JMIR Cancer

Impact Factor (2024): 3.3
Volume 6 (2020), Issue 1 ISSN 2369-1999 Editor in Chief: Naomi Cahill, PhD, RD

Contents

Original Papers

Original Paper

A Novel Mobile Phone App Intervention With Phone Coaching to Reduce Symptoms of Depression in Survivors of Women's Cancer: Pre-Post Pilot Study

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Abstract

Background: Psychological distress is a major issue among survivors of women's cancer who face numerous barriers to accessing in-person mental health treatments. Mobile phone app–based interventions are scalable and have the potential to increase access to mental health care among survivors of women's cancer worldwide.

Objective: This study aimed to evaluate the acceptability and preliminary efficacy of a novel app-based intervention with phone coaching in a sample of survivors of women's cancer.

Methods: In a single-group, pre-post, 6-week pilot study in the United States, 28 survivors of women's cancer used iCanThrive, a novel app intervention that teaches skills for coping with stress and enhancing well-being, with added phone coaching. The primary outcome was self-reported symptoms of depression (Center for Epidemiologic Studies Depression Scale). Emotional self-efficacy and sleep disruption were also assessed at baseline, 6-week postintervention, and 4 weeks after the intervention period. Feedback obtained at the end of the study focused on user experience of the intervention.

Results: There were significant decreases in symptoms of depression and sleep disruption from baseline to postintervention. Sleep disruption remained significantly lower at 4-week postintervention compared with baseline. The iCanThrive app was launched a median of 20.5 times over the intervention period. The median length of use was 2.1 min. Of the individuals who initiated the intervention, 87% (20/23) completed the 6-week intervention.

Conclusions: This pilot study provides support for the acceptability and preliminary efficacy of the iCanThrive intervention. Future work should validate the intervention in a larger randomized controlled study. It is important to develop scalable interventions that meet the psychosocial needs of different cancer populations. The modular structure of the iCanThrive app and phone coaching could impact a large population of survivors of women's cancer.

(JMIR Cancer 2020;6(1):e15750) doi:10.2196/15750

KEYWORDS

mobile apps; mental health; mHealth; women; cancer survivors

Introduction

Background

A large body of literature demonstrates that survivors of cancers that almost exclusively affect women (ie, those who have completed treatment for breast, endometrial, and gynecologic cancers) have large and unmet psychosocial care needs [1-5]. Studies have found that during primary cancer treatment, the emotional needs of patients are often neglected [6-8], and this pattern continues into survivorship. Depression, which affects between 10% and 25% of survivors of women's cancer [4,9,10], is perhaps the most studied psychosocial effect of cancer treatment. For example, among individuals with breast cancer, those who report a clinical level of depression report 2½ times as many unmet psychosocial needs compared with those without significant depression [2]. Untreated symptoms of depression can lead to poor quality of life [11], increased mortality [12,13],

and high economic costs [14]. Furthermore, studies find that depression is closely linked with other health behaviors, such as sleep disturbance and difficulty in regulating emotions [15,16]. It is, therefore, imperative to develop and test effective, scalable, and accessible psychosocial interventions to meet the growing needs of survivors of women's cancer.

Interventions that emphasize skills acquisition, such as cognitive behavioral therapy and acceptance-based therapies (eg, mindfulness), have been shown to effectively reduce symptoms of depression in cancer survivors [17-20]. However, numerous barriers prevent them from receiving adequate in-person treatment [21]: high financial cost [22], high time investment [23], social stigma [24], and a severe shortage of trained psychotherapists [25-27]. Combined, these barriers lead to almost half of the survivors to report unmet psychosocial care needs [3,8,28-31]. For example, although psychosocial interventions have been found to reduce depressive symptoms for early stage breast cancer patients [32,33], more recent research has identified the need to address depression symptoms up to 5 years following primary cancer treatment [34,35].

Mobile phone apps are frequently cited as a way of extending cost-effective care [36,37]. The percentage of US adults who own an internet-enabled mobile phone has steadily increased from 35% in 2011 to 77% in 2018, including 73% of US adults aged 50 to 64 years [38]. Numerous studies have demonstrated the efficacy of app-based interventions in reducing mood-related symptoms in the general population [37,39-42]. App-based interventions decrease barriers associated with traditional in-person interventions for cancer survivors because treatment is affordable, can be made more readily available by removing logistical issues (ie, travel and scheduling), can offer an efficient use of time (ie, no delays to begin treatment and self-pacing), and is no longer limited by proximity to available psychotherapists. However, despite high demand from survivors of women's cancer for receiving care through digital means [43-46], few interventions specifically target mental health and well-being in this rapidly growing population. Empirical reviews of apps in cancer [47,48] fail to identify any publicly available mental health interventions for survivors of women's cancer.

Coaching to Enhance Engagement to Digital Interventions

Despite the promise of mobile interventions to increase scalability and access to mental health care, engagement is a major problem [49]. Engagement is necessary for treatment success, as a dose-response relationship has been observed in psychological treatment broadly [50] and in digital health interventions [51,52]. Numerous studies have found that poor engagement is a widespread concern across digital interventions, leading to dropout rates often as high as 50% [49,53-55], and meta-analyses have found that dropout rates are particularly high among depressed participants [56-58]. Similar rates of dropout have been noted in Web- and app-based interventions for cancer populations as in the general population [59-61]. Thus, despite the need for app-based interventions to reduce the impact of symptoms of depression in survivors of women's cancer, existing interventions have not been designed to optimize engagement, which can restrict outcomes.

A growing amount of work has evaluated human support strategies to promote engagement, such as phone coaching [39,62,63], that may be particularly useful for promoting engagement among women. Studies have found that compared with men, women use health services more [64], prefer mediated social interaction [65], and tend to favor dyadic social relationships [66]. These findings indicate that integrating human support with an app-based intervention could be an effective strategy to increase engagement among survivors of women's cancer. The Efficiency Model of Support [63] is a model for how to provide a provision of support to users of a digital health app. Specifically, the model highlights 5 ways that users might fail to benefit from a health app. These include issues related to the usability of the program, fit of the app to meet one's needs, knowledge of how to use the program, and implementation failures [63]. On the basis of model, the role of the coach is to support users in using and benefiting from an app-delivered intervention, by identifying and targeting factors (eg, lack of understanding of how to use the app or how the app can improve daily life) that may lead users to fail to benefit from the program, and providing support to overcome those factors. This study paired an app intervention with phone coaching to enhance engagement and thus promote outcomes.

This Study

In a sample of survivors of women's cancer in the United States who completed their active cancer treatment within the last 5 years, the primary goals of this study were to evaluate the acceptability and preliminary efficacy of a novel app-based intervention (iCanThrive) over a 6-week period and to inform the sample size for a larger trial [67]. The iCanThrive app was designed as a clinical intervention that teaches skills for coping, reducing distress, and promoting strengths (see description below in section titled iCanThrive App). We define acceptability similar to others [68] as a multifaceted construct that pertains to how much users of an intervention find it to be appropriate and the degree to which it meets their needs [68]. In this study, acceptability was evaluated through the user experience domains of usefulness, ease of use, ease of learning, and satisfaction of using the app. Symptoms of depression were assessed at baseline, 6 weeks after the intervention (postintervention), and 4 weeks after the intervention period (4-week follow-up). Owing to the positive relationship between depression and sleep disturbance [16] and because iCanThrive teaches skills for regulating affect, additional outcomes assessed were self-reported sleep disturbance and emotional self-efficacy. Acceptability data were collected at the postintervention assessment.

