK provided overall guidance for the evaluation and provided extensive revisions of the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Intervention characteristics.

[[PDF File \(Adobe PDF File\), 290KB - cancer_v4i1e3_app1.pdf](#)]

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Abbreviations

AAP: American Academy of Pediatrics

ACIP: Advisory Committee on Immunization Practices

CDC: Centers for Disease Control and Prevention

CE: continuing education

HPV: human papillomavirus

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Original Paper

YouTube Videos as a Source of Information About Clinical Trials: Observational Study

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Abstract

Background: Clinical trials are essential to the advancement of cancer treatment but fewer than 5% of adult cancer patients enroll in a trial. A commonly cited barrier to participation is the lack of understanding about clinical trials.

Objective: Since the internet is a popular source of health-related information and YouTube is the second most visited website in the world, we examined the content of the top 115 YouTube videos about clinical trials to evaluate clinical trial information available through this medium.

Methods: YouTube videos posted prior to March 2017 were searched using selected keywords. A snowballing technique was used to identify videos wherein sequential screening of the autofill search results for each set of keywords was conducted. Video characteristics (eg, number of views and video length) were recorded. The content was broadly grouped as related to purpose, phases, design, safety and ethics, and participant considerations. Stepwise multivariable logistic regression analysis was conducted to assess associations between video type (cancer vs noncancer) and video characteristics and content.

Results: In total, 115 videos were reviewed. Of these, 46/115 (40.0%) were cancer clinical trials videos and 69/115 (60.0%) were noncancer/general clinical trial videos. Most videos were created by health care organizations/cancer centers (34/115, 29.6%), were oriented toward patients (67/115, 58.3%) and the general public (68/115, 59.1%), and were informational (79/115, 68.7%); altruism was a common theme (31/115, 27.0%). Compared with noncancer videos, cancer clinical trials videos more frequently used an affective communication style and mentioned the benefits of participation. Cancer clinical trial videos were also much more likely to raise the issue of costs associated with participation (odds ratio [OR] 5.93, 95% CI 1.15-29.46) and advise patients to communicate with their physician about cancer clinical trials (OR 4.94, 95% CI 1.39-17.56).

Conclusions: Collectively, YouTube clinical trial videos provided information on many aspects of trials; however, individual videos tended to focus on selected topics with varying levels of detail. Cancer clinical trial videos were more emotional in style and positive in tone and provided information on the important topics of cost and communication. Patients are encouraged to verify and supplement YouTube video information in consultations with their health care professionals to obtain a full and accurate picture of cancer clinical trials to make an adequately informed decision about participation.

KEYWORDS

clinical trial; cancer clinical trial; social media; internet; YouTube videos; health information

Introduction

The release of new cancer treatments to market has outpaced all other therapeutic areas [1], with the introduction of 70 oncology treatments for more than 20 different tumor types over the past 5 years alone [2]. Bringing a new cancer treatment to the clinical setting is a complex process that extends over many years from the initial discovery and development in the laboratory through Food and Drug Administration (FDA) approval for use [3]. Integral to this process are the heavily FDA-regulated clinical trials that rigorously determine the safety and effectiveness of new and promising treatments among humans in an experimental setting [4].

Clinical trials are designed to answer specific research questions and are, thus, governed by strict protocols and eligibility criteria. Informed consent documents, which provide potential participants with detailed information about the purpose of the study, procedures to be performed, potential harms and benefits of the experimental agents used, and the voluntary nature of participation, are federally mandated to ensure that participants make informed decisions regarding enrollment. Much of the information presented to a patient is complex, incorporating translational research, biomarker selection, and sophisticated study designs into trials [5], but the level of health literacy remains low in the adult US population [6]. Fewer than 5% of adult cancer patients enroll in clinical trials [7], the most commonly cited barriers being lack of awareness or knowledge regarding clinical trials [8-14] and the reluctance to be randomized [15-19].

In one study, 92% of cancer patients reported the internet as the resource that empowered them when making treatment decisions and provided them with information with which to engage their physicians in discussion [20]. Cancer patients also use the internet to seek clarification, more detailed information, or reassurance about what was learned after a clinical encounter about clinical trials [21,22]. Much of the clinical trial information available online has been characterized as variable in quality with poor readability [23]. While clinical trial search tools are relatively easy to locate on the internet using various search engines, both content and functionality were also highly variable, and users needed a fair amount of knowledge about their condition and good web navigation skills to access the relevant information [24]. In a study that simulated the search for treatments of four common cancers by naïve cancer patients without clinical trial knowledge, only 85% of cancer-treatment sites mentioned clinical trials on the landing page and only 68% provided links to trials [23]. Another study that evaluated the navigability of comprehensive cancer center websites to clinical trial information observed that clinical trial content is narrow in scope with trial descriptions written at a college reading level,

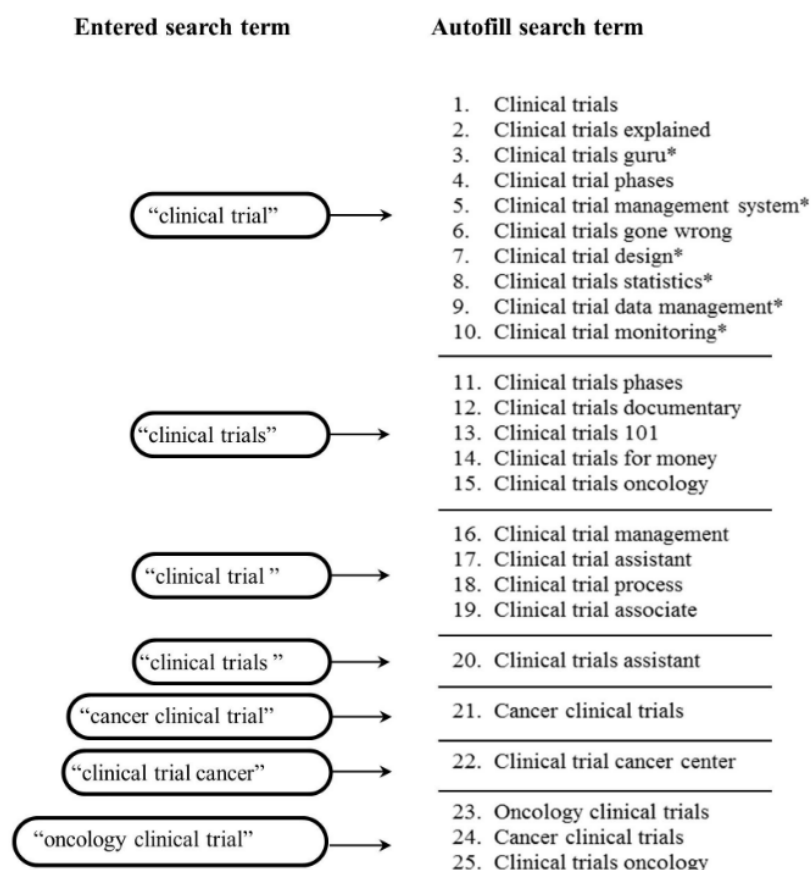
thereby limiting understanding for the average user [25]. When the written word proves to be challenging, consumers may turn to video-based information.

First introduced in 2005, YouTube is the second most visited website worldwide, and it has become an increasingly important medium through which health information is exchanged between and shared by consumers and health care professionals, government and nongovernment agencies, and industries [26]. Recent statistics indicate that currently, 300 hours of videos are uploaded to YouTube every minute and almost 5 billion videos are watched by 30 million visitors every day [27]. Despite the extensive reach and pervasive use of YouTube videos, little is known about videos related to cancer clinical trials; thus, the aim of this study was to evaluate the content of the most widely viewed YouTube videos related to clinical and cancer clinical trials.

Methods

YouTube videos posted prior to March 2017 were searched for using the keywords “clinical trial(s)” (426,000 videos), “cancer clinical trial(s)” (352,000 videos), “clinical trials cancer” (611,000 videos), and “oncology clinical trial” (619,000 videos). To reduce bias introduced in the display of videos by the search engine due to the location and search history of the study computer, searches were conducted using the incognito mode of Google Chrome in a single day, with results captured for later assessment [26]. A snowballing technique was used to select videos for review wherein sequential screening of the autofill search results for each set of keywords was conducted. A total of 25 search term options were initially identified (Figure 1); 6 search term options were deemed irrelevant and excluded. The first 30 videos from each of the 19 remaining search term options were recorded; duplicate videos were removed, yielding 291 cancer clinical trial videos. YouTube uses a complex algorithm to rank video quality that is based on the duration the video has been watched. Longer viewer time indicates that the video is most likely appropriate for the search terms employed, which results in a higher ranking and greater likelihood of the video appearing on top of a search list [28].

Videos with <200 views (n=77) and those deemed irrelevant (n=80) were removed. Of the remaining 134 videos, additional 19 videos were found to be irrelevant upon viewing and were excluded from the final analysis. The remaining 115 videos were reviewed by 4 independent reviewers (GCH, SAM, KMS, and MB). Interrater reliability of the video characteristics and content-related variables, excluding the number of views, video length, and “thumbs up” and “thumbs down” was assessed by a fifth reviewer (CHB) and was found to be high among a randomly selected 10% sample (Cohen kappa=0.85).

Figure 1. Keywords and search terms. Asterisk indicates terms considered irrelevant and excluded.

The following video characteristics were assessed: number of views, length of the video in minutes, year published, country of origin, video source (nonprofit organization, health care provider/organization or cancer center, school/educational organization, pharmaceutical or biotech company, clinical research organization, or other), and YouTube video category (nonprofits and activism, science and technology, education, people and blogs, or other). Style of communication was categorized as affective versus cognitive.

Videos were coded as affective in style if the content was presented verbally with overt positive or negative emotion that was persuasive in nature, whereas videos in which the content was delivered nonpersuasively, verbally or nonverbally, and without overt emotion were coded as cognitive in style. Also evaluated was the tone of the video (positive, negative, or neutral). Themes arising in the video (altruism/positive emotions, risks and dangers of clinical trials, advancing science, importance of volunteering for clinical trials, and other), the intended audience (patients, general public, caregivers, health care professionals, students, and research personnel assessed as to whom the information was being addressed), and the manner of presentation (lecture/course format/webinar, interview, testimonial, advertisement for paid participation, and other) were also evaluated. Viewer perceptions concerning the videos were also captured by assessing the “thumbs up,” “thumbs down,” and comment counts. Using the National Cancer Institute (NCI) Clinical Trials Information for Patients and Caregivers [29] series of documents as the reference

standard, the content of each video was grouped *a priori* into five broad categories: clinical trial purpose, trial phases, study design, safety and ethics, and participant considerations. Reviewers derived the themes embedded in the content throughout the video viewing process; categorization of themes (eg, altruism/positive emotions, risks/dangers, advancing science, importance of volunteering, and other) was based on reviewer consensus.

Descriptive analyses, including calculation of frequency distributions, means (SD), and ranges, were performed. To assess video characteristics and content differences between videos for cancer clinical trials and clinical trials in general or videos with a focus on a disease other than cancer, univariable analyses using chi-square test for categorical variables and analysis of variance for continuous variables were conducted. Stepwise multivariable logistic regression models, controlling for the year of publication, were constructed to assess the associations between video type (cancer vs noncancer) and variables with *P* values <.05 in the univariable analysis, controlling for the year of upload. All analyses were performed using IBM SPSS (version 24) [30]. Institutional review boards of each author’s respective institution deemed nonhuman subject research exempted from review.

Results

The 115 videos related to clinical trials were viewed by approximately 11 million viewers with a mean number of 94,360 (SD 827,883) views each (Table 1).

Table 1. Characteristics of YouTube videos related to clinical trials.