Methods

Overview

This was a single-group, 6-week, pre-post pilot study design among survivors of women's cancer in the United States who completed their active cancer treatment in the last 5 years. The decision to use a 6-week duration was based on the duration of brief face-to-face psychotherapy (typically 6-8 weeks) as well as prior reviews of mobile health (mHealth) studies finding that the duration of app-based interventions ranges between 6 days

and 8 weeks [69]. Acceptability was assessed at the postintervention assessment. Self-reported symptoms of depression, emotional self-efficacy, and sleep disturbance were administered at baseline, postintervention, and 4-week follow-up.

Participants and Procedure

A total of 28 survivors of women's cancer (mean age 59.6 years, SD 10.5) were recruited from a community research cohort in the United States that included patients from 2 large regional cancer centers in the United States with catchment areas serving rural and nonrural communities. Women aged older than 18 years were eligible to join the cohort if they had received a diagnosis of stage 1, 2, or 3 breast, cervical, ovarian, or endometrial/uterine cancer and if they were more than 6 months from completing their active cancer treatment (surgery, chemotherapy, or radiation). Women in this study reported being diagnosed with the following types of cancer (they could choose more than 1): breast (n=13), bladder (n=1), cervical (n=1), ovarian (n=7), and endometrial (n=9). On average, the duration between their last cancer treatment and the beginning of study enrollment was 2.5 years (range 1.4-3.9 years). Most participants self-identified as white (26/28, 94%), followed by black (1/28, 3%) and multiracial (1/28, 3%). Rural-urban commuting area (RUCA) codes version 2.0 from the US Department of Agriculture were used to evaluate the geographic characteristics of the sample. RUCA codes range from 1 (most metropolitan) to 10 (most rural). Participants hailed from a range of locations, with 64% (18/28) living in an area characterized as metropolitan (RUCA 1-3), 18% (5/28) living in an area characterized as micropolitan (RUCA 4-6), and 18% (5/28) living in an area characterized as rural (RUCA 7-10).

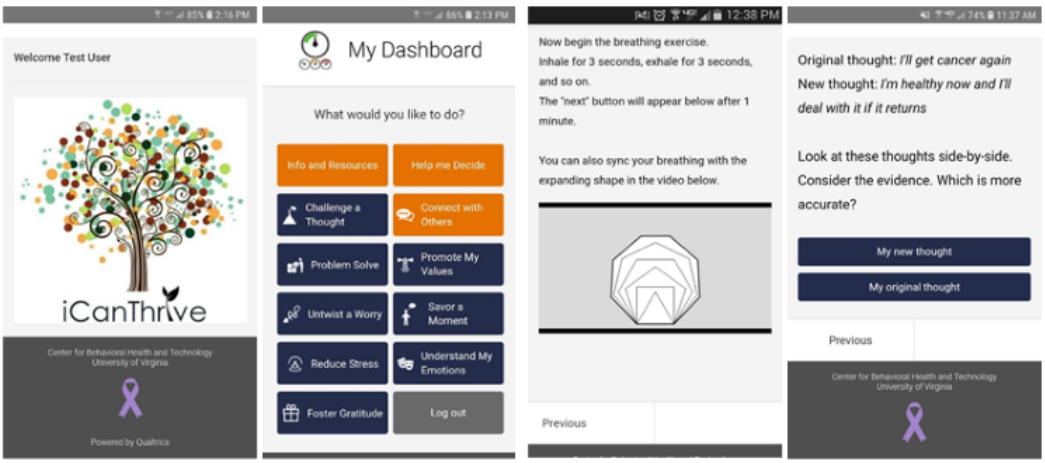
A target sample size of 30 was chosen based on sample size recommendations from prior work for a pilot study [67]. This sample size is sufficient for detecting a large effect size for change in depression symptoms, at 80% power, although 1 purpose of conducting this pilot study was to collect initial data to inform a sample size calculation for a larger trial [67]. To reduce barriers for participation, inclusion criteria were limited to the following: (1) woman cancer survivor who completed their active cancer treatment in the last 5 years, (2) aged at least 18 years, and (3) owned a mobile phone or is willing to carry one around if provided. As this pilot study evaluated a brand-new app intervention, given the resource demands of prescreening individuals for depression, a decision was made to recruit an unselected sample of cancer survivors who expressed an interest in participating in the study.

Mailers containing a brief information flyer were sent to a total of 174 survivors of women's cancer in the registry, followed by an email inquiry about their potential interest. Of these, 28 women responded, and all were deemed eligible and enrolled in the study. Interested individuals were asked to review and sign the consent form on a secure Qualtrics Web page. Research staff described the aims of the study and reviewed the study timeline with participants before they signed the consent. Participants then completed a Web battery of questionnaires and scheduled a coaching call (designed to last 30 min) to take place sometime within the next week, which marked the initiation of the intervention. After 6 weeks (postintervention), participants completed another battery of self-report measures online. Finally, participants completed the same battery of self-report measures 4 weeks after the intervention period. They also provided feedback about their experiences of using the app and coaching. Participants were compensated with a US $50 gift card for providing feedback. The data that support the findings of this study are available on reasonable request from the corresponding author.

iCanThrive App

The iCanThrive app was available for public download on the Google Play Store in the United States. The app is user initiated, meaning that users launch and use the app when and where they desire. On launching the iCanThrive app, users are presented with a brief splash screen that contains the app logo and a lavender ribbon that is commonly used to raise awareness of cancer survivors (Figure 1, top left), before automatically directing them to the *My Dashboard* screen (Figure 1, top right). The depiction of a flourishing tree was chosen as the app logo to signify growth and skills acquisition as a means for empowering survivors of women's cancer [70].

Figure 1. Screenshots of the iCanThrive app.



The core functionality of the app is composed of 8 exercise modules. Each module focuses on a specific aspect of mental health and well-being drawn from basic tenets of cognitive behavioral therapy (eg, reducing worry and problem solving), acceptance-based therapies (eg, mindfulness and emotional awareness), and positive psychology (eg, fostering gratitude and savoring positive experiences). See Table 1 for a description of the 8 iCanThrive modules and their objectives. Selecting a module immediately initiates an interactive exercise that guides the user through each step. For example, if a user selects the *Challenge a Thought* module from the *My Dashboard* screen, they are guided through an interactive exercise that leads them through the steps of writing down a negative or distorted recurring thought, determining what class of negative thought it falls under, and ultimately generating a new, alternative thought (Figure 1, bottom right). If a user selects the *Reduce Stress* module, they can engage in a diaphragmatic breathing exercise that presents them with a 1-min triangle breathing video they can use to synchronize their breath (Figure 1, bottom left). Users also complete a distress thermometer to assess change in psychosocial distress before and after completing the exercise. At the end of each module, users are given an option to log out of the app or navigate back to the *My Dashboard* screen. Exercises were designed to be completed within 2 min and require few instructions to complete.

Table 1. Description of iCanThrive modules and their objectives.

Module	Objective
Challenge a Thought	Enhances the ability to identify and challenge distorted thinking patterns. Guides users through a cognitive restructuring exercise.
Problem Solve	Promotes problem-solving skills. Users are led through an exercise that identifies ways to reach a goal while weighing the pros and cons of each strategy.
Untwist a Worry	Provides an interactive exercise to decrease worry. Users are led to consider the actual probabilities and costs of negative events happening and strategies to cope.
Reduce Stress	Increases relaxation skills. Users can choose to listen to short guided mindfulness audios or engage in an interactive diaphragmatic breathing exercise.
Foster Gratitude	Promotes a grateful outlook. Users are prompted to identify things they are grateful for and how to acknowledge them in daily life.
Promote My Values	Promotes awareness of values and ways to strive for fulfilling values in daily life.
Savor a Moment	Increases positive affect by leading user to recall and recount past positive experiences.
Understand My Emotions	Enhances emotional awareness. Users are led through an exercise to identify the emotions they are experiencing, the causal factors involved, and how their emotions are linked to their thoughts and behaviors.

The app contains additional functions that (1) allow users to learn more about the psychological constructs the app targets and connect users to trusted third-party sites (eg, American Cancer Society main website) that contain information about cancer support services and other electronic sources, (2) allow users to connect with other iCanThrive users through an anonymous discussion board, and (3) recommend 1 of the 8 exercise modules based on a series of questions that assess the user's emotional and psychological state. Users were not specifically required to access these functions during the intervention period. As these functions were peripheral to the 8 exercise modules, their utilization is not reported. Each instance of an app launch was automatically logged and stored in the system supporting the app. This enabled us to track the total number of app launches across the study period.

Phone Coaching

A manualized and detailed coaching protocol was developed based on the Efficiency Model of Support [63]. Similar coaching protocols have been implemented in other studies evaluating mental health apps [39]. The goals of coaching, which were listed in the coaching manual, are to address usability issues, increase engagement with the app, promote fit by assessing cancer survivors' needs, promote knowledge of the skills found in the app, and encourage implementation of the skills in daily life [63]. Usability concerns include issues related to the usability of the intervention, fit of the intervention tool to one's needs, knowledge of how to use the intervention, and implementation failures. The coaching manual provided a structure to coaching calls, including specific language to use and questions to ask. The structure that was prescribed by the coaching manual enabled coaches to methodically discuss each of the coaching goals. Coaches were instructed to focus on app-related issues and to refrain from doing more traditional counseling with participants. Participants were explicitly told that their coach is not trained in counseling or crisis management. An initial 30-min coaching call focused on orienting participants to downloading and using the app, setting expectations of the coach's role, assessing how the app may meet participants' needs, and building rapport. Participants were told that they could contact coaches at any time with any app-related questions via email or phone. Following the initial coaching call, participants received a text message (via Qualtrics Short Message Service tool) every week to remind them to try 2 new exercise modules in the app. Overall, 2 coaches with a bachelor's degree were trained and monitored by the lead author (PC). Coaches received a detailed coaching manual and attended weekly supervision meetings throughout the duration of the trial. Finally, an unstructured 5-min phone call 4 weeks after the initial coaching call served as a check-in to make sure that participants did not have any lingering concerns or questions.

Self-Report Measures

Psychosocial Outcomes

Depression

The Center for Epidemiologic Studies Depression Scale (CES-D [71]), 10-item version [72], was used to assess for symptoms of depression. The CES-D-10 is a well-validated and accepted measure of symptoms of depression in cancer populations [73,74]. Participants respond (0=rarely or none of the time and 3=all of the time) to 10 items that assess symptoms related to depression (eg, *I felt lonely* and *I felt depressed*). Participants are asked to base their responses on how they have felt over the past week. A cutoff score of 10 or greater, from a possible score range of 0 to 30, has been used to indicate a clinically significant level of depression in older adults [72].

Emotional Self-Efficacy

The Patient-Reported Outcomes Measurement Information System (PROMIS [75]) Self-Efficacy for Managing Emotions subscale (version 1.0, Short Form 4a) was used. PROMIS scales are well validated and widely used in health research. Participants respond (1=I am not at all confident and 5=I am very confident) to 4 items that assess behaviors related to emotion regulation and self-management (eg, *I can handle negative feelings* and *I can find ways to manage stress*). Scores range from 1 to 20. Consistent with PROMIS scoring recommendations, raw summed scores were converted into *t* scores for analyses, with higher scores indicating greater emotional self-efficacy.

Sleep Disturbance

The PROMIS [75] Sleep Disturbance subscale (version 1.0, Short Form 4a) was used to assess sleep. Participants respond (1=not at all and 5=very) to 4 items that assess sleep quality and related behaviors (eg, *My sleep was refreshing* and *I had difficulty falling asleep*). Scores range from 1 to 20. Higher scores indicate greater sleep disturbance. Raw summed scores were converted into *t* scores for analyses.

User Experience

The USE [76] short form was used to examine the usability and satisfaction of the iCanThrive app. It is composed of 21 items that assess user experience (eg, “I would recommend it to a friend,” “It is easy to learn to use it,” and “It is simply to use”), which comprise the domains of Usefulness, Ease of Use, Ease of Learning, and Satisfaction. Items are scored on a 7-point Likert scale (1=strongly disagree and 7=strongly agree). The USE measure is a well-validated scale that is commonly used to evaluate the user experience of mHealth interventions [77,78]. Moreover, 10 additional items were used to assess aesthetic appeal of the app, concerns about data privacy, usefulness of coaching calls, the degree to which iCanThrive meets a need for survivors of women’s cancer, and whether users would, in theory, be interested in being a coach for other survivors of women’s cancer. Participants rated each item on a 5-point Likert scale (1=not at all and 5=very). Table 2 contains the 10 additional items and their descriptive statistics.

Table 2. Feedback items (scale ranged from 1 to 5) and descriptive statistics (n=19).

Item	Values
1. How satisfied are you with the iCanThrive program in general? mean (SD)	4.06 (1.0)
2. How much did you like the way the iCanThrive program looked? mean (SD)	4.33 (0.69)
3. How much did the program keep your interest and attention? mean (SD)	3.56 (1.25)
4. How good of a fit was the program for you? mean (SD)	3.50 (1.34)
5. How worried were you about your privacy in using iCanThrive? mean (SD)	1.33 (0.69)
6. How likely would you be to continue using the program on your own? mean (SD)	3.00 (1.37)
7. How useful were the coaching phone calls in using the app? mean (SD)	4.22 (0.94)
8. How useful were the text message reminders in using the app? mean (SD)	4.13 (1.31)
9. How much do you think the iCanThrive program meets a need for women cancer survivors? mean (SD)	4.06 (1.21)
10. Would you be interested in being an iCanThrive coach for other women cancer survivors? (yes/no; N=19), n (%)	Yes=9 (47); no=10 (53)

Data Analysis

Outcome data were stored in a secured Qualtrics server for highly sensitive data. Analyses were performed in SPSS version 25.