Variable	Total (n=115)	Cancer related (n=46)	Noncancer related (n=69)	P value
Number of views	10,851,366	1,475,392	9,375,974	
Mean (SD)	94,359.7 (827,883.4)	32,073.7 (180,025.0)	135,883.7 (1,059,819.2)	.20
Range	216-8,810,958	226-1,223,520	216-8,810,958	
Length of video (minutes)				
Mean (SD)	7.95 (11.2)	6.6 (6.9)	8.8 (13.3)	.03
Range	0.57-61.0	0.8-35.9	0.6-61.0	
Year published, n (%)				.48
2005-2010	16 (13.9)	9 (19.6)	7 (10.1)	
2011-2012	29 (25.2)	10 (21.7)	19 (27.5)	
2013-2014	39 (33.9)	14 (30.4)	25 (36.2)	
2015-2016	31 (27.0)	13 (28.3)	18 (26.1)	
Country of origin, n (%)				.09
United States	94 (81.7)	41 (89.1)	53 (76.8)	
Other	21 (18.3)	5 (10.9)	16 (23.2)	
Video source, n (%)				<.001
Nonprofit organization	22 (19.1)	10 (21.7)	12 (17.4)	
Health care organization/cancer center	34 (29.6)	23 (50.0)	11 (15.9)	
School/educational organization	7 (6.1)	0 (0.0)	7 (10.1)	
Pharma/biotech	8 (7.0)	1 (2.2)	7 (10.1)	
CRO ^a /recruitment agency	19 (16.5)	3 (6.5)	16 (23.2)	
Other	25 (21.7)	9 (19.6)	16 (23.2)	
YouTube category, n (%)				.47
Nonprofits & activism	24 (20.9)	13 (28.3)	11 (15.9)	
Science & technology	41 (35.7)	14 (30.4)	27 (39.1)	
Education	30 (26.1)	10 (21.7)	20 (29.0)	
People & blogs	10 (8.7)	5 (10.9)	5 (7.2)	
Other	10 (8.7)	4 (8.7)	6 (8.7)	
Communication style, n (%)				
Affective	49 (42.6)	25 (54.3)	24 (34.8)	.04
Cognitive	79 (68.7)	29 (63.0)	50 (72.5)	.29
Tone, n (%)				.04
Positive	74 (64.3)	35 (76.1)	39 (56.5)	
Negative	9 (7.8)	4 (8.7)	5 (7.2)	
Neutral	32 (27.8)	7 (15.2)	25 (36.2)	
Theme, n (%)				
Altruism/positive emotions	31 (27.0)	18 (39.1)	13 (18.8)	.016
Risks/dangers	11 (9.6)	4 (8.7)	7 (10.1)	1.00
Advancing science	9 (7.8)	5 (10.9)	4 (5.8)	.48
Importance of volunteering	13 (11.3)	6 (13.0)	7 (10.1)	.63
Other	9 (7.8)	2 (4.3)	7 (10.1)	.31
Intended Audience, n (%)				
Patients	67 (58.3)	37 (80.4)	30 (43.5)	<.001

Variable	Total (n=115)	Cancer related (n=46)	Noncancer related (n=69)	P value
General public	68 (59.1)	25 (54.3)	43 (62.3)	.39
Caregivers	1 (0.9)	1 (2.2)	0 (0.0)	.56
Health care professionals	13 (11.3)	4 (8.7)	9 (13.0)	.47
Students	6 (5.2)	0 (0.0)	6 (8.7)	.08
Research personnel	6 (5.2)	1 (2.2)	5 (7.2)	.40
Presentation, n (%)				
Lecture/course/webinar	69 (60.0)	26 (56.5)	43 (62.3)	.53
Interview	16 (13.9)	6 (13.0)	10 (14.5)	.83
Testimonial	31 (27.0)	17 (37.0)	14 (20.3)	.048
Advertisement	6 (5.2)	4 (8.7)	2 (2.9)	.22
Other	21 (18.3)	7 (15.2)	(20.3)	.49
Viewer Perceptions				
Thumbs up				
Mean (SD)	963.7 (9920.3)	33.3 (132.9)	1584.0 (12806.1)	.11
Range	0-10,6415	0-897	0-10,6415	
Thumbs down				
Mean (SD)	285.1 (2963.3)	18.0 (116.1)	463.01 (3825.2)	.11
Range	0-31,777	0-788	0-31,777	
Comments				
Mean (SD)	99.4 (1009.4)	1.5 (3.4)	164.6 (1302.9)	.10
Range	0-10,824	0-15	0-10,824	

^aCRO: clinical research organization.

Forty-six of 115 (40.0%) videos discussed cancer clinical trials versus 69/115 (60.0%) that either focused on other diseases (eg, Parkinson's disease) or were general discussions of clinical trials, not related to any specific disease. The mean length of a video was approximately 8 min (SD 11.2) and the majority (94/115, 81.7%) of the videos were produced in the United States. Videos created by health care organizations, including cancer centers, predominated (34/115, 29.6%), and many were posted under the "science and technology" theme of YouTube.

Overall, videos were oriented toward patients (67/115, 58.3%) and the general public (68/115, 59.1%), tended to be cognitive (79/115, 68.7%) in nature, and were presented as a lecture/course/webinar (69/115, 60%). The most popular theme among clinical trial videos was altruism and other positive emotions associated with clinical trial participation (31/115, 27.0%) followed by the importance of volunteering for trials (13/115, 11.3%).

Compared with noncancer-related videos, cancer clinical trial videos were shorter in length (6.6 vs 8.8 min, $P=.03$) and were more often created by health care organizations (23/46, 50.0% vs 11/69, 15.9%, $P<.001$). More than half of the cancer videos used an affective approach compared to about one-third of noncancer videos ($P=.04$) and, compared to noncancer videos, more often expressed a positive tone (35/46, 76.1% vs 39/69, 56.5%, $P=.04$) toward clinical trials and focused on altruism and other positive emotions (18/46, 39.1% vs 13/69, 18.8%,

$P=.016$). Compared with only 43.5% (30/69) of noncancer videos ($P<.001$), 80% (37/46) of cancer videos were geared toward a patient population and were most often presented as testimonials (patient and physician; 37% (17/46) vs 20.3% (14/69), $P=.048$).

With regard to the content, the most commonly mentioned item was the purpose of a clinical trial (62/115, 53.9%), followed by the fact that clinical trials are conducted in phases (44/115, 38.3%), information about specific phases (Phase I=46/115, 40.0%, Phase II=37/115, 32.2%, and Phase III=40/115, 34.8%), there is eligibility criteria for entering a trial (37/115, 32.2%), and that there are benefits to participating in a clinical trial (38/115, 33.0%; Table 2). Cancer-related clinical trial videos more often mentioned that Phase I studies evaluate how the drug effects the body and are used to determine potential side effects (4/46, 8.7% vs 0/69, 0%, $P=.02$) and that they may be offered in cases when no standard treatment options exist (5/46, 10.9% vs 0/69, 0%, $P=.009$) compared with noncancer-related videos. Cancer-related videos also differed from noncancer-related videos in that cancer-related videos more frequently mentioned the benefits of clinical trial participation, such as better care and monitoring (21/46, 45.7% vs 11/69, 15.9%, $P<.001$), participants could be the first to benefit from an experimental treatment if it works (19/46, 41.3% vs 7/69, 10.1%, $P<.001$), and their participation could very well help others in the future (20/46, 43.5% vs 13/69, 18.8%, $P=.004$).

Table 2. Clinical trial YouTube video content.

Variable	Total (n=115), n (%)	Cancer related (n=46), n (%)	Noncancer related (n=69), n (%)	P value
Purpose				
Mentions purpose in general	62 (53.9)	28 (60.9)	34 (49.3)	.22
Test new drugs/devices in human subjects	20 (17.4)	10 (21.7)	10 (14.5)	.32
Determine a safe drug dose	10 (8.7)	2 (4.3)	8 (11.6)	.31
Determine drug efficacy	5 (4.3)	1 (2.2)	4 (5.8)	.65
Test a research question	3 (2.6)	1 (2.2)	2 (2.9)	1.00
Trial phases				
Mentions there are phases in general	44 (38.3)	16 (34.8)	28 (40.6)	.53
Phase I	46 (40.0)	18 (39.1)	28 (40.6)	.88
Determine dosing	33 (28.7)	13 (28.3)	20 (29.0)	.93
Assess safety	15 (13.0)	9 (19.6)	6 (8.7)	.09
Determine method of administration	15 (13.0)	5 (10.9)	10 (14.5)	.57
Small sample size	24 (20.9)	6 (13.0)	18 (23.1)	.09
Healthy volunteers	6 (5.2)	2 (4.3)	4 (5.8)	1.00
Compensation for participation	3 (2.6)	1 (2.2)	2 (2.9)	1.00
How the drug affects the body/side effects	4 (3.5)	4 (8.7)	0 (0.0)	.02
When no other standard treatment options are available	5 (4.3)	5 (10.9)	0 (0.0)	.009
Phase II	37 (32.2)	15 (32.6)	22 (31.9)	.93
Determine effect on disease course	31 (27.0)	13 (28.3)	18 (26.1)	.80
<100 sample size	20 (17.4)	4 (8.7)	16 (23.2)	.045
Phase III	40 (34.8)	17 (37.0)	23 (33.3)	.69
Compare to standard treatment	32 (27.8)	16 (34.8)	16 (23.2)	.17
>100 sample size	24 (20.9)	7 (15.2)	17 (24.6)	.22
Phase IV	13 (11.3)	3 (6.5)	10 (14.5)	.19
Postmarketing testing for side effects	8 (7.0)	3 (6.5)	5 (7.2)	1.00
Study design				
Randomized controlled trial	29 (25.2)	13 (28.3)	16 (23.2)	.54
Reduce bias	14 (12.2)	5 (10.9)	9 (13.0)	.73
Control group	24 (20.9)	12 (26.1)	12 (17.4)	.26
Interventional group	24 (20.9)	10 (21.7)	14 (20.3)	.85
Blinding	16 (13.9)	5 (10.9)	11 (15.9)	.44
Placebo trial	25 (21.7)	8 (17.4)	17 (24.6)	.36
Research team	33 (28.7)	16 (34.8)	17 (24.6)	.24
Safety and ethics				
FDA ^a regulatory process	9 (7.8)	4 (8.7)	5 (7.2)	1.00
Written protocols/strict guidelines	12 (10.4)	4 (8.7)	8 (11.6)	.76
Eligibility criteria	37 (32.2)	17 (37.0)	20 (29.0)	.37
Protection of safety	30 (26.1)	10 (21.7)	20 (29.0)	.39
IRB ^b	12 (10.4)	4 (8.7)	8 (11.6)	.76
DSMB ^c	5 (4.3)	3 (6.5)	2 (2.9)	.39
FDA	19 (16.5)	8 (17.4)	11 (15.9)	.84

Variable	Total (n=115), n (%)	Cancer related (n=46), n (%)	Noncancer related (n=69), n (%)	P value
Ethical conduct of research	4 (3.5)	2 (4.3)	2 (2.9)	1.00
Informed consent	34 (29.6)	13 (28.3)	21 (30.4)	.80
Explanation of purpose, procedures, benefits, and harms	29 (25.2)	14 (30.4)	15 (21.7)	.29
Voluntary nature of participation	31 (27.0)	16 (34.8)	15 (21.7)	.12
Ability to withdraw at any time	20 (17.4)	11 (23.9)	9 (13.0)	.13
Participant considerations				
Potential benefits				
Mentions benefits in general	38 (33.0)	19 (41.3)	19 (27.5)	.12
Better care and monitoring	32 (27.8)	21 (45.7)	11 (15.9)	<.001
First to benefit if treatment works	26 (22.6)	19 (41.3)	7 (10.1)	<.001
Help others in the future	33 (28.7)	20 (43.5)	13 (18.8)	.004
Potential risks				
Mentions risks in general	29 (25.2)	10 (21.7)	19 (27.5)	.48
Not always better than standard treatment	4 (3.5)	2 (4.3)	2 (2.9)	1.00
No guarantee of effectiveness	19 (16.5)	9 (19.6)	10 (14.5)	.47
Unknown side effects	18 (15.7)	5 (10.9)	13 (18.8)	.25
Costs associated with participation	16 (13.9)	12 (26.1)	4 (5.8)	.002
Communication with physician	32 (27.8)	24 (52.2)	8 (11.6)	<.001
Communication with family	11 (9.6)	8 (17.4)	3 (4.3)	.03
Quality of life	16 (13.9)	11 (23.9)	5 (7.2)	.01

^aFDA: Food and Drug Administration.

^bIRB: institutional review board.

^cDSMB: Data Safety Monitoring Board.

Additionally, the cost associated with participation (12/46, 26.1% vs 4/69, 5.8%, $P=.002$), the importance of communication with one's doctor (24/46, 52.2% vs 8/69, 11.6%, $P<.001$) and family (8/46, 17.4% vs 3/69, 4.3%, $P=.03$), and the quality of life (11/46, 23.9% vs 5/69, 7.2%, $P=.01$) were all mentioned more often in cancer-related videos than in noncancer-related videos.

Results of the multivariable regression analysis demonstrated that compared with noncancer clinical trial videos, videos related to cancer clinical trials are much more likely to have been created by health care organizations, including cancer centers (odds ratio [OR] 5.95, 95% CI 1.70-20.88), to mention the costs associated with clinical trial participation (OR 5.93, 95% CI 1.15-29.46) and to advise patients to communicate with their physician about cancer clinical trials (OR 4.94, 95% CI 1.39-17.56; [Table 3](#)).

Table 3. Video characteristics and content associated with cancer clinical trial YouTube videos.

Variable	Odds ratio (95% CI)	P value
Year published		
2005-2012	Reference	
2013-2016	1.87 (0.61-5.70)	.27
Video source		
Other (school, CRO ^a , education, other)	Reference	
Health care/cancer center	5.95 (1.70-20.88)	.005
Communication style		
Affective	0.63 (0.18-2.18)	.47
Tone		
Negative	Reference	
Positive	3.78 (0.41-35.20)	.24
Neutral	1.45 (0.31-6.77)	.63
Theme		
Altruism/positive emotions	2.26(0.55-9.34)	.26
Intended audience		
General public	2.25 (0.71-7.12)	.17
Participant considerations		
Potential benefits	—	—
Better care and monitoring	2.30 (0.63-8.41)	.21
First to benefit if treatment works	2.19 (0.65-7.41)	.21
Costs associated with participation	5.83 (1.15-29.46)	.033
Communication with physician	4.94 (1.39-17.56)	.013
Communication with family	1.03 (0.14-7.63)	.98
Quality of life	2.15 (0.50-9.20)	.30

^aCRO: clinical research organization.

Discussion

Principal Findings

Our review of the 115 top viewed YouTube videos revealed that a large proportion of these videos are devoted to cancer clinical trials. Overall, clinical trial videos convey information that is aimed at both patients and the general population audiences. The majority of the videos presented the viewer with the overall purpose of a clinical trial and many discussed the phases of clinical trials and the fact that criteria are used to determine a patient's eligibility for enrollment. Beyond these topics, the video content varied widely, with most touching upon selected topics (eg, phases of clinical trials, federal regulations, informed consent or benefits of enrollment, and the importance of communication with a physician). Interestingly, none discussed the concept of clinical equipoise.

Cancer clinical trial videos were more positive in tone and more frequently used an affective communication style. They tended to emphasize altruism, the importance of volunteering to participate in a trial, and the benefits of participation more so than did non-cancer videos. Further, cancer clinical trial videos

were nearly six times as likely to be created by a health care organization or a cancer center and were much more likely than noncancer trial videos to communicate practical information about clinical trial participation costs and to encourage dialogue with one's physician.