Study adherence and app usage were analyzed using descriptive statistics. A per-protocol analysis approach was adopted using paired *t* tests to analyze whether the use of iCanThrive was associated with changes in psychosocial outcomes (ie, depression, emotional self-efficacy, and sleep disturbance) before versus after the intervention period. Paired *t* tests were also used to examine whether there was a significant difference in psychosocial outcomes from baseline to the 4-week follow-up. User experience data were analyzed descriptively by obtaining means and standard deviations.

Results

Study Adherence and App Usage

Of 28 cancer survivors, 20 (71%) completed the postintervention assessment, and 19 cancer survivors completed the 4-week follow-up assessment. Of the 8 individuals who dropped out of the study, 5 did not engage in the initial coaching call and, therefore, did not initiate treatment, and 3 individuals lost

contact after completing the coaching call. Thus, of 23 cancer survivors who initiated treatment, 20 (87%) completed the postintervention assessment, and 19 (83%) completed the 4-week follow-up assessment. The iCanThrive app was launched a median of 20.5 times (mean 23.2, SD 16.8; range 1-59; IQR=25) over the 6-week intervention period, which is generally higher than other apps that have produced significant improvements in mental health outcomes [79,80]. The median duration of use per app launch was 2.1 min. A total of 3 participants requested additional contact with coaches during the course of the study. Of those, 2 participants wanted to clarify the timing of when they should try new exercise modules, and 1 participant asked if they could tell a friend about the app.

Psychosocial Outcomes

Table 3 contains descriptive statistics of psychosocial outcomes. There was a significant reduction in symptoms of depression from baseline to postintervention (t19=2.22; *P*=.04; 95% CI 0.08 to 2.72). Despite survivors reporting a lower level of depression symptoms at the 4-week follow-up than at baseline, this effect did not reach significance (t16=0.82; *P*=.42; 95% CI −0.93 to 2.11). There was no significant difference in symptoms of depression from postintervention to the 4-week follow-up (t18=1.13; *P*=.27; 95% CI −0.63 to 2.11). Among those who completed the 6-week intervention (n=20), at baseline, a total of 6 individuals had depression scores at or above the CES-D-10 cutoff (≥10) for clinically significant depression. At postintervention, 1 individual was above this threshold. At the 4-week postintervention follow-up, a total of 3 individuals were above this threshold.

Table 3. Means and standard deviations of psychosocial outcomes at each time point.

Outcome	Baseline (n=28), mean (SD)	Postintervention (n=20), mean (SD)	4-week follow-up (n=19), mean (SD)
Depression symptoms	6.25 (3.85)	4.85 (2.92)	5.47 (3.78)
Emotional self-efficacy	48.37 (6.50)	50.23 (5.44)	50.59 (6.29)
Sleep disruption	48.47 (6.88)	44.37 (8.16)	43.92 (6.74)

There was a slight increase in emotional self-efficacy from baseline to postintervention, although this effect did not reach significance (t_{19}=1.33; *P*=.20; 95% CI −4.79 to 1.07). Despite women reporting greater emotional self-efficacy at the 4-week follow-up than at baseline, this effect did not reach significance (t_{18}=1.56; *P*=.14; 95% CI −5.35 to 0.79). Finally, there was a significant reduction in sleep disruption from baseline to postintervention (t_{19}=3.41; *P*=.003; 95% CI 1.59 to 6.62), and there continued to be a significant difference in sleep disruption from baseline to the 4-week follow-up (t_{18}=3.71; *P*=.002; 95% CI 1.97 to 7.11).

User Experience

Overall, survivors of women's cancer reported very high levels of ease of use (mean 6.12 out of 7, SD 0.91) and ease of learning (mean 6.49 out of 7, SD 0.71) the iCanThrive app. They also reported an acceptable level of usefulness (mean 4.87 out of 7, SD 1.55) and a high level of satisfaction (mean 5.19 out of 7, SD 1.36) of the app. As seen in Table 2, they also reported that they generally liked how the app looked (mean 4.33 out of 5, SD 0.69), that the app was at least somewhat effective at keeping their attention (mean 3.56 out of 5, SD 1.25), and that the app strongly endorsed the utility of phone coaching to supplement their use of the app (mean 4.22 out of 5, SD 0.94). Mean scores for the overall fit of the intervention (mean 3.50 out of 5, SD 1.34) and interest in continuing to use the app (mean 3.00 out of 5, SD 1.37) indicated generally favorable ratings, although the standard deviations suggest a large amount of variance in how users rated these items. Individuals also reported having little concern over privacy issues of the app (mean 1.53 out of 5, SD 0.52). Finally, users reported, on average, that iCanThrive meets an important need for survivors of women's cancer (mean 4.06 out of 5, SD 1.21). Roughly half (9/19, 47%) of the women who completed the study indicated that they would be willing to serve as a coach for other survivors of women's cancer to help them use the app.

Discussion

Principal Findings

Overall, the app usage metrics and patient-reported outcomes from this pilot study support the use of iCanThrive as a clinical intervention in survivors of women's cancer. To our knowledge, there are no published trials of app-based interventions with phone coaching that specifically target mental health outcomes among survivors of women's cancer. The findings of this study suggest that survivors of women's cancer, many of whom live in nonmetropolitan areas, can engage with and benefit from a mobile intervention. Few trials of app-based interventions report follow-up data on outcomes. In this study, despite symptoms of depression being lower at the 4-week follow-up assessment than at baseline, the difference was not significant. It is likely that this effect would be significant with a larger sample size and with a clinically depressed sample. However, the sustainability of these gains should be a focus of development for future interventions. For example, although women used iCanThrive over 6 weeks, a longer intervention period could yield larger and long-lasting gains.

In general, feedback scores from women was largely positive, although future iterations of the app should consider some changes. In this study, feedback scores were lowest for items related to fit and long-term engagement after the trial period. Sustained engagement is a widespread issue facing mobile and app-based interventions [49], many of which rely on users to initiate. An alternative method of content delivery involves leveraging adaptive designs. For example, a Just-in-Time Adaptive Intervention [81] aims to provide the right type and amount of support, at precisely the right time, by continually

assessing and adaptive to the user's state. Future trials of iCanThrive may evaluate the utility of continuously assessing a user's emotional state passively through mobile phone sensors [82] or via self-report instruments to trigger interventional content when the user is most vulnerable (eg, a user is asked to engage in a breathing exercise when their emotional state is on a downward trajectory). In addition, future work should explore integrating components to the intervention that assist the user in making decisions about what exercises to engage in. For example, some mental health apps have evaluated the usefulness of automated recommender systems that encourage users to try intervention content that most closely matches their current needs [83]. The goals of these types of strategies are to promote fit and engagement with digital interventions.

By providing a provision of light human support, iCanThrive is different from most other app-based mental health interventions, and the use of phone coaching likely enhanced users' engagement with the app (based on app usage and relatively low dropout rates compared with other digital intervention studies). Although the decision to add phone coaching was based on the communication preferences in women versus men [65], not all women will use an app-based intervention the same way. Some may benefit from phone coaching, whereas others may not. Thus, although women in this trial strongly endorsed the utility of phone coaching, future trials should consider whether to provide phone coaching to a subset of women who need it most. For example, using a Sequential, Multiple Assignment, Randomized Trial [84], it may be possible to identify individuals who struggle to engage with the app and provide them with additional resources. Addressing support needs on an individual basis will maximize the scalability and impact of an app-based intervention by making efficient use of available resources (eg, money and coach's time). Furthermore, future studies may wish to explore the benefits of training lay individuals to become coaches, as almost half of the participants in this trial reported that they would be interested in coaching future survivors of women's cancer. Training individuals who have completed the intervention to become coaches could increase the scalability of a digital intervention while promoting engagement.

Limitations

This study and its findings should be interpreted in light of several limitations. Given the size and characteristics of the current sample, these findings may not be generalizable to subsets of women with a specific form of cancer or phase. The participants in the study were not selected based on a threshold of depressive symptoms, and future studies may wish to recruit a clinically depressed sample. One might expect the impact of iCanThrive on symptoms of depression, emotional self-efficacy, and sleep disturbance to be even greater among those with a clinical level of depression. Findings related to the potential impact of iCanThrive on symptoms of depression and sleep disruption should also be replicated in a larger sample of survivors of women's cancer. For example, in this study, it was found that depression symptoms, although lower at the 4-week postintervention follow-up (vs baseline), was not significantly different than at baseline, which may be attributed to the small sample size and limited power. We urge caution in using pilot studies to guide power calculations for larger trials [85]. Furthermore, it is important to consider other possible outcomes to assess, such as social functioning and positive affect. It will also be important to evaluate iCanThrive in a randomized controlled trial, as this study used a single-group, pre-post design. Thus, it is important to not overinterpret the findings of this study because of the absence of a control condition. Finally, it will be important for future studies to collect in-depth qualitative feedback to improve the iCanThrive app and phone coaching protocol.

Conclusions

Taken together, these findings support the acceptability and preliminary efficacy of iCanThrive for reducing mood symptoms in survivors of women's cancer. There were significant reductions in symptoms of depression and sleep disruption from baseline to postintervention, which supports the potential usefulness of examining iCanThrive in future trials. In addition, participants found the app-based intervention to be easy to use and generally useful for improving their mood, which was consistent with data on user engagement. They also reported high levels of satisfaction with iCanThrive and felt that it met an important need for survivors of women's cancer.

Acknowledgments

This research was aided by a grant from the Virginia Kincaid Charitable Trust Award Grant and grant #IRG 81-001-26 from the American Cancer Society.

Conflicts of Interest

None declared.

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Abbreviations

CES-D: Center for Epidemiologic Studies Depression Scale
mHealth: mobile health
PROMIS: Patient-Reported Outcomes Measurement Information System
RUCA: rural-urban commuting area

Edited by H Wu; submitted 02.08.19; peer-reviewed by E Coups, A Baglione, C Maheu, J Johnson; comments to author 28.10.19; revised version received 13.11.19; accepted 09.12.19; published 06.02.20.

Please cite as:
Chow PI, Drago F, Kennedy EM, Cohn WF
A Novel Mobile Phone App Intervention With Phone Coaching to Reduce Symptoms of Depression in Survivors of Women's Cancer: Pre-Post Pilot Study
JMIR Cancer 2020;6(1):e15750
URL: http://cancer.jmir.org/2020/1/e15750/
doi:10.2196/15750
PMID:

Original Paper

Use of Mental Health Apps by Patients With Breast Cancer in the United States: Pilot Pre-Post Study

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Abstract

Background: Nearly half of the patients with breast cancer experience clinically significant mental distress within the first year of receiving their cancer diagnosis. There is an urgent need to identify scalable and cost-efficient ways of delivering empirically supported mental health interventions to patients with breast cancer.

Objective: The aim of this study was to evaluate the feasibility of in-clinic recruitment for a mobile phone app study and to evaluate the usability and preliminary impact of a suite of mental health apps (IntelliCare) with phone coaching on psychosocial distress symptoms in patients recently diagnosed with breast cancer.

Methods: This pilot study adopted a within-subject, 7-week pre-post study design. A total of 40 patients with breast cancer were recruited at a US National Cancer Institute–designated clinical cancer center. Self-reported distress (Patient Health Questionnaire-4) and mood symptoms (Patient-Reported Outcomes Measurement Information System depression and anxiety scales) were assessed at baseline and postintervention. App usability was assessed at postintervention.

Results: The minimum recruitment threshold was met. There was a significant decrease in general distress symptoms, as well as symptoms of depression and anxiety, from baseline to postintervention. Overall, participants reported high levels of ease of app use and learning. Scores for app usefulness and satisfaction were reinforced by some qualitative feedback suggesting that tailoring the apps more for patients with breast cancer could enhance engagement.

Conclusions: There is a dire need for scalable, supportive interventions in cancer. The results from this study inform how scalable mobile phone–delivered programs with additional phone support can be used to support patients with breast cancer.

International Registered Report Identifier (IRRID): RR2-10.2196/11452

(JMIR Cancer 2020;6(1):e16476) doi:10.2196/16476

KEYWORDS

breast cancer; mental health; mHealth

Introduction

Background

Nearly 50% of the women diagnosed with breast cancer report clinically significant levels of distress (ie, elevated symptoms of depression or anxiety) within the first year of receiving their cancer diagnosis [1-4]. Untreated symptoms of depression and anxiety in patients with breast cancer lead to poor quality of life [5], increased mortality [6,7], and high economic costs [8]. Although therapies that emphasize skills acquisition, such as cognitive behavioral therapy and acceptance-based therapy, have demonstrated efficacy in reducing distress in patients with breast cancer [9-12], almost half of the patients with breast cancer report unmet supportive care needs [13-16]. One reason is the reliance on in-person delivery of mental health services, which poses numerous barriers, such as high financial cost [17], high time investment [18,19], social stigma [20], and a severe shortage of trained therapists [21-23]. Despite increased efforts by clinicians and researchers to assess for distress during the cancer treatment process, distress management through mobile technology remains an overlooked component of care [14,24,25].

Mobile Phone Apps for Patients With Cancer

Mobile phone apps are frequently cited as a potential method of extending effective care in a cost-effective manner [26-28]. Given that 81% of American adults own a mobile phone [29], it is an ideal platform from which to deliver brief, empirically supported interventions to anyone who needs them. Models of internet interventions [30] and behavioral intervention technologies [31] highlight key strengths of mobile health (mHealth) interventions: portability, accessibility, and the ability to program an automated intervention to adapt to a user's input. Numerous randomized controlled trials demonstrate the efficacy of app-based interventions in reducing the symptoms of depression and anxiety [32-36], including those that are coupled with support from a coordinator [32,37,38]. However, empirical reviews of apps for patients with cancer [25,39] fail to identify any publicly available mental health intervention that target patients with breast cancer. Thus, despite the potential scalability and impact of an app-based intervention that teaches distress management skills to patients with breast cancer, more work is needed.