Limitations

Much attention was taken in the selection of the videos reviewed in this study to represent the most commonly viewed YouTube videos about clinical trials however, selecting the top 30 videos with greater than 200 views may have introduced a selection bias. Since the YouTube video ranking algorithm places videos with longer user viewing times at the top of the list and overlap was found in the videos in the top 30 for the search terms, our inclusion criteria likely captured the most widely viewed YouTube videos related to clinical trials. Further, we postulated that any bias introduced by the algorithm would similarly influence the videos displayed when a consumer uses the same search term and that the impact of less-viewed videos would be minimal. Despite using search terms specific to cancer clinical trials, we found that a large proportion of clinical trial videos were not related to cancer. While this was an unexpected

finding, a consumer using our search terms would likely have the same experience. Whether or not viewers were engaged for the full duration of any video is unknown as 30 seconds of YouTube watching is considered a “viewing” [31]. This study is also limited in that it was cross-sectional in design and is further compounded by the fact that new videos are continually being uploaded on YouTube. Finally, this study focused solely on English language videos.

Comparison With Prior Work

To date, no other study has evaluated the contents of YouTube videos regarding clinical trials. More than 800 peer-reviewed publications reporting on the quality and content of YouTube videos relating to public health topics ranging from anorexia [32] to Zika virus [33] now exist, which is cause for concern regarding the power of this medium to communicate information accurately and responsibly to the general public. The decision to take part in a cancer clinical trial is a complex one, and the most common barrier to participation is lack of knowledge about cancer clinical trials [33]. Two separate studies found that the internet and media are the primary sources for learning about clinical trials [34] and that the information “read, saw, or heard” about a study was a major influence on the decision to participate. Further evidence supports that seeking information about one’s illness can be viewed as a key coping strategy, which may lead to health-promotive activity and facilitate psychosocial adjustment to illness [35]. Use of the internet as a source of health-related information, however, has been likened to drinking from a fire hose and not knowing the source of the water [36], a sentiment that can easily be applied to

YouTube video viewing. Because there exists no arbiter of the truth or accuracy of the material posted on YouTube, many question both the credibility and accuracy of the information and find that the content is influenced by perspectives of the video source [37-42]. Currently, the NCI acknowledges the importance of social media as a source of health-related information, and through its Cancer Moonshot Initiative, seeks to leverage this platform to provide patients with reliable information by developing a social media best practices toolkit. Information learned in this study showed that the majority of the clinical trial information communicated was accurate, as determined using NCI information for comparison [29] and was conveyed in a positive and compassionate manner. The coverage of topics however, was spotty, and the sufficiency and quality of information was lacking many times.

Conclusions

Overall, YouTube clinical trial videos provided information on many aspects of clinical trials, particularly cancer clinical trials. Few covered the full range of concepts needed to make an informed decision about participation; the majority focused on selected topics and provided varying levels of detail, leaving the viewer with an incomplete view of key concepts and partially informed. Given the abundance of clinical trial videos and relative ease of access to this information, care must be taken by patients and their families to verify and supplement YouTube video information with consultations with their healthcare professional to obtain a full and accurate picture of cancer clinical trials, thus, to make an adequately informed decision about participation.

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Authors' Contributions

GCH and SAM developed the study design and contributed to the data collection. MB, CHB, and KMS conducted data collection. GCH and LS conducted data analysis. GCH, SAM, MB, CHB, KMS, LS, MK, FLB, and GKS contributed to the interpretation of findings and manuscript preparation.

Conflicts of Interest

None declared.

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Abbreviations

CRO: clinical research organization
DSMB: Data Safety Monitoring Board
FDA: Food and Drug Administration
NCI: National Cancer Institute
OR: odds ratio

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Original Paper

Acceptability of a Mobile Phone App for Measuring Time Use in Breast Cancer Survivors (Life in a Day): Mixed-Methods Study

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Abstract

Background: Advancements in mobile technology allow innovative data collection techniques such as measuring time use (ie, how individuals structure their time) for the purpose of improving health behavior change interventions.

Objective: The aim of this study was to examine the acceptability of a 5-day trial of the Life in a Day mobile phone app measuring time use in breast cancer survivors to advance technology-based measurement of time use.

Methods: Acceptability data were collected from participants (N=40; 100% response rate) using a self-administered survey after 5 days of Life in a Day use.

Results: Overall, participants had a mean age of 55 years (SD 8) and completed 16 years of school (SD 2). Participants generally agreed that learning to use Life in a Day was easy (83%, 33/40) and would prefer to log activities using Life in a Day over paper-and-pencil diary (73%, 29/40). A slight majority felt that completing Life in a Day for 5 consecutive days was not too much (60%, 24/40) or overly time-consuming (68%, 27/40). Life in a Day was rated as easy to read (88%, 35/40) and navigate (70%, 32/40). Participants also agreed that it was easy to log activities using the activity timer at the start and end of an activity (90%, 35/39). Only 13% (5/40) downloaded the app on their personal phone, whereas 63% (19/30) of the remaining participants would have preferred to use their personal phone. Overall, 77% (30/39) of participants felt that the Life in a Day app was *good* or *very good*. Those who agreed that it was easy to edit activities were significantly more likely to be younger when compared with those who disagreed (mean 53 vs 58 years, $P=.04$). Similarly, those who agreed that it was easy to remember to log activities were more likely to be younger (mean 52 vs 60 years, $P<.001$). Qualitative coding of 2 open-ended survey items yielded 3 common themes for Life in a Day improvement (ie, convenience, user interface, and reminders).

Conclusions: A mobile phone app is an acceptable time-use measurement modality. Improving convenience, user interface, and memory prompts while addressing the needs of older participants is needed to enhance app utility.

Trial Registration: ClinicalTrials.gov NCT00929617; <https://clinicaltrials.gov/ct2/show/NCT00929617> (Archived by WebCite at <http://www.webcitation.org/6z2bZ4P7X>)

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KEYWORDS

cancer; technology; time management; mHealth; physical activity

Introduction

Background

As mobile phone technology becomes more widely accessible, so does its potential to act as a platform for high-reach physical activity promotion with increased personalization. This area of research is particularly relevant for breast cancer survivors, as it remains one of the most common cancers among women, regardless of race or ethnicity, with approximately 252,710 expected new cases in 2017 [1]. Moreover, it has been recently estimated that over 3.1 million US women either have a history of breast cancer or have a current cancer diagnosis [2]. Interventions targeting physical activity are common, as it is one of the few modifiable risk factors for breast cancer development and outcomes [3]. However, a majority of breast cancer survivors fail to achieve the US Department of Health and Human Services federal guidelines of 150 min per week of moderate intensity physical activity [4]. This is of particular concern as inactivity and sedentary behaviors have been shown to be a risk factor independent of physical activity [5,6]. Furthermore, recent emphasis has been placed on the importance of promoting leisure-time physical activity for mortality benefits [7-9]. To address these high rates of physical inactivity, effective interventions are needed. A better understanding of activity patterns and time use among survivors would help inform these efforts by providing a more comprehensive evaluation of an individual's day-to-day activities.

Gaps in the Literature

One limitation of physical activity research to date has been inadequate data relevant to the activitystat hypothesis, which suggests that an increase in physical activity in 1 domain often leads to a decrease in another domain in an effort to keep energy expenditure constant through biological regulation [10,11]. Moreover, recent research aimed at examining shifts in time-use domains found that domains such as Physical Activity, Self-Care, and Active Transport increased, whereas Television/Videogames domains decreased after a structured exercise intervention [12,13]. Failure to recognize shifts in activity domains could lead to inaccurate postintervention assessments of physical activity and time-use measurements, which have been shown to be important tools for elucidating the actual impact of physical activity program [14]. Furthermore, it is theorized that self-awareness can be promoted by bringing attention to one's behavior in close temporal proximity to its occurrence, which may influence behavioral and cognitive changes [15]. Therefore, technology-supported time-use measurements may be advantageous for both physical activity measurement and promotion.

In general, many published studies in this area of research have utilized the Multimedia Activity Recall for Children and Adolescents (MARCA), a computerized self-report instrument for time-use measurement [14], which has since been adapted for use among adult populations and demonstrated both validity and reliability [16]. The MARCA has also been applied in a

variety of settings, and previous uses include examining activity patterns among older Australian workers [17] and adolescents [18-20], as well as 5-year-old children [21]. Despite wide applicability of the MARCA, one limitation of currently available measurements include inability to provide a continuous measurement of time use, as it relies on 24-hour recall rather than real-time assessment within the context of daily life. Moreover, a mobile phone version of the MARCA does not currently exist, which limits its applicability in an increasingly wireless environment. In an effort to address this, this study utilized a time-use measurement app named Life in a Day that allows participants to track activities throughout their day. Life in a Day is a mobile app that was developed by the Division of Cancer Control and Population Sciences at the US National Cancer Institute in collaboration with MEI Research, Ltd. The app allows self-tracking of customizable activities (eg, personal care, house cleaning, walking the dog), which offers researchers insight into how people utilize their time. To our knowledge, no other study has examined time use among breast cancer survivors. Data regarding the acceptability of such a measure is critical to further research testing how time-use alterations could be employed to optimize physical activity promotion in this at-risk population. The purpose of this study was to evaluate the acceptability of the Life in a Day app for time use among breast cancer survivors recruited from 2 (one Midwestern and one Southeastern) US cities. Moreover, this study explored the relationship between baseline characteristics of participants and Life in a Day user experiences.

Methods

Study Design

This study utilized a posttest-only, embedded evaluation research design with concurrent quantitative and qualitative data collection [22]. Self-administered participant satisfaction surveys were completed after a 5-day trial of a time-use measurement app by a subsample of breast cancer survivors completing baseline assessments in a larger randomized physical activity-controlled trial (registered on ClinicalTrials.gov, NCT00929617). Approval for this study was granted by the Institutional Review Boards at both participating study sites, and informed consent was obtained before initiating study activities.

Participants

Participants in this study included adult women aged 18 to 70 years with a history of ductal carcinoma in situ or stage I-III breast cancer who had completed primary treatment (ie, surgery, radiation, and/or chemotherapy). All participants met eligibility criteria for the parent study, which are described in detail in a previous report [23] and included being ≥ 8 -weeks post surgery, English speaking, medically cleared by a physician, and insufficiently active (ie, ≤ 30 min of vigorous physical activity or ≤ 60 min of moderate physical activity per week, on average, during the past 6 months). Exclusion criteria for the larger parent study also included the following: (1) dementia or organic brain

syndrome; (2) medical, psychological, or social characteristics that would interfere with ability to fully participate in program activities and assessments (eg, psychosis and schizophrenia); (3) contraindication to participation in a regular physical activity program; (4) metastatic or recurrent disease; (5) inability to ambulate; and (6) elective surgery planned during the duration of the intervention, which would interfere with intervention participation (eg, breast reconstructive surgery). As previously described [23], strategies for recruitment included community advertising, worksite email lists, and medical network channels (eg, physician referrals).

Protocol

Following study enrollment, participants attended an orientation session in which they either received a mobile device (ie, Android) with the Life in a Day time-use measurement app (National Cancer Institute prototype version) installed or chose to download the app on their personal phone if it was an Android device. Staff instructed participants on how to generate a user profile and log daily activities within the app. Participants also received a paper-based start-up instruction guide with this information for reference if needed. Participants had access to 23 user customizable activity buttons, one private button, and

a *more activities* button (see [Figure 1](#)). When customizing activity buttons, the search term was queried against a keywords list and matching activity descriptions were displayed. If no suitable activity description was listed, participants could then create a new activity. Other features of Life in a Day included a start and stop timer for tracking, the option to track concurrent activities, and the ability to edit logged activities.

Following orientation, participants were asked to use the time use app to log all activities for 5 consecutive 24-hour days (including sleep time) by pressing the appropriate customized button at the beginning of the activity and again at the end. When logging activities during this period, participants were asked to select up to 3 categories (eg, walking, errand, or appointment) to identify the purpose of the activity. Participants could review and, if necessary, edit tracked activities from the daily log screen of the app (see [Figure 2](#)). For the purpose of this study, activity was not limited to physical activity. After the 5-day trial was completed, research staff members double-checked the phone to ensure all time was tracked. Participants then returned the study-provided mobile device to study staff and completed a questionnaire assessing functionality and satisfaction with the time use app (see [Multimedia Appendix 1](#)).

Figure 1. Customizable activity buttons for Life in a Day time use mobile app.