App Design and Coaching to Promote Engagement

An app-based mental health intervention can be deployed where and when a patient needs it most, guiding users through brief and practical skills training to manage their distress. However, there are some weaknesses to app interventions, including software bugs, ownership of a compatible mobile device, and poor engagement and usage. Specifically, many apps suffer from poor engagement for a variety of reasons, such as requiring lengthy engagement times that do not match user preferences [40]. In reality, people use apps in short, frequent bursts and tend to prefer apps that support a limited set of tasks [41]. Thus, an app intervention that is designed to provide quick and targeted interventions can potentially fit well with patients with breast cancer who are receiving active cancer treatment and who must deal with the inevitable sequelae of anticancer care, including time constraints and conflicts with work and outside activities [35].

Studies suggest that pairing an app with human support (eg, coaching via phone, SMS text messaging) can further increase engagement and usage, thereby promoting outcomes [37,38]. On the basis of the Efficiency Model of Support [38], a human coach can support participants in using and benefiting from an app intervention. Coaches work with users to set goals and target potential points at which users may fail to benefit from the app (ie, addressing obstacles to effective use), which increases accountability and promotes engagement [38].

The aim of this study was to conduct a pilot study that evaluated a set of brief, targeted app interventions that promote mental health. The IntelliCare platform is a collection of apps that utilize an elemental, skills-based approach to improving mental health [32,42]. Table 1 contains descriptions of the IntelliCare apps and their purposes. Many of the exercises contained in the apps can be completed in less than a minute. Exercises are meant to be intuitive, requiring few instructions to complete, and most of these exercises can be found on the first screen that is presented by the app. Each app has a *Help* feature that contains educational and technical content regarding the specific app in question. A total of two trials of 8-week interventions showed significant and substantial reductions in depression and anxiety symptom severity among noncancer patients with average app use of 195 to 216 times, with a median use of less than 1 min [32,42]. However, these results may not be generalizable to patients with breast cancer who face unique challenges and life circumstances, which makes them potentially unique from other populations.

There were two broad aims of this study. The first was to examine, in a single-group pre-post design, the feasibility and usability of the IntelliCare apps in patients recently diagnosed with breast cancer to inform a larger trial. We examined recruitment and retention rates to inform a potential future randomized trial. On the basis of the considerations of the size of the clinic from which participants were recruited, as well as the decision to recruit patients early in the breast cancer diagnostic pathway (at a time when it may not be appropriate to participate in a study that requires an immediate face-to-face consent and app download process), a threshold of 1 to 2 participants per week was the threshold to determine feasibility of in-clinic recruitment for a larger study [43]. The second aim was to examine the usability and preliminary impact of the IntelliCare apps in reducing distress in patients recently diagnosed with breast cancer. Note, this study initially sought to recruit the caregivers of patients with breast cancer; however, because of low enrollment, we decided to exclude the caregivers from the analyses. It was hypothesized that patients newly diagnosed with breast cancer would have decreases in general distress symptoms, as well as depression and anxiety symptoms, over a 7-week intervention period [43]. Quantitative and open-ended feedback was collected at the end of the study to evaluate usability and satisfaction of using the apps and coaching.

Table 1. Description of IntelliCare apps, their objectives, and which apps were available for each type of mobile phone platform at the time of the study.

App name	Objective	Mobile phone platform
Aspire	Promotes awareness of and striving toward personal goals and values. Helps users identify their values and keep track of their progress.	Android
Day to Day	Promotes knowledge about ways to bolster mood. Users receive a daily stream of knowledge tidbits and are prompted to build on a theme every day (eg, cultivate gratitude and problem solve).	Android and iOS
Daily Feats	Promotes goal setting and attainment. An in-app calendar allows users to track their successes and identify new tasks to complete.	Android and iOS
Worry Knot	Promotes knowledge about worry and provides an interactive exercise to decrease worry. The app also tracks the user's progress and provides tailored feedback on ways to distract oneself from worrying thoughts.	Android and iOS
Social Force	Encourages users to identify supportive individuals in their life. The app prompts users to reach out to these people for encouragement.	Android
My Mantra	Increases self-efficacy and a positive perspective of oneself. The app prompts users to come up with personal mantras and to construct personalized photo albums that serve as reminders of these mantras.	Android and iOS
Thought Challenger	Increases the ability to identify and challenge negative thinking patterns. Guides users through a cognitive restructuring exercise and tracks the output of past exercises.	Android and iOS
iCope	Promotes coping and positive reinforcement by having users write and send themselves messages when encouragement is most needed.	Android
Purple Chill	Increases relaxation skills by providing a library of mindfulness and guided meditation audio files.	Android
MoveMe	Promotes mood through physical activity. The app prompts users to schedule exercises and provides instructional videos and lessons to increase motivation to exercise.	Android
Slumber Time	Promotes healthy sleeping by prompting users to keep an active sleep diary. The app also provides a checklist of things to do before bedtime to promote healthy sleep habits.	Android
Boost Me	Promotes positive mood by having users schedule positive activities throughout the day. A mood tracker allows users to see their progress and the impact of different activities on their mood.	Android

Methods

Overview

This was a single-group, 7-week pre-post study of patients with breast cancer in the United States. The decision to use a 7-week duration was based on the duration of brief face-to-face psychotherapy (typically 6-8 weeks) and previous reviews finding that the duration of app interventions usually range between 6 days and 8 weeks [44]. All participants received the IntelliCare apps and coaching. Self-report measures were obtained at baseline and postintervention to examine mental health outcomes. Additional measures were administered at the end of the study to evaluate user satisfaction and ways to improve the intervention for a future trial.

Participants

A total of 40 female patients with breast cancer (age: mean 56.8 years, SD 11.6 years) actively receiving cancer treatment were enrolled over a course of 29 weeks. Among those that indicated their race, most participants self-identified as white (31/38, 82%), followed by black (4/38, 11%), Hispanic (1/38, 3%), American Indian or Alaska Native (1/38, 3%), and multiracial (1/38, 3%). The median number of days from cancer diagnosis to study enrollment was 21 days. Among those who reported their breast cancer stage, 11% (3/28) of the patients were diagnosed with stage 0, 25% (7/28) of the patients were diagnosed with stage 1, 39% (11/28) of the patients were diagnosed with stage 2, and 25% (7/28) of the patients were diagnosed with stage 3. Rural-urban commuting area (RUCA) codes V3.0 from the United States Department of Agriculture were determined using participant zip codes. RUCA codes range from 1 (most metropolitan) to 10 (most rural) and are based on US Census tract data of population density, urbanization, and daily commuting. In this study, 47% (17/36) of the participants resided in an area characterized as most urban or metropolitan (RUCA=1), 42% (15/36) of the participants resided in an area characterized as metropolitan or micropolitan (RUCA=2-6), and 11% (4/36) of the participants resided in an area characterized as small town or rural (RUCA=7-10).

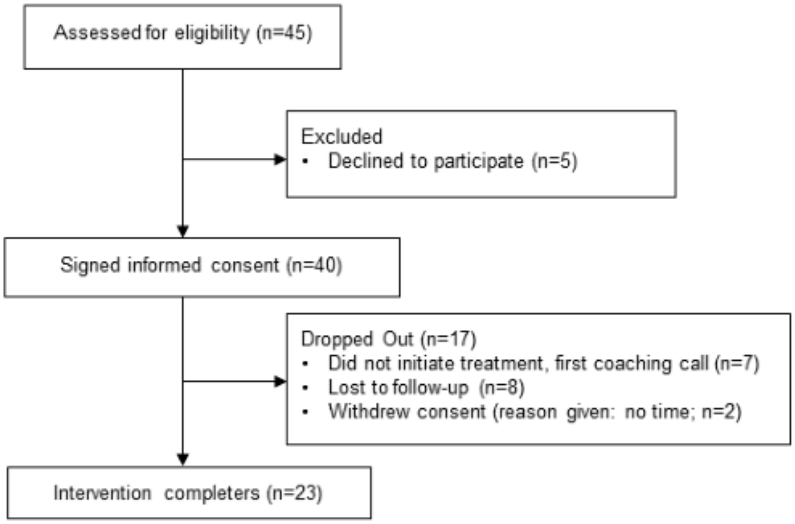
To limit barriers to entry, inclusion criteria were limited to the following: (1) patient diagnosed with breast cancer within the last 2 months, (2) age at least 18 years, (3) proficient in English at a sixth-grade level, and (4) has a mobile phone or is willing to carry one around if provided. Participants were not required to have a minimum level of familiarity with mobile devices or technology. Note, a total of 12 caregivers were also enrolled and were provided the same apps. Owing to the low number of caregivers enrolled, in this study, we focused on data obtained from patients with breast cancer.

Procedure

Patients with breast cancer were recruited from a breast care clinic in a US National Cancer Institute–designated clinical cancer center. Surgical oncologists and nurses handed out a study flyer to patients with breast cancer during a normal scheduled visit. Patients had an opportunity to speak to a

research staff member, who provided more details about the study and answered questions. If an eligible patient expressed interest in participating, the patient was led through the consenting process by a research staff member. Research staff described the aims of the study, introduced the IntelliCare apps, and reviewed the study timeline. After providing written consent, participants scheduled a 30-min coaching call (see description below) that took place sometime within the next 10 days with a research staff member, which marked the initiation of their treatment in the study. Participants were guided to download the apps in the consent session, but they were told not to open them until the coaching call. Participants then completed a battery of measures that took approximately 10 to 15 min to complete. Following the initial coaching call, participants received an SMS text message (via Qualtrics' SMS tool) every week to remind them to try two new exercise modules in the app. After 7 weeks (postintervention), participants completed another battery of self-report measures on the Web. They also provided feedback about their experiences of using the app and coaching. See Figure 1 for information on patient recruitment and flow. Participants were compensated with a US $50 gift card for providing feedback. Informed consent was obtained from all individual participants included in the study. All procedures performed were in accordance with the ethical standards of the University of Virginia Institutional Review Board (IRB-HSR# 20648) and with the 1964 Helsinki declaration.

Figure 1. Study flow.



Materials

Participants used their own personal mobile phone. A concerted effort was made to include both Android and iOS users into the study, given the differences between users of these platforms in previous work [26]. A total of 3 participants did not own a mobile phone or have an appropriate mobile phone plan that enables downloading and using a native mobile phone app, and they were provided with a Samsung S7 Android phone with an unlimited data plan. These individuals were able to use the phones for nonstudy purposes. All IntelliCare apps were available for Android users, and a total of five apps (ie, Thought Challenger, Worry Knot, Daily Feats, My Mantra, and Day To Day) were available to iOS users at the time of the study. Android users were instructed to try two new apps every week for the first 6 weeks and to use any combination of apps for the seventh week. iOS users were instructed to try one new app every week for the first 5 weeks and to use any combination of apps for the sixth and seventh weeks. Among the initially enrolled 40 female patients with breast cancer, 31 had an Android phone and 9 had an iOS phone.

Phone Coaching

A manualized coaching protocol was adopted from a previous IntelliCare study [32], based on the Efficiency Model of Support [38]. The goals of coaching are to address usability issues, increase engagement with the app, promote fit of the intervention by assessing the needs of patients with cancer, promote knowledge of the skills found in the app, and encourage implementation of the skills in daily life [38]. Usability concerns include issues related to the usability of the intervention, fit of the intervention tool to one's needs, knowledge of how to use the intervention, and implementation failures. Coaches were instructed to focus on app-related issues and to refrain from engaging in traditional counseling with participants. An initial coaching call (designed to last 30 min) focused on orienting participants to downloading and using the app, setting expectations of the coach's role, assessing how the apps may meet participants' needs, and building rapport. Participants were told that they could contact coaches at any time with any app-related questions. A total of 2 coaches with a bachelor's degree were trained and closely monitored by the lead author (PC). Finally, an unstructured 10-min phone call 3 weeks after the initial coaching call served as a check-in to make sure that participants did not have any lingering concerns or questions.

Measures

General Psychological Distress

The Patient Health Questionnaire-4 (PHQ-4) [31] is widely used in cancer settings as a brief screener of general distress and symptom burden, and it is well validated in both general

and clinical samples [31,32]. Individuals are asked to rate (0=not at all and 3=nearly every day) the degree to which they experienced different states (eg, "Little interest or please in doing things") over the past 2 weeks. Scores range from 0 to 12; a score of 6 to 8 indicates moderate mood symptoms, whereas a score of 9 and higher indicates severe mood symptoms. The PHQ-4 was administered at baseline and postintervention.

Symptoms of Depression and Anxiety

Depression symptoms were assessed with the 4-item scale from the Patient-Reported Outcomes Measurement Information System (PROMIS) [30] 29-item profile version 2.0 (PROMIS-29 Profile v2.0). PROMIS, a US National Institutes of Health Roadmap program, provides sensitive and reliable measures of patient-reported outcomes. Participants are asked to report (1=never and 5=always) the degree to which they experienced various depressed states (eg, "I felt worthless" and "I felt hopeless") over the past 7 days. Continuous anxiety symptoms were assessed with the 4-item scale from the PROMIS-29 Profile v2.0. Participants are asked to report (1=never and 5=always) the degree to which they have experienced different anxious states (eg, "My worries overwhelmed me" and "I felt fearful") over the past 7 days. The PROMIS scales were administered at baseline and postintervention. Consistent with PROMIS scoring recommendations, raw summed scores were converted into T-scores for analyses, with higher scores indicating greater symptom levels.

User Feedback

User feedback was assessed at postintervention. The USE-short form [45] was used to examine usability and satisfaction of the IntelliCare app suite as a whole. It is composed of 21 items that assess user experience (eg, "I would recommend it to a friend," "It is easy to learn to use it," and "It is simply to use"), which comprises the domains of usefulness, ease of use, ease of learning, and satisfaction. Items are scored on a 7-point Likert scale (1=strongly disagree and 7=strongly agree). The USE measure is a well-validated scale that is commonly used to evaluate the user experience of mHealth interventions [46,47].

Participants also provided open-ended feedback during telephone interviews with the research staff. The interviews covered the following topics related to the apps: general impressions, design quality, technical needs, and design suggestions to promote app implementation and usage. In addition, participants were asked to provide feedback on the following aspects of phone coaching: general experience with coaches, usefulness of coaching, additional or unmet coaching needs, suggestions to improve the coaching experience.