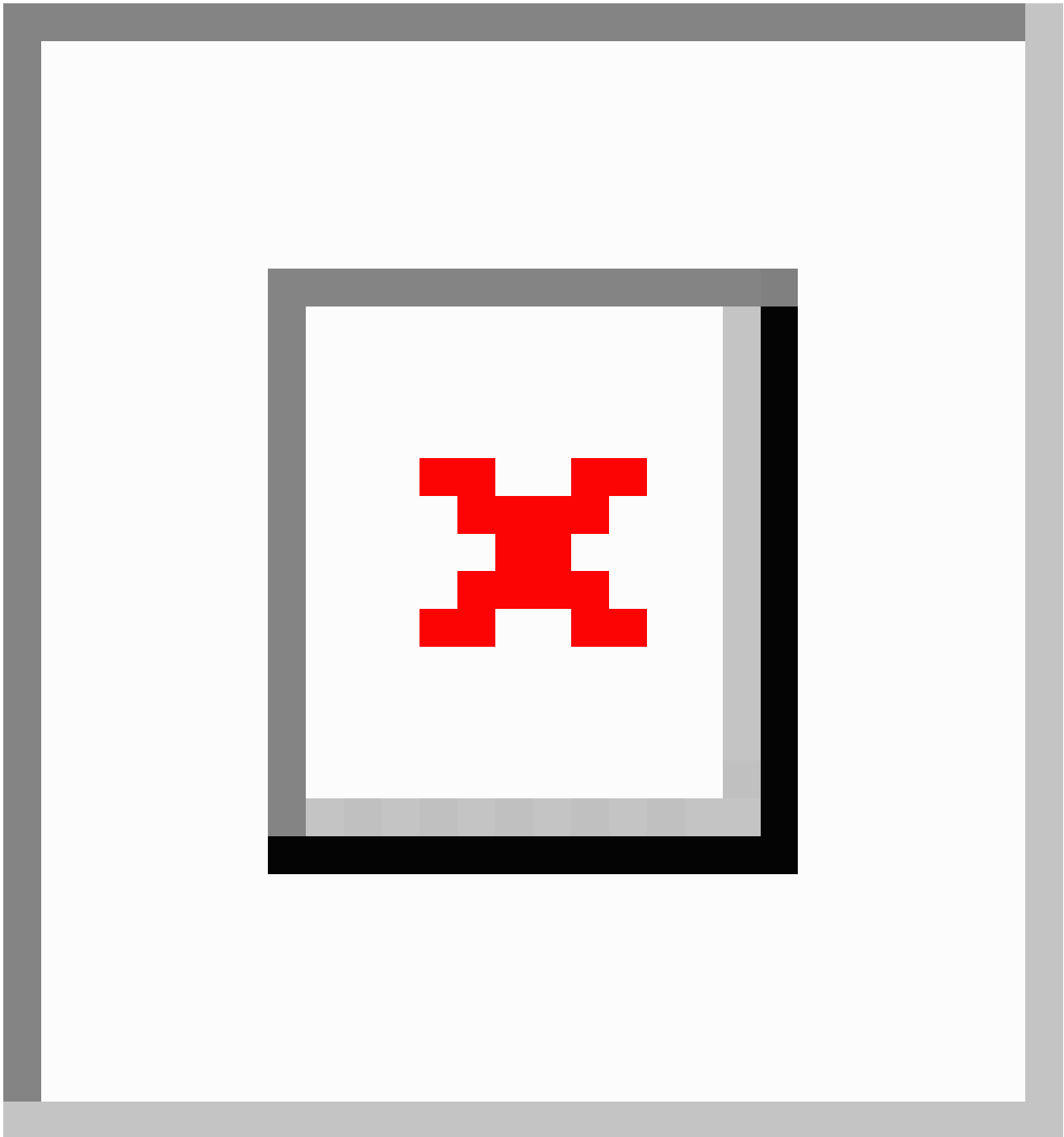
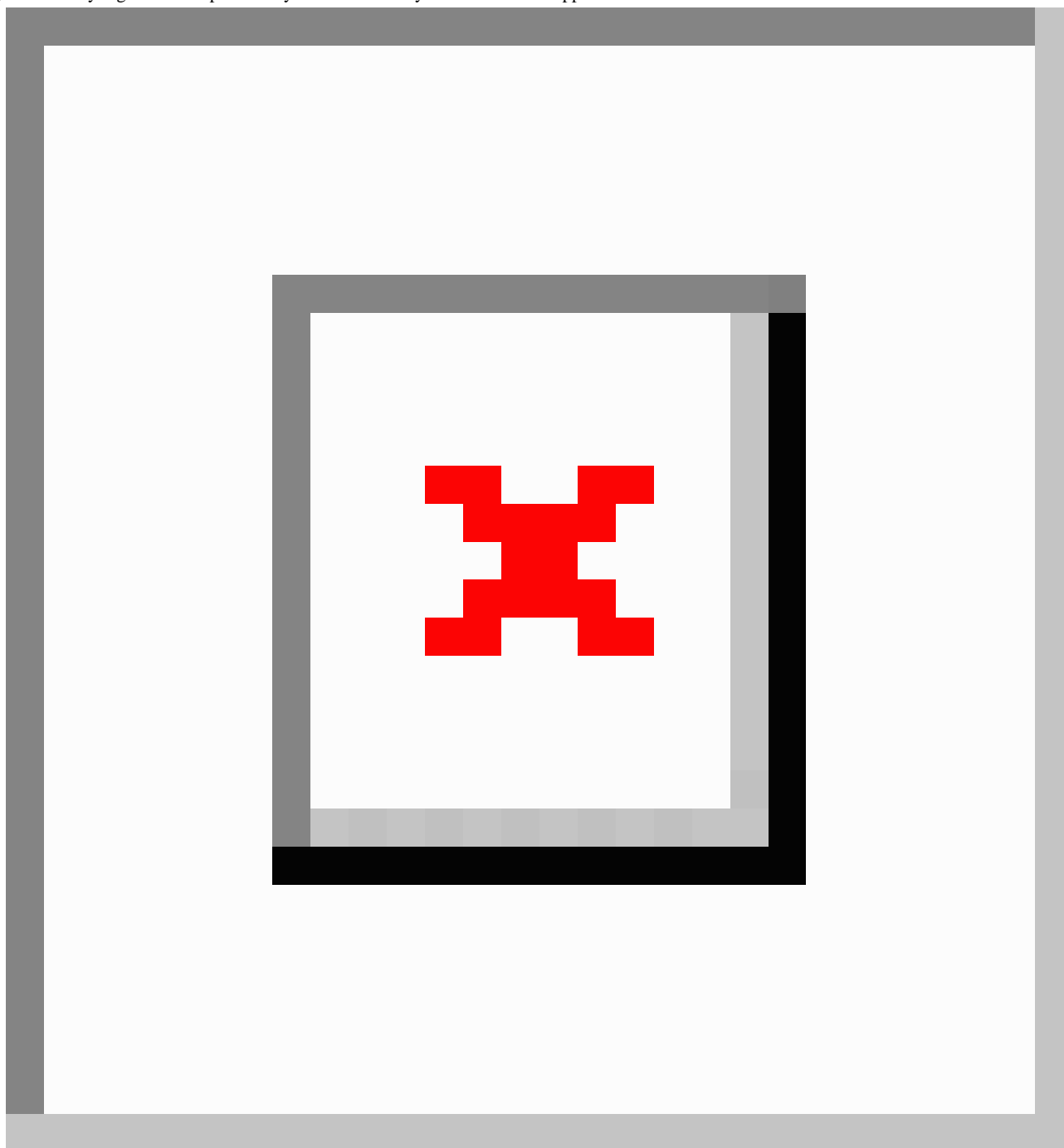


Figure 2. Daily log with example activity for Life in a Day time use mobile app.



Measurements

Demographic and Memory Measures

A self-administered questionnaire assessed baseline demographics (age, race or ethnicity, education, household income, and marital status). Participants also self-reported cancer-related information such as cancer stage, treatment(s) received, and time since treatment. As memory could influence acceptability of the app use, participants self-reported memory difficulties using the 10-item Frequency of Forgetting scale using a 7-point Likert scale [24]. Higher scores indicate less perceived memory difficulty. The subscore used in this study had a possible range of 5-35 (based on 5 of the 10 items). This

scale has previously demonstrated reliability and construct validity similar to the respective 33-item version [24].

Life in a Day Satisfaction Questionnaire

A self-administered 16-item questionnaire assessed functionality and participant experiences with the time use app (see [Multimedia Appendix 1](#)). The questionnaire was designed based upon principles of technology adoption [25,26] and included a mixture of 5-point Likert-scale, yes or no, and open-ended items on various qualities of the app. Participants were asked to rate their agreement with statements such as “Learning to use the Life in a Day app was easy,” “Navigating the Life in a Day app was clear and understandable,” and “I enjoyed using the Life in a Day app.” Likert-scale items ranged from 1 (Completely

Disagree) to 5 (Completely Agree). Additionally, participants were asked to rate the Life in a Day app for tracking activity on a scale of 1 (Very Poor) to 5 (Very Good). Participants were also asked if they downloaded the app on their personal phone. One open-ended item asked participants who did not agree that “it was easy to remember to log their activities using the app” to suggest what could be done to make it easier. This item was limited to those who disagreed with the statement to minimize unnecessary participant burden. Another open-ended item asked all participants to provide the research team with any other comments on the Life in a Day app. Open-ended items were independently coded by 3 research team members using a conventional content analysis approach, in which codes are derived from the data and defined during qualitative data analysis [27,28]. The coders compared passages, resolved discrepancies in the coding, and agreed on the coding for each evaluation response. Themes from the feedback emerged and are described below.

Statistical Analysis

Statistical analyses were conducted using SAS 9.4 (SAS Institute Inc, USA). Sample characteristics and Life in a Day satisfaction questionnaire data were summarized using descriptive statistics. Independent samples *t*-tests were conducted to examine the relationship between sample characteristics and satisfaction questionnaire responses. Survey items using a 5-point Likert-scale were categorized as either disagree (score of 1-3) or agree (score of 4 or 5) to assess potential associations between sample characteristics and agreement status for each questionnaire item.

Results

Participant Characteristics

A total of 40 participants (response rate of 100%) completed the satisfaction questionnaire after a 5-day trial of the Life in a Day mobile phone app. Sociodemographic, cancer-related, and self-reported memory characteristics are presented in [Table 1](#).

Table 1. Baseline sociodemographic, cancer, and memory characteristics (N=40).

Characteristics	Statistics
Gender (female), n (%)	40 (100)
Age in years, mean (SD)	55 (8)
Education in years, mean (SD)	16 (2)
Race/ethnicity, n (%)	
White	29 (73)
African American	9 (22)
Other	2 (5)
Annual household income (US \$), n (%)^a	
<10,000	2 (5)
10,000-19,999	1 (3)
20,000-34,999	4 (10)
35,000-49,000	6 (15)
≥50,000	26 (65)
Marital status, n (%)	
Single	3 (8)
Married	22 (55)
Divorced/separated	9 (22)
Widowed	4 (10)
Not married	2 (5)
Cancer stage, n (%)	
0	4 (10)
I	17 (42)
II	15 (38)
III	4 (10)
IV	0 (0)
Prior chemotherapy treatment, n (%)	
Yes	30 (75)
No	10 (25)
Prior radiation treatment, n (%)	
Yes	22 (55)
No	18 (45)
Time since diagnosis, n (%)	
Less than 1 year	4 (10)
1 to <2 years	12 (30)
2 to <3 years	7 (18)
3 to <4 years	6 (15)
4 to <5 years	2 (5)
5 or more years	9 (22)
Frequency of forgetting (subscore; possible range 5-35)	23 (6)

^an=39.

Overall, participants had a mean age of 55 years (SD 8) and completed 16 years of school (SD 2). Moreover, the study sample was a majority white (73%, 29/40), married (55%, 22/40), and had an annual income ≥US \$50,000 (65%, 26/39).

All participants enrolled in the study were female, and most had undergone prior chemotherapy (75%, 30/40) or radiation (55%, 22/40) treatments. Reported time since cancer diagnosis varied between participants, although most (90%, 36/40) indicated that it had been more than a year.

Acceptability of Life in a Day

A summary of quantitative responses to Life in a Day evaluation questionnaire items is presented in [Multimedia Appendix 2](#). Participants generally agreed that the time use app was easy to learn (83%, 33/40) and would prefer to use it compared with paper-and-pencil activity tracking (73%, 29/40). Furthermore, 60% (24/40) of participants felt that neither did they find tracking their time use with the app for 5 days as too much nor was it too time-consuming (68%, 27/40). Most agreed that the app was easy to read (88%, 35/40) and navigate (80%, 32/40) on the mobile phone and that it was easy to log activities using the activity timer (90%, 35/40). Overall, 77% (30/40) of participants rated the Life in a Day app as good or very good.

Participant age was found to be associated with 2 Life in a Day survey items. Participants who agreed it was easy to edit activities were statistically significantly younger when compared with those who disagreed (mean 53 vs 58 years, $P=.04$). Similarly, those who agreed that it was easy to remember to log activities were more likely to be younger than those who disagreed (mean 52 vs 60 years, $P<.001$). [Figure 3](#) displays the mean age by agreement status for each questionnaire item. Educational attainment, frequency of forgetting, and study site were not associated with survey responses.

Qualitative Feedback Related to Life in a Day and Suggestions for App Improvements

The qualitative dataset consisted of 35 comments across 2 survey items from the sample of 40 participants. For survey item 13a (“what could have made it easier?”), 14 out of 40 (35%) participants provided responses. Moreover, 21 out of 40 (53%) participants provided responses to survey item 16 (other

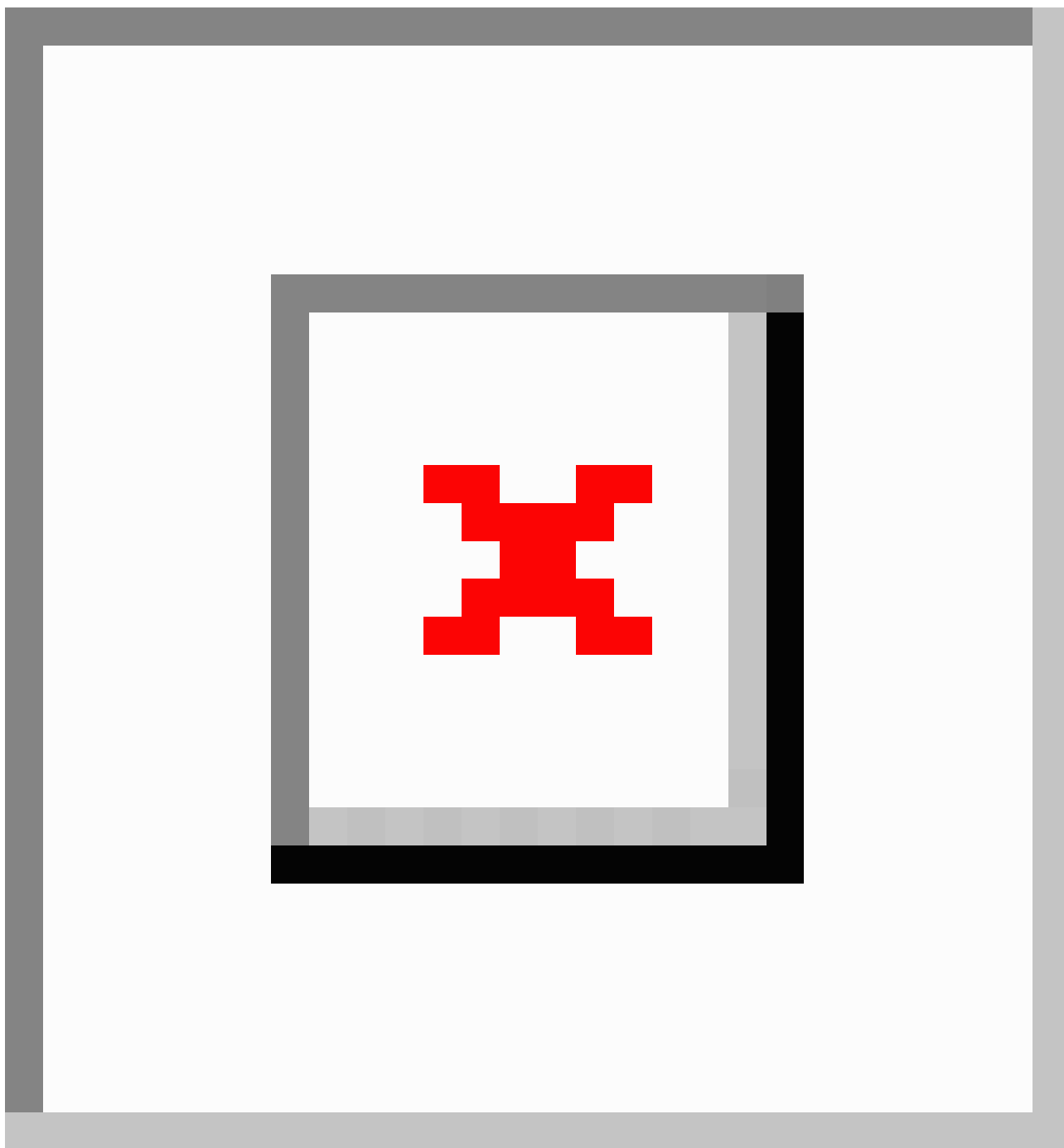
comments). A total of 26 out of 40 participants (65%) responded to at least one of the open-ended survey items, whereas 9 provided comments on both. Qualitative coding of these 2 open-ended survey items yielded several major themes for improving the Life in a Day app. A list of themes and subthemes identified via conventional content analysis is provided in [Textbox 1](#).

Participant Feedback Related to Ease of Remembering to Log Activities in the Time Use App for Cancer Survivors

Participants only completed this open-ended follow-up item if they stated that it was not easy to remember to log activities with the app. A total of 14 participants completed this open-ended item. As noted in [Figure 1](#), this item was significantly associated with participant age. Participants who completed this open-ended item had a mean age of 60 years, which was slightly higher than that of the sample. A mixed-methods data joint display of participant feedback (ie, representative quotes) by age category (<60 years vs ≥60 years) is presented in [Table 2](#). Age categories were determined by the mean age of respondents and are provided to allow for the comparison of perspectives from younger and older participants.

One theme that emerged from the responses was the need for an adjustment period when first using the app with practice time being particularly important for the participants ≥60 years. Issues with multitasking were commonly identified in participant responses (both age groups). Difficulties arose with activity tracking when participants were involved in activities such as running errands or caretaking. In addition to difficulties with tracking activity due to multitasking, some participants expressed the need for a built-in reminder system for the app, with older participants expressing difficulty with the cognitive load burden specifically ([Table 2](#)). Finally, older participants indicated difficulty with the app interface due to unfamiliarity with technology.

Figure 3. Life in a Day participant mean age by survey item agreement. All statistically significant ($P < .05$) interactions are denoted with an asterisk (*).



Textbox 1. Themes and subthemes from open-ended survey items. Item 13a “What could have made it easier?” was answered by 14 participants and item 16 “Other comments” was answered by 21 participants.

Item 13a. What could have made it easier?

- User interface
 - Multitasking
- Convenience
 - General
 - Personal phone
 - Wearability
- Reminders
- Adjustment period
- Improved set-up/orientation
- Platform expansion
- Minimization of cognitive overload

Item 16. Other comments

- User interface
 - Adding activities
 - Changing activities
 - Changing categories
 - Choosing categories
 - Editing activities
 - Multitasking
- Convenience
 - Personal phone
 - Readability
 - Wearability
- Burden
 - General
 - Easier than pen and paper
 - Preferred pen and paper
 - Time
- Adjustment period
- Improved training
- Insight into time use
- Instruction clarity
- Minimization of cognitive overload
- Comfort with technology

Table 2. Joint display of participant responses by age category.

Item	Representative open-ended responses
What could have made it easier?^a	
Age <60 years	
Participant A	“Trial was too short. I needed a small period to get adjusted to having the app.”
Participant B	“If there could be a way to have this device on you, it would be easier to remember to change the activities. Often I had to go find where my phone was, and if I could not locate it, I could not ‘call it’ to locate it!”
Participant C	“I didn’t add enough activities to cover my day adequately and did not adjust it once I left the office.”
Participant D	“...give me a electric shock so that I would remember.”
Age ≥60 years	
Participant E	“My biggest problem was remembering to change from one activity to another—running errands was a real pain!”
Participant F	“I did not have a place to keep it. I had to wear pockets and it was difficult to remember to carry it. Would be focused on other things.”
Participant G	“It is hard to remember to track every activity. A sound prompt every 1/2 to 2 hours to remind you to check and see if you are on track and logging the correct or current activity. For example, when you are on the go, and not thinking ahead from 1 thing to the next.”
Participant H	“...time/practice [this was all new so it was easy to forget].”
Other comments^b you have regarding the Life in a Day app	
Age <60 years	
Participant B	“I found it awkward keeping up with my phone; my real cell phone; the paper handout describing the quick start guide, especially if I was multitasking. Much of my 5 days usage was with my mom who is in a wheelchair, is diabetic, and requires much help. So as I said, trying to keep up with her, keep up with the phone, change my activities, go back to her, take care of myself and family and things I needed to do, go find the phone to change my activities, etc. did become somewhat overwhelming and confusing. Perhaps a device that can be on the person and simplified would be better [at least for people like me!]”
Participant I	“...I found it interesting to document my day. Hopefully, it will encourage me to make some changes for the good to my lifestyle.”
Participant J	“I’m not particularly savvy with the use of all smart ph. I have a blackberry. Honestly, I probably needed a bit more training but my fault for not asking.”
Age ≥60 years	
Participant K	“It would be easy to track if you did the same activity for 6-8 hours. However, I might sit down and do accounting for my company, then jump up and load clothes, then jump in the car and travel to the store. I have too many activities during the day for this app. I felt as if it ‘took over my life.’ Not good for an active person that changes activities all day long.”
Participant F	“Did not do correct categories. Item was easy, I was the problem. Does not come easily for me so when I am focused on doing my responsibilities using app suffered.”
Participant H	“I would have less of a problem if this was not a brand new thing for me. The phone seemed to have a mind of its own sometimes. It did not function as easily as it should have probably because I didn't know how to correct an error or find the right item when it went astray.”
Participant E	“I felt the activity tracker did not provide a way to accurately track my activity. TV time, for example, does not mean long term activity as I am constantly up- getting dogs in and out, taking care of my husband, answering the phone, etc.”

^aRepresentative open-ended responses chosen from the 14 respondents.

^bRepresentative open-ended responses chosen from the 21 respondents.

Participant Feedback Related to General Comments About the Time Use App

Participants were asked if they had any comment regarding the app, and these responses also highlighted issues regarding comfort with technology and burden (eg, time). A total of 21 participants completed this open-ended item. Several participants described experiences in which it was difficult or inconvenient

to operate the app due to it not being installed on a personal phone or available in a platform for wearable devices. As presented in [Table 2](#), one participant explained how these limitations made it inconvenient for tracking activity.

Some participants identified barriers to activity tracking as it relates to the Life in a Day app user interface. Specifically, scenarios involving numerous successive activities were often referenced, and participants found it difficult to perform tasks

such as adding or editing activities in these situations. As mentioned before, quantitative data from the survey indicates that older cancer survivors were significantly less likely to agree that it was easy to edit activities. Participants highlighted the need for a more user-friendly interface for individuals with busy lifestyles. Despite the aforementioned limitations with the Life in a Day trial, participants did anticipate positive benefits from utilizing the Life in a Day app.

Discussion

Principal Findings

This mixed-methods study of the Life in a Day time use app provides insight into the acceptability of utilizing mobile apps for activity tracking among breast cancer survivors and advances efforts to address physical inactivity among this population. The Life in a Day app for time-use measurement demonstrated satisfactory acceptability (ie, favorable satisfaction questionnaire ratings), with 77% (30/39) rating it as *Good* or *Very Good*. From our qualitative examination of responses to the satisfaction survey, several themes were identified. Although participants indicated overall satisfaction with the time use app, events involving multitasking or consecutive activities were often portrayed as a barrier to successful activity tracking, and participants made suggestions for helping them remember to change activities within the app (ie, sound prompts). An additional barrier to tracking included the burden of carrying an extra phone due to limited platform availability (ie, Android devices only at time of the study). This was especially relevant in situations involving aforementioned multitasking, and participants suggested the incorporation of reminder prompts or wearable devices might help alleviate difficulties with tracking in these scenarios. Differences in quantitative responses by older participants may have been related to difficulties expressed with the cognitive load burden and app interface.

Our utilization of quantitative data allowed further exploration into characteristics (ie., age, education, frequency of forgetting) that may have contributed to satisfaction survey responses. Although no associations were found regarding education or frequency of forgetting, results from the analyses indicated that age was significantly associated with both perceived ease of editing activities and ease of remembering to log activities. These findings suggest that older cancer survivors may have increased difficulty when engaged in these 2 aspects of mobile activity tracking. Responses to several other elements of Life in a Day were found to have an agreement rate >80% (ie, easy learning to use the app, easy to read, clear navigation, easy to log activities). These responses were not significantly associated with age and highlight strengths of the app perceived by the overall sample rather than younger or older cancer survivors only. Recently, a 2016 study of health intervention delivery modalities among cancer survivors found that age was negatively correlated with preferences for mobile phone apps [29]. However, results from this study suggest that modality preferences may be shifting, particularly among female breast cancer survivors.

To our knowledge, this is the first trial testing the acceptability of a time use app in cancer survivors. Additionally, Life in a

Day goes beyond existing time use-measurement tools such as the previously described computerized MARCA by utilizing a platform for select mobile devices.

Life in a Day also aims to address limitations associated with 24-hour recall by creating opportunities for real-time assessment, although the option for recall assessment could be used if an activity was missed.

However, some relevant ecological momentary assessment (EMA) studies have been conducted. Although EMA can be used to measure time use, it is distinct from the current app in that EMA uses repeated sampling techniques (eg, every 45 min) to measure behavior or experience rather than continuous, ongoing measurement and, thus, may rely more on retrospection. Moreover, EMA is generally used to study specific behaviors of interest (eg, panic attack/s) [30] compared with general time use activities as in this study and gives the Life in a Day app more general, widespread application for assessing lifestyle behaviors.

Moreover, 2 past EMA studies were conducted on specific behaviors (vs general time use) in populations similar to this study (eg, sleep, symptoms, and mood among breast cancer patients receiving chemotherapy [31] and exercise adoption among endometrial cancer survivors [32]). These studies involved longer-term assessments (3 daily assessments for 3 weeks and twice daily assessments for 10- to 12-day periods every 2 months for a total of 6 months, respectively) than this study (5 consecutive days); however, the data collection relied more on retrospection (vs real-time assessment) and occurred via handheld computers (vs mobile phone).

Another 2 EMA studies were conducted in a different population (college students), with 1 work focused on mind wandering [33] and the other on general time use (vs specific behavior/s), like this study [34]. These examinations differed from the prior 2 EMA studies as assessments were conducted via an app on mobile phones/PDAs designed to capture activities in the past hour or 20 min, respectively (involved less retrospection). Comparisons with this study include similar or longer follow-up periods (hourly assessments for 1 week and twice daily assessments for 3 weeks, respectively) and the use of text messages [33] or push notifications with alarms [34] to prompt participant responses. Our study required participant initiation of the app to track time use. Given that some participants in this study requested reminder prompts, however, incorporating this as an optional function could benefit future studies exploring time use among cancer survivors.

Strengths and Limitations

Overall strengths of the trial include the use of innovative technology to provide insights into time use of cancer survivors with generally high rates of physical inactivity. Additionally, our mixed-methods approach allowed for a more in-depth understanding of participant experiences with the Life in a Day app. Moreover, our data can assist with developing interventions to improve acceptability and use among older individuals. Limitations of this study include the use of open-ended questions that may limit the breadth of qualitative data obtained as exemplified by the small number of responses across our 2

open-ended survey items. Nevertheless, data obtained yielded qualitative information that expanded our understanding of the age differences noted, with the quantitative data achieving the purpose desired when using a mixed-methods approach. Our study was also limited by a small sample size and completion of the evaluation after only 5 days of app use. Moreover, limited platform availability at the time of the study (Android phones only) may have restricted the number of participants who downloaded the app on their personal phone, which may limit generalizability to future use as platform availability increases. For those participants unable to download the app, the adoption of an extra phone might have confounded acceptability findings. Furthermore, time spent orienting participants to the app might be considered a limitation of this study, as participants attended one 30-min session before beginning the trial to learn the Life in a Day time-use system. Our findings also might not be generalizable beyond groups meeting the study inclusion criteria (eg, noncancer survivors).