Data Analysis

Outcome data were stored in a secured Qualtrics server for highly sensitive data. Analyses were done in SPSS Statistics for Windows, version 25.0 (IBM Corp, Armonk, NY).

Quantitative user data were analyzed descriptively by obtaining means and SDs. Qualitative feedback data were reviewed for emerging themes. Specifically, responses were coded on the domains of the following: (1) ways to improve the design and user interface of the apps, (2) the specific apps that were most helpful (and why), (3) the specific apps that were least helpful (and why), (4) obstacles and barriers to using the apps, and (5) ways to improve the usefulness of coaching calls [43].

Paired *t* tests were used to analyze self-reported outcome data among patients with breast cancer [43] and to examine whether the use of the IntelliCare apps was associated with changes in distress and symptoms of depression and anxiety before vs after the 7-week intervention.

Results

Feasibility of In-Clinic Recruitment

See Figure 1 for information on study flow. A total of 45 patients with breast cancer were assessed for eligibility, of which 40 signed the informed consent form. A total of 23 patients with breast cancer completed the 7-week intervention, and 17 individuals prematurely dropped out because of noninitiation of treatment (ie, failure to complete the first coaching call), lost contact, and withdrawal of consent because of the perceived time burden of being in the study.

Patients with breast cancer were recruited over a span of 29 weeks, from March 2018 to September 2018. Thus, the minimum recruitment threshold of in-clinic recruitment of 1 to 2 participants was met (note, the recruitment rate is higher if the 12 caregivers who provided informed consent are included in the total count). Incremental adjustments were made during the trial to increase the efficiency of the patient recruiting process. Specifically, we were able to identify key personnel (ie, nurses and patient navigators) and clinic procedures to more easily identify eligible patients. These changes did not have an impact on the study procedures after the informed consent form was signed. A paper discussing the challenges and potential solutions of in-clinic recruitment for mHealth pilot studies, based on our experience of conducting this study, is forthcoming.

Distress and Mood Symptoms

Table 2 contains the descriptive statistics of psychosocial outcomes. On the basis of the PROMIS T-scores, there were significant reductions in symptoms of depression (t_{22}=2.35; *P*=.03; 95% CI 0.32 to 5.03; Cohen *d*=0.52) over the 7-week intervention period. Although there was also a reduction in symptoms of anxiety (t_{22}=2.05; *P*=.05; 95% CI −0.05 to 7.52; Cohen *d*=0.45), this did not reach significance.

Consistent with the previous findings, patients with breast cancer reported significant reductions in general psychological distress (PHQ-4) [48] over the 7-week intervention period (t_{22}=2.61; *P*=.02; 95% CI 0.23 to 2.03; Cohen *d*=0.55). At baseline, among those who completed the 7-week study, 22% (6/28) of patients reported at least a moderate level of distress, whereas 8% patients (3/38) reported at least a moderate level of distress at postintervention.

App Usage

The median number of total IntelliCare app launches was 97, roughly equal to two app launches per day over the course of

the trial. Table 3 contains additional app usage statistics for the individual apps.

Table 2. Means and SDs of psychosocial outcomes at each time point, along with the results of paired *t* tests.

Outcomes	Baseline, mean (SD)	Postintervention, mean (SD)	*P* value
Depression symptoms	53.77 (9.60)	51.09 (10.45)	.03
Anxiety symptoms	60.26 (8.84)	56.53 (9.67)	.05
General distress	3.96 (2.65)	2.83 (2.48)	.02

Table 3. Median number of app launches and median duration of app launches of individual IntelliCare apps.

App name	App launches (number)	Duration (in seconds)
Aspire	10.5	20
Day to Day	20	48
Daily Feats	33	38
Worry Knot	11.5	32.5
Social Force	2	27.5
My Mantra	5	21
Thought Challenger	7	19
iCope	7	27
Purple Chill	24	17
MoveMe	6.5	20
Slumber Time	9	35
Boost Me	10	78

Feedback

Patients with breast cancer rated the apps highly in terms of ease of use (mean 5.62, SD 1.3) and ease of learning (mean 5.67, SD 1.6) on the USE-short form. In general, participants had favorable yet relatively lower ratings for the domains of usefulness (mean 4.26, SD 1.8) and satisfaction (mean 4.05, SD 1.9).

A closer examination of the qualitative feedback of the patients with breast cancer supported the quantitative findings. Thematic analyses revealed that many participants found the apps very easy to use. A common theme was that despite not being computer or technologically savvy, participants found the apps to be fairly easy to use. Participants also reported that they generally liked the simple, straightforward design, which helped them to navigate the apps. Another theme that emerged was the utility of phone coaching. Participants reported that their interactions with coaches were pleasant and helpful in using the apps. There was general agreement that coaches helped patients with breast cancer feel supported while in the study, and the frequency and duration of phone calls were not viewed as overly burdensome, although none wanted more phone calls with coaches. It is worth noting that the sentiment of phone coaching as useful was not unanimous, as a minority of participants felt that phone coaching was unnecessary.

Additional themes hinted at ways to improve the IntelliCare apps for patients with breast cancer. A common theme was that participants reported that the look and feel of the apps, including the content (eg, examples of distressing thoughts), were not relevant to someone with breast cancer (eg, “the apps are not relevant to someone going through cancer...some questions or things don’t pertain to cancer” and “you should tailor [the apps] to situational cancer”). Another recurring theme was related to the timing of app use in relation to cancer stage and treatment progress. Many patients with breast cancer reported that the apps may be most useful for patients diagnosed with a more severe stage of cancer (eg, stage 3 or 4) or those undergoing chemotherapy.

Discussion

Principal Findings

Overall, patients with breast cancer found the apps easy to use and navigate. Feedback obtained at the end of the study highlighted several areas for potential improvement, all of which entail making the apps more relevant for patients with breast cancer and their experiences.

This study established the feasibility of recruiting patients newly diagnosed with breast cancer to engage in an mHealth intervention from a relatively small breast surgery oncology clinic. Receiving a cancer diagnosis is a life-changing moment for many individuals. Psychosocial distress is known to peak around the time of breast cancer diagnosis and the early stages of cancer treatment [49,50]. Thus, recruiting individuals around the time of diagnosis is a significant challenge to evaluating mobile app interventions. To meet the minimum threshold of feasibility (1 to 2 participants per week) [43], our team needed to adjust to the structure and flow of the clinic. For example, a

significant amount of time was devoted to introducing the study to nurses and patient navigators. Research assistants had to coordinate with the clinic staff to present the study to eligible patients. Researchers who are interested in conducting an mHealth pilot study in patients newly diagnosed with cancer are encouraged to factor in clinic space, staff, and patient flow when designing their study and calculating enrollment figures.

Patients with breast cancer identified several areas of improvement for a future trial. As the IntelliCare apps were designed for use in the general population, many patients reported wanting the appearance and content of the apps to reflect their experiences. A wealth of studies demonstrate the importance of tailoring digital interventions for end users [51,52]. In recent years, there has been a notable rise in the awareness of breast cancer