Conclusions and Implications

This line of research explores the acceptability of mobile time-use measurement among breast cancer survivors and has

potential for informing future physical activity intervention development. Although further study is needed to determine usability of the Life in a Day time use app, this study demonstrated acceptability among this population, with survey responses highlighting areas of improvement in which future research should address. Our quantitative analyses indicate that participants generally perceived adding forgotten activities in the app as difficult, regardless of age. This finding suggests an area of improvement relevant to all survivors. This study also has several public health implications. First, such apps require further refinement and testing but will likely provide more accurate time-use data than retrospective surveys and can be used to augment documentation of physical activity recorded by accelerometry. Additionally, such apps could help promote better health in cancer survivors by making them more aware of their habits and providing potential insights into how and when physical activity could be added to their daily life. The integration of such apps could substantially benefit public health, given the rising number of survivors and the large need for physical activity in this population.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Life in a Day phone app evaluation.

[\[PDF File \(Adobe PDF File\), 36KB - cancer_v4i1e9_app1.pdf\]](#)

Multimedia Appendix 2

Life in a Day survey item and percent agreement (N=40).

[\[PDF File \(Adobe PDF File\), 26KB - cancer_v4i1e9_app2.pdf\]](#)

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Abbreviations

EMA: ecological momentary assessment

MARCA: Multimedia Activity Recall for Children and Adolescents

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Original Paper

Development of a Web-based Family Intervention for BRCA Carriers and Their Biological Relatives: Acceptability, Feasibility, and Usability Study

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Abstract

Background: Carriers of breast cancer gene (*BRCA*) mutations are asked to communicate genetic test results to their biological relatives to increase awareness of cancer risk and promote use of genetic services. This process is highly variable from family to family. Interventions that support communication of genetic test results, coping, and offer decision support in families harboring a pathogenic variant may contribute to effective management of hereditary cancer.

Objective: The aim of this paper was to describe the development of the Family Gene Toolkit, a Web-based intervention targeting *BRCA* carriers and untested blood relatives, designed to enhance coping, family communication, and decision making.

Methods: We present findings from focus groups regarding intervention acceptability and participant satisfaction and from a pre-post pilot study with random allocation to a wait-listed control group regarding intervention feasibility and usability.

Results: The Family Gene Toolkit was developed by a multidisciplinary team as a psycho-educational and skills-building intervention. It includes two live webinar sessions and a follow-up phone call guided by a certified genetic counselor and a master's prepared oncology nurse. Each live webinar includes two modules (total four modules) presenting information about *BRCA* mutations, a decision aid for genetic testing, and two skill-building modules for effective coping and family communication. Participants in focus groups (n=11) were highly satisfied with the intervention, reporting it to be useful and describing clearly the important issues. From the 12 dyads recruited in the pre-post pilot study (response rate 12/52, 23%), completion rate was 71% (10/14) for intervention and 40% (4/10) for wait-listed control groups.

Conclusions: Acceptability and satisfaction with the Family Gene Toolkit is high. On the basis of the findings from usability and feasibility testing, modifications on timing, delivery mode, and recruitment methods have been implemented.

Trial Registration: ClinicalTrials.gov NCT02154633; <https://clinicaltrials.gov/ct2/show/NCT02154633> (Archived by WebCite at <http://www.webcitation.org/6yYNvLPjv>)

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KEYWORDS

BRCA families; family-based intervention study; Web-based intervention study; psycho-educational and skills-building intervention study; communication and coping; patient decision-aid; genetic testing

Introduction

Background

Women with germline mutations in the *breast cancer (BRCA) type 1* and *BRCA type 2* genes (hereafter *BRCA*) have a 55% to 70% chance of developing breast cancer and 17% to 59% chance of ovarian cancer by the age of 70 years, where the equivalent lifetime risks in the general population are 12% and 1.3%, respectively [1]. These women also have an increased risk for early cancer onset, before screening recommendations apply, and for triple-negative tumors, that is tumors that test negative for estrogen, progesterone, and human epidermal growth factor *receptor 2* (HER2) and do not respond to hormonal therapy (eg, tamoxifen) or therapies that target HER2 receptors, (eg, herceptin) [2]. Germline *BRCA* mutations are inherited in an autosomal dominant manner; for every *BRCA* carrier, first, second, and third degree relatives have 50%, 25%, and 12.5% risk, respectively, for inheriting the pathogenic variant [3]. The availability of genetic testing for *BRCA* mutations is a significant milestone for effective cancer control, as blood relatives can be tested with almost 100% accuracy [4]. Genetic counseling and testing provide information about available risk management options (eg, screening at a younger age). Testing also confirms the non-inheritance of an identified mutation, preventing unnecessary early-onset screening in true negative relatives [5].

Underutilization of genetic testing among biological relatives indicates that its potential benefits are not communicated effectively [6-10]. Barriers to family communication include lack of understanding of genetic information, often hampering the ability of the family to cope with health threats associated with the pathogenic variant [11]. Lack of communication skills and lack of effective coping strategies (eg, avoidance) inhibit disclosure of test results to relatives [12,13]. Although helping family members learn more about their cancer risk is a leading motivation among women pursuing genetic testing [14,15], positive test results may also generate conflicts. Poor communication about implications of increased cancer risks associated with the pathogenic variant may leave family members unaware of the need for genetic counseling. Poorly informed decisions motivated by anxiety, fear, exaggerated perceptions of risk, together with lack of knowledge often lead to decisional conflict among biological relatives [16-21]. Interventions supporting disclosure of genetic test results and enhancing helpful coping (eg, information seeking) in mutation-harboring families could contribute to more open communication about cancer risks, informed decisions for genetic testing, and better management of hereditary breast and ovarian cancer (eg, prophylactic mastectomy and salpingo-oophorectomy in mutation carriers).

We identified 32 patient decision aids (PtDAs) targeting women who were confirmed mutation carriers or at risk of carrying a

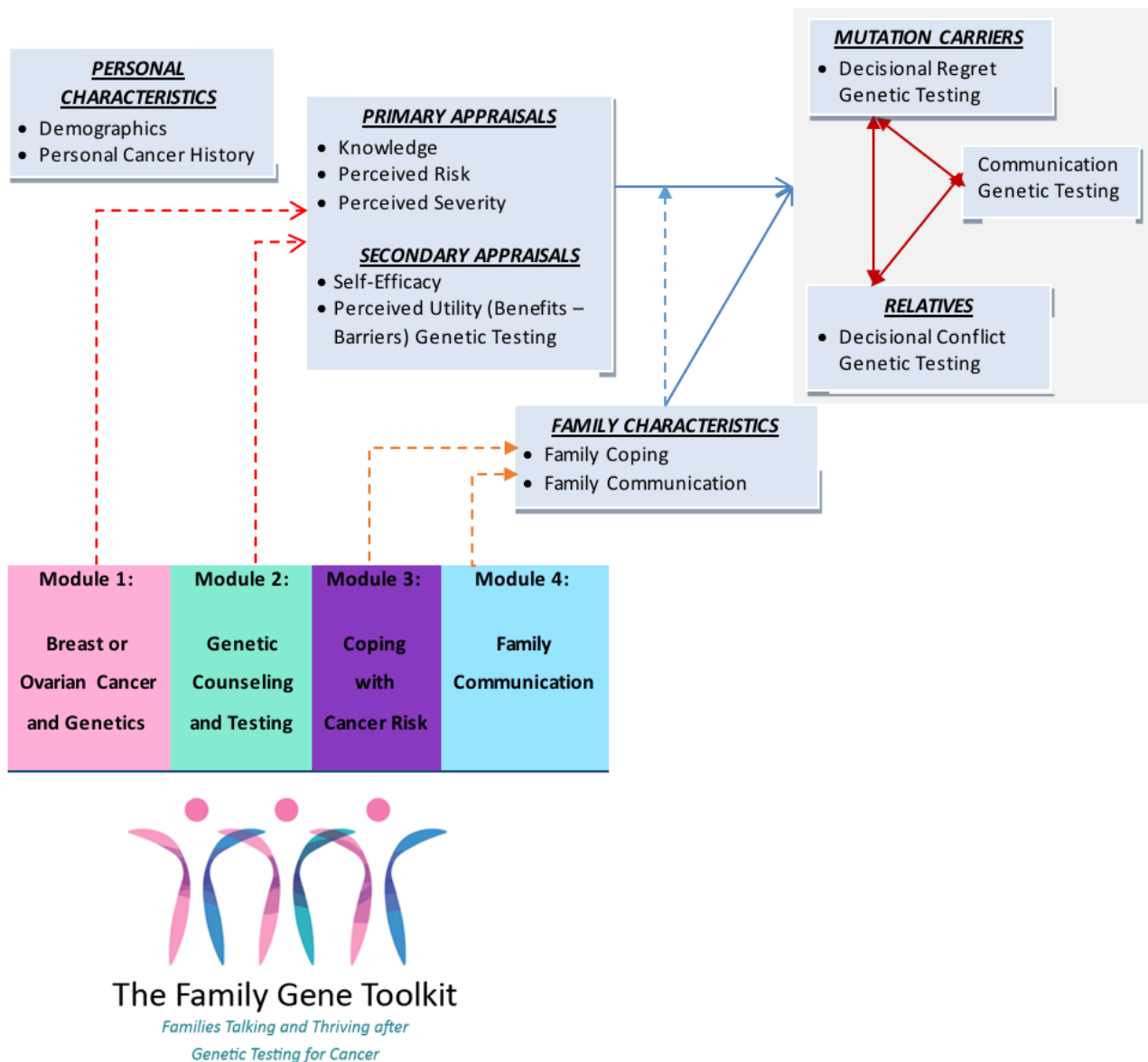
pathogenic variant (Multimedia Appendix 1). These PtDAs have been designed to improve decision making for genetic testing (n=12), decision making for cancer risk management options (n=7), increase understanding of cancer genetics (n=4), enhance active coping and well-being after a pathogenic variant has been identified (n=3), and provide support for disclosing genetic test results to family members (n=6; Multimedia Appendix 1). Commonly examined outcomes were satisfaction with the intervention (n=12), knowledge of breast and ovarian cancer genetics (n=14), intention to use genetic testing and values clarification (n=10), emotional burden (n=12), perceived breast cancer risk and/or risk of carrying a pathogenic variant (n=5), behavioral changes (eg, preventive surgery and exercise; n=6), and family communication for test results (n=4). Outcomes across studies were consistent regarding satisfaction with the PtDA and increased knowledge of breast or ovarian cancer genetics. Findings for other outcomes were often inconsistent.

PtDAs were delivered in several ways, the most common being face-to-face or group-enhanced counseling (n=13), followed by booklet or leaflet or printed material (n=10). Fewer studies used noninteractive CD-ROMs or other computer-based sources (n=5), whereas more recent studies used Web-based, online, interactive modules (n=4). Most PtDAs targeted women after they had been referred for genetic counseling or after confirmation that a *BRCA* mutation had been identified (n=20). Fewer PtDAs targeted biological relatives of mutation carriers or women with strong family history (n=7), and only two PtDAs included both mutation carriers and biological relatives (Multimedia Appendix 1).

BRCA mutations affect the whole family, and genetic testing can cause tensions among family members [22,23]. Most of the above PtDAs targeted only mutation carriers and did not include relatives. Communication of genetic results in families is a two-way exchange that takes place between mutation carriers and relatives. It depends on understanding genetic information, communication skills, and coping competencies of everyone involved. Explaining genetic information to biological relatives is most effective when combined with effective coping strategies for cancer risk (eg, seeking expert advice) and decreasing decisional conflict for genetic testing.

To address these gaps, the specific aims of this study were to develop an interactive, Web-based communication, coping, and decision-support PtDA targeting *BRCA* carriers and biological relatives (Family Gene Toolkit); determine the acceptability of the Family Gene Toolkit and participant satisfaction using focus groups; and examine usability and feasibility in a pre-post pilot study. In this paper, we first present the development of the Family Gene Toolkit and then the methods and results of two sequential studies. The first study involved focus groups that assessed acceptability and participant satisfaction. The second study was a pre-post pilot that assessed usability and feasibility.

Figure 1. Theoretical framework guiding the development of the Family Gene Toolkit.



Development of the Family Gene Toolkit

The development of the Family Gene Toolkit and selection of outcomes were based on the theory of stress and coping [24] adapted to reflect the needs of *BRCA* families. The model integrates bio-psychological family adaptation in genetic illness [25], consequences of genetic testing from a stress and coping perspective [26], and decision making and decision support for genetic testing associated with hereditary breast and ovarian cancer [27]. Stress occurs when primary appraisals of a health problem threaten a person's psychological and physical well-being. Secondary appraisals regarding risks and benefits associated with the health problem and the availability of coping resources can either exacerbate stress or mitigate it. Perceived lack of family support regarding genetic testing may increase stress after a pathogenic variant has been identified, whereas self-efficacy in managing cancer risks may reduce stress. The theoretical framework guiding the study was tested with 168 families at risk for hereditary breast or ovarian cancer [11] (Figure 1).

The Family Gene Toolkit is a psycho-educational and skills-building intervention targeting *BRCA* families. It was developed by a multidisciplinary team, including three expert nurses in psychosocial oncology, communication, and executive cognitive function; a genetic counselor; and a physician expert in *BRCA* mutations. The content was based on empirical findings from a descriptive study with 168 at-risk families [11,28], a meta-analysis of interventions targeting cancer patients and their family caregivers [29], feedback from a psychologist with expertise in decision making for genetic testing who was not involved in the development in the intervention, and feedback from two *BRCA* families (two female carriers and two female relatives). The intervention prototype targets family dyads consisting of a female mutation carrier and a female biological relative.

The Family Gene Toolkit has been designed to address challenges related to the quantity and complexity of genetic information patients are asked to understand and communicate [30,31]. First, understanding the context of hereditary breast

and ovarian cancer (HBOC; eg, of mutation, prognosis, prevention, and treatment) is important for decision making. Second, patients' understanding of the accuracy of the genetic test and the difference between specificity (accurate detection of a variant) and sensitivity (accurately determining that a variant is not present) influences their understanding of how test results will or will not affect decision making about prevention and treatment. Third, genetic diseases are chronic and require ongoing coping and self-management. Patients' ability to self-manage and actively cope with health challenges should be addressed. Finally, patients' values and communication skills are important because of family implications.

Considerations of subsequent family communication about genetic cancer risk and personal values are critical. The four modules of the Family Gene Toolkit embrace the above challenges and cover these topics (Figure 2):

- *Module 1: breast cancer and genetics* provide background information about breast cancer development and the role of heredity (module 1A). It explains the epidemiology and probabilities of the disease with and without a germline *BRCA* mutation. A module for *ovarian cancer and genetics* (module 1B) was developed for ovarian cancer patients. Risks associated with other cancers connected to *BRCA* mutations in both genders, ie, prostate and pancreatic cancers and melanoma, are also presented in module 1.
- *Module 2: genetic counseling and testing* provides decisional support for genetic testing to relatives, including a description of the counseling process, potential risks, benefits, limitations of genetic testing, and possible results. It incorporates formal elements of PtDAs based on the International Patient Decision Aids Standards criteria [32] and patient testimonials about accepting or refusing testing.


- *Module 3: coping with cancer risk* discusses common challenges faced by *BRCA* families, including an overview of different coping styles, the importance of active coping, and practical tips to facilitate active coping with different personal and family challenges. It is designed to enhance active coping and family support concerning hereditary cancer risk and includes narratives from mutation carriers to support these points.
- *Module 4: family communication* presents testimonials about the responsibility to share test results, the importance of open family communication about the mutation, common issues that arise during this process, and practical ways to avoid conflicts. It provides a five-steps training designed to enhance communication skills in family members.

The Family Gene Toolkit is delivered over a period of 4 weeks by two expert clinicians (ie, a certified genetic counselor and a master's prepared oncology nurse) using two live webinars (PowerPoint presentations with live audio) and one brief follow-up phone call. Dyads log in to a password-protected website synchronously (same time on different computers) to attend the live webinars. The first webinar includes modules 1 and 2, facilitated by a certified genetic counselor. The second is offered a week later; it includes modules 3 and 4, facilitated by a master's prepared oncology nurse. Each webinar lasts 60 min (45 min presentation and 15 min for questions and answers). A live webinar was considered the optimal mode of delivery because it enabled real-time face-to-face interaction among family members and expert clinicians, enhancing the credibility of the intervention. Family members could easily access the program from home, which is less costly and more convenient than traveling to a clinical site. Convenience and easy access are essential to disseminate the program more widely in the future [33]. Each participant also receives a 15-min phone call with the genetic counselor and the nurse, tailored to address individual concerns (Figure 3).

Figure 2. Examples from the four modules of the Family Gene Toolkit.

Webinar 1.

Breast Cancer and Genetics




The Family Gene Toolkit

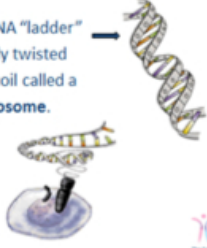
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What is a chromosome?

DNA




The DNA "ladder" is tightly twisted into a coil called a **chromosome**.



Possible genetic test results

Positive for a mutation
A mutation that is definitely linked to cancer was found



Negative for a mutation
No known mutation was found

Inconclusive result

Sometimes a mutation is found, but we do not know if it is linked to cancer.
Testing more family members and additional investigation may help.

DOES THIS MATTER TO ME?

Here are some "PROS" that may help us decide if genetic testing is the right choice for us

	Not at all	Not much	Neutral	A little	A lot
I want to know if I have a damaged gene	0	1	2	3	4
I want to learn more about my cancer risk	0	1	2	3	4
A doctor has advised me to get the test	0	1	2	3	4
I want to take an active role in my healthcare	0	1	2	3	4
I want to know more about my future health	0	1	2	3	4
If positive, I want to manage my cancer risk	0	1	2	3	4
If negative, I will feel relieved	0	1	2	3	4
I want to help my relatives know their cancer risk	0	1	2	3	4
TOTAL					

Webinar 2.

Coping styles

We all use various coping styles

Avoidance

delaying
withdrawing
substance abuse
denying



Where am I?

Active


managing risk
finding support
problem solving
accepting

Coping with family strains

- Children model coping styles from parents
- Men may feel excluded from "women's world"
- Spouses, partners, and family members may not know how to help
- Parents often feel guilt or shame



Family Communication and Genetic Test Results



The Family Gene Toolkit

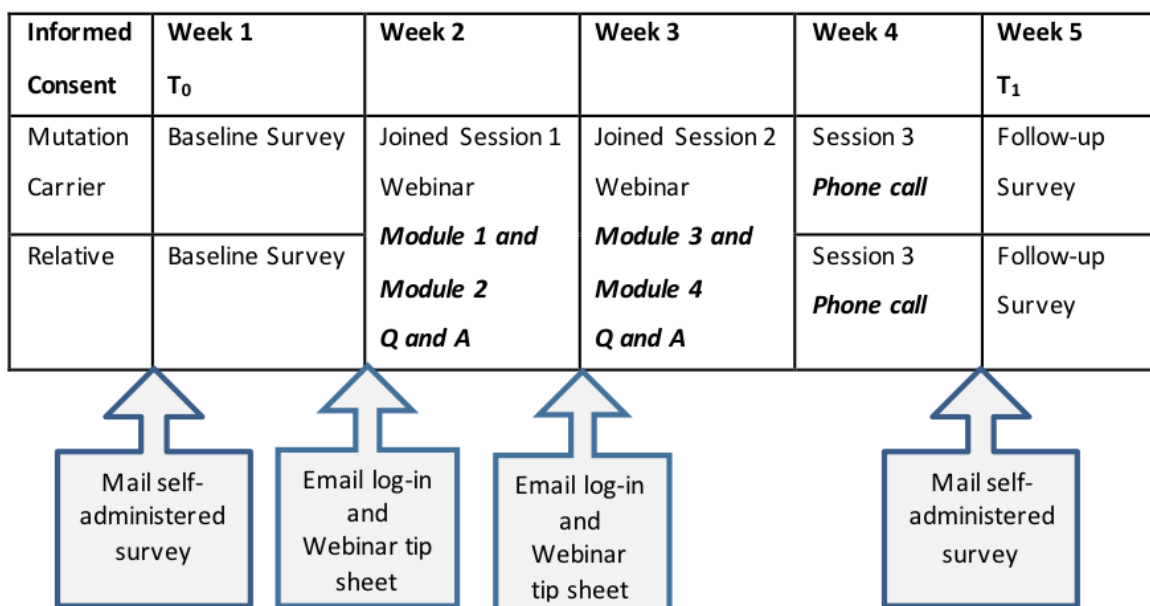
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Family Communication Rubric

Use this tool to help get started with the family communication process. Keep notes for every step of the process.

Step	Question	Your answer
1	Who to tell first?	_____
2	How? Where?	_____
3	When?	_____
4	How will you prepare?	_____
5	What do you think it will happen? • How does it make you feel? • How do you think the other person will react?	_____

Figure 3. Procedures of the Family Gene Toolkit.



Methods

Study 1: Focus Groups to Assess Acceptability and Participant Satisfaction

After developing the prototype modules, focus groups assessed acceptability and patient satisfaction. Focus groups included women who were older than 18 years and were *BRCA* mutation carriers or female relatives (first- or second-degree, or first cousin) who had not previously received genetic testing. The institutional review board (IRB) of a university-affiliated Comprehensive Cancer Center approved the study. Participants were shown a prototype of the Family Gene Toolkit as a PowerPoint presentation in a 2-hour, face-to-face session. Discussions were audiotaped and transcribed *verbatim*. Team members analyzed transcripts for common responses. A 6-item survey assessed intervention acceptability, ease of use, clarity, appropriate length, level of detail, relevance, interest, and satisfaction (Likert scale 1=low to 7=high) [34,35]. Participants rated their overall satisfaction with the content, the extent it could help with communication and decision making, and the format and appearance of the program.

Study 2: Pre-Post Pilot to Assess Usability and Feasibility

Suggestions for improvement from the focus groups were incorporated in the prototype intervention. A pre-post pilot study with random allocation to a wait-listed control group was planned to assess usability and feasibility of the updated Family Gene Toolkit delivered in a webinar format (Multimedia Appendix 2). A different certified genetic counselor and master's prepared oncology nurse were trained to deliver the intervention.

Webinars (PowerPoint presentations with live audio) and phone calls were recorded to assess protocol fidelity. The study was approved by all involved IRBs.

The following sources were used to identify *BRCA* carriers over a period of 18 months: a genetic clinic and the online Clinical

Trial Registration Unit from a university-affiliated Comprehensive Cancer Center, a genetic clinic affiliated with a local tertiary hospital, a local online support group and another study assessing use of genetic services in women with early-onset breast cancer [36]. Similar eligibility criteria applied to mutation carriers and relatives: older than 18 years, identified with a pathogenic *BRCA* variant or female relatives (first- or second-degree, or first cousin) who had not undergone genetic testing, carriers willing to invite one female relative, could read and write in English, and provide consent. *BRCA* carriers self-referred to the study were asked to submit a copy of their test results or sign a release form to ascertain their eligibility with the testing company.

BRCA carriers received an invitation letter from the medical director of the respective clinic and an informed consent form. When phone numbers were available, invitation letters were followed by a phone call 3 to 4 weeks later. Upon receiving the signed consent, a genetic counselor identified eligible relatives from the carrier's family history. Carriers received a letter explaining they could invite a relative of their choice among those included in the list. Once both members of the dyad (ie, *BRCA* carrier and relative) returned a signed consent form, they each received a paper and pencil baseline survey. Upon receipt of the completed survey, the webinars and the 15-min phone calls were scheduled. The dyad received via email a link to the webinar, along with information on how to log in to the website. One week after completing the webinars and the phone call, participants received the follow-up survey. Dyads randomly assigned to the wait-listed control group received the baseline and follow-up surveys 4 weeks apart.

Validated instruments assessed family communication, [37] knowledge of breast cancer risk factors [38] and breast cancer genetics [28], perceived breast cancer risk [39], fear of cancer recurrence [40], decisional conflict [41], coping [42], self-efficacy [43] and intention to undergo genetic testing [44,45]. Access to genetic services was assessed with multiple response questions regarding a provider recommendation, eg,

my doctor said I don't need it; availability of services, eg, clinics are too far away; accessibility of services, lack of transportation; and acceptability of services, eg, I would rather not know if I have a mutation connected to cancer.

Results

Results From Study 1 (Focus Groups)

A purposeful sample of 25 *BRCA* carriers from a genetic risk clinic was invited in the focus groups. Three focus groups were conducted (N=11; 10 mutation carriers and one niece; 44% acceptance rate) to determine the acceptability of the Family Gene Toolkit and participant satisfaction. All 11 participants were white and in the age range of 32 to 60 years (mean age 46, SD 12); most were married or partnered (n=8), college educated (n=9), with an annual family income greater than US \$80,000 (n=6). All 11 participants rated their level of comfort and skills using computers as very high (1=low to 7=high; 6.7 [SD 0.48] and 6.1 [SD 0.32], respectively) and their level of comfort and skills using the Internet as very high (1=low to 7=high; 6.6 [SD 0.52], 6.1 [SD 0.57], respectively).

Participants were highly satisfied with the Family Gene Toolkit (6.80 [SD 0.42]), pleased (6.88 [SD 0.35]), and contented (6.63 [SD 0.52]). The content of each module was rated highly on importance and usefulness and was not confusing or did not make participants feel uncomfortable. Participants also reported high satisfaction with the communication module and the decision aid for genetic testing ([Multimedia Appendix 3](#)). Participants valued the narratives and testimonials used to illustrate relevant content. They also reported that the intervention could reduce a current gap in health care delivery; it was useful and relevant. Satisfaction with the appearance and length of the modules was high. Participants suggested including more information about testing children, how to support relatives who test negative and husbands, and management of cancer risk. They preferred live webinars involving contact with an expert to a website as a more effective educational tool. However, they thought that scheduling could interfere with the success of this approach. When asked about the best time frame to intervene (eg, immediately after the diagnosis), some participants indicated they would prefer the program immediately after they were identified as *BRCA* carriers, and others thought this would be an added burden. There was no consensus on timing ([Multimedia Appendix 4](#)). Information obtained from the focus groups and the content experts was incorporated in the prototype of the intervention.

Results From Study 2 (Pre-Post Test Pilot)

Over 18 months, 82 potentially eligible mutation carriers were identified for the pre-post pilot study. Some mutation carriers

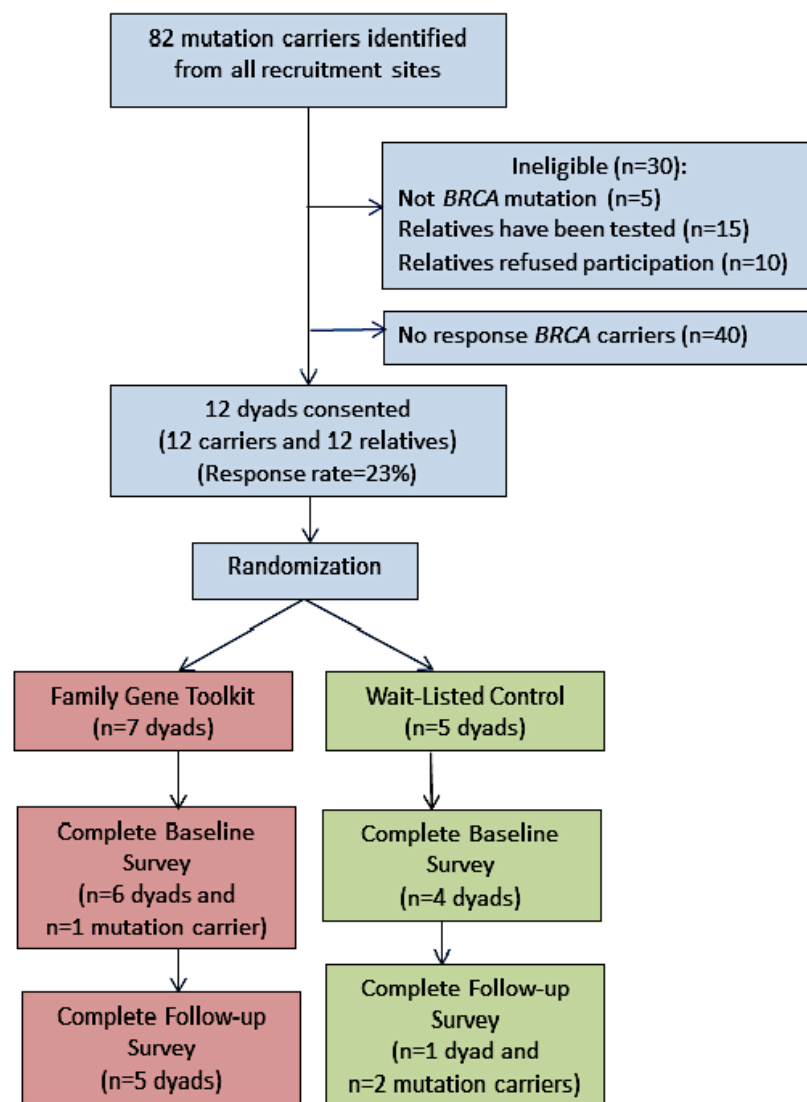
were ineligible to participate (n=30) because they carried another mutation, or because all relatives had been tested or had refused participation. Signed consent forms were returned from 12 mutation carriers (response rate (12/52, 23%) and 12 relatives (12 dyads; n=24). Only first-degree relatives accepted participation (eight sisters; one daughter; one mother). Reasons for relative nonparticipation are unknown as the research team only had direct contact with relatives after they had signed a consent form. Dyads were randomized either to the Family Gene Toolkit (n=7 dyads) or to the wait-listed control (n=5 dyads, see [Figure 4](#)).

A completed baseline survey was returned from 10 dyads (n=20) at baseline. All participants were white, in the age range of 8 to 62 years (mean 41, SD 13); most were college educated (n=16), worked full time (n=14), married or partnered (n=11), and with family annual income greater than US \$80,000 (n=10). Of the 10 *BRCA* carriers (mean years since genetic testing 4.4, SD 3.2), 4 were diagnosed with invasive breast cancer, 3 with ductal carcinoma *in situ*, 1 with ovarian cancer, and 2 with other forms of cancer.

Carriers were older than relatives (49 [SD 7] vs 34 [SD 3], $t_2=2.871$, $P=.01$). A completed follow-up survey was returned from 5 dyads in the intervention group and from 1 dyad and two mutation carriers in the wait-listed control group. Completion rates were 71% (10/14) and 20% (2/10) for the intervention and the control groups, respectively ([Figure 4](#)). Known reasons for withdrawal were scheduling conflicts (n=3 relatives) and pursuing genetic testing during the intervention (n=1 relative).

We assessed family communication, knowledge of breast cancer risk factors, and breast cancer genetics; coping, perceived breast cancer risk, fear of cancer recurrence and decisional regret in mutation carriers, and decisional conflict, self-efficacy, and intention for genetic testing in relatives ([Multimedia Appendix 5](#)). Due to the small sample size, statistical evaluation of intervention effects was not undertaken. However, we evaluated facilitators of genetic testing listed by mutation carriers and relatives. Common facilitators were acceptability of genetic services (eg, *I wanted to know more about my future cancer risk*; n=8), followed by accessibility of services (eg, *my medical insurance covered the cost of the test*; n=4), and availability of services (eg, *the clinic was close to home*; n=2). Barriers for genetic testing for relatives were related to accessibility of genetic services (eg, *I can't get time off work*; n=4), followed by acceptability of testing (eg, *I would rather not know if I have a mutation connected to cancer*; n=3), and availability of services (eg, *genetic clinics are too far away*; n=1).

Figure 4. Consolidated Standards of Reporting Trials (CONSORT) diagram for mutation carrier and relative recruitment and random assignment to Family Gene Toolkit versus wait-listed control group. *BRCA*: breast cancer genes.



Discussion

Principal Findings

This paper presents the development and pilot testing of a psycho-educational and skills-building intervention targeting *BRCA* families. The Family Gene Toolkit is designed to provide comprehensive support to *BRCA* families and addresses the challenges faced by mutation carriers and untested relatives. It is a theory-based intervention leveraging the core factual knowledge of biology and medicine and the nondirectionality of genetic counseling. The program also leverages nursing expertise helping patients with a life-threatening diagnosis and addresses needs for family cohesion during times of adversity. Acceptance of the intervention and high participant satisfaction suggests that the Family Gene Toolkit appears to have the potential to meet the needs of these families. However, assessment of acceptability, usability, and feasibility indicated that the method of intervention delivery needed some fine-tuning. The information obtained from the pre-post usability and feasibility studies assisted with further intervention development and testing.

Acceptability of the Intervention: Participant Satisfaction Was High

Focus groups valued the Family Gene Toolkit. Participants were highly satisfied with the intervention and reported it was a much-needed service. They were highly satisfied with modules addressing coping and family communication, usefulness, and the completeness of information. Satisfaction was also high with module appearance, formatting, and the quotes used to illustrate pertinent content. These levels of satisfaction suggest that *BRCA* families valued support for decision making, coping, and family communication, in addition to the support they receive from current health care services.

Enhancing Usability: The Intervention Is Needed When the Breast Cancer Mutation Is Identified.

Information from about 35% of mutation carriers indicated that “timing” of intervention influenced the usability of the Family Gene Toolkit. Many mutation carriers were not eligible to participate because all their relatives had already been tested. Of the relatives who participated in the pre-post pilot study, none had undergone genetic testing even though the mutation

was diagnosed on average 4.4 years previously in their family. Relatives reported that genetic testing was not their priority and that they would rather not know if they had a cancer-predisposing mutation. Relatives who did not accept participation in the study could have possibly refused genetic counseling several times in the past and perhaps were not open to an intervention for family communication, coping, and decision support. These observations suggest that the optimal time for delivering the Family Gene Toolkit is shortly after a positive test result. Future sessions should probably be planned between 3 to 6 months after the *BRCA* mutation is identified. Moreover, prospective recruitment of newly diagnosed *BRCA* families will help identify more mutation carriers whose relatives were not tested and may increase acceptance among relatives who are more open to receiving expert information.

Enhancing Feasibility: The Intervention Should Be Delivered as an Asynchronous Website

PtDAs employ various methods for development and evaluation, making comparisons very difficult [46,47]. However, very few PtDAs were developed as interactive Web-based platforms. The growing demand for genetic services makes tele-genetics an attractive option for increasing access, equity, and cost-effectiveness [48]. Technology-enabled genetic counseling is an acceptable option among patients [49], while costs are half those of traditional face-to-face consultations [50]. Web-based PtDAs match face-to-face consultations in both educating patients about genetic screening and decreasing decisional conflict [51,52].

Focus groups indicated that live webinars with certified specialists were credible and reliable sources of information and could provide tailored answers to family members. However, the live webinars have to accommodate participants' schedules, a significant challenge because of differences in lifestyles and time zones, which in turn affected the feasibility of the intervention. Reconfiguring the Family Gene Toolkit as an "asynchronous" website (ie, participants log in on their own without a live presentation) will also address the issue of optimal timing for intervention delivery by allowing mutation carriers and relatives to access the intervention when they feel ready to discuss the mutation with their family. This will give the families time to consider the decision-making process independent of a specific appointment.

Reconfiguration of the delivery mode has to capture the high relevance of a "live" information-providing session along with ease of using the Web. Two possible approaches for an asynchronous website are envisioned. A targeted version involves recordings of the two webinars and provides all participants with the same information. This approach can be efficacious in increasing knowledge about cancer genetics [53]. A tailor-made approach involves an interactive website that provides information relative to cancer diagnosis, relationship of relative to the mutation carrier, etc. This approach, although more costly to develop initially, was more efficacious with another family- and Web-based intervention [54].

Enhancing Recruitment: Personal Contact to Mutation Carriers and Relatives

Although we have successfully used the same recruitment method (patient recruiting relative) in our prior studies targeting women completing genetic testing and young breast cancer survivors [11,14,55], the usability and feasibility study indicated that recruitment of mutation carriers and relatives for a family-based intervention requires personal contact and follow-up phone calls. The pre-post pilot study indicated that personal contact with mutation carriers is a necessary first step to assess their eligibility to participate in the Family Gene Toolkit (ie, confirmed *BRCA* mutation, with not all relatives having been tested). Second, the intervention can help them prepare how to suggest family participation in an intervention study with their relative and help minimize relative refusal rate. Enhanced collaboration with clinicians and clinical settings is expected to help increase participation in a family-based intervention.

Limitations

The prototype of the Family Gene Toolkit was tested with a homogeneous sample of white, middle to upper class women, recruited from a midwestern US state. Its acceptability and patient satisfaction cannot be guaranteed with diverse and minority families and families from lower socioeconomic status. Recruitment rate among carriers and relatives was lower than expected possibly because of delayed contact (ie, average time postgenetic testing for mutation carriers was 4.4 years, and most of the biological relatives had already undergone genetic testing). Moreover, relatives were significantly younger than mutation carriers, and they may have had specific needs that were not addressed during the recruitment process. Young women at risk of hereditary cancer often have heightened perceptions of risk, chronic depression, and anxiety [56-58], which may interfere with their willingness to participate in the study. Finally, in the prototype model of the Family Gene Toolkit, we focused on *BRCA* pathogenic variants, although panel testing has identified multiple genes associated with hereditary breast and ovarian cancer. *BRCA* mutations are most commonly associated with HBOC. We developed the prototype addressing the most common pathogenic variants to examine whether this was helpful to mutation carriers and relatives. Modifications include addressing other pathogenic variants and tailoring the Family Gene Toolkit to individuals with other types of cancer and to specific needs of younger women.

Conclusions

Expanding genetic care has created a need for easy access to this information. Advances in technology are followed by an increase in Web-based health interventions, under the assumption that they provide easy and convenient access to this specialized information [33,59]. Communicating hereditary cancer risks at the familial and professional level poses several challenges both at the medical and social level and requires interprofessional collaboration. The Family Gene Toolkit, though it is not the only PtDA targeting *BRCA* families, addresses the needs of the family as the unit of care. It leverages expertise of a multidisciplinary health care team, which is

increasingly recognized as a necessary requirement to address the complex needs of *BRCA* families at the individual, societal, and health policy level. The Family Gene Toolkit is a sustainable Web-based PtDA that can help optimize health care delivery and can greatly contribute to personalized health care.

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Authors' Contributions

MCK assisted in recruiting mutation carriers, MDHHS IRB Log #201304-11-EA. Jacquelyn Campbell, PhD, RN, FAAN (School of Nursing, Johns Hopkins University) and Afaf I Meleis, PhD, DrPS (Hon), FAAN, LL (School of Nursing, University of Pennsylvania) provided mentoring to MCK during the Robert Wood Johnson Foundation–Nurse Faculty Scholars Program.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Patient decision aids for *BRCA* mutation carriers and biological relatives.

[[PDF File \(Adobe PDF File\), 551KB - cancer_v4i1e7_app1.pdf](#)]

Multimedia Appendix 2

Pre-post pilot study design.

[[PDF File \(Adobe PDF File\), 328KB - cancer_v4i1e7_app2.pdf](#)]

Multimedia Appendix 3

Satisfaction with the Family GeneToolkit- Focus groups short survey.

[[PDF File \(Adobe PDF File\), 351KB - cancer_v4i1e7_app3.pdf](#)]

Multimedia Appendix 4

Acceptability of the Family Gene Toolkit - Focus groups interview questions.

[[PDF File \(Adobe PDF File\), 329KB - cancer_v4i1e7_app4.pdf](#)]

Multimedia Appendix 5

Instrument scores in the pre-post pilot study.

[[PDF File \(Adobe PDF File\), 331KB - cancer_v4i1e7_app5.pdf](#)]

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Abbreviations

- BRCA:** breast cancer genes
- HBOC:** hereditary breast and ovarian cancer
- HER2:** human epidermal growth factor receptor 2
- IRB:** institutional review board
- PtDA:** patient decision aid

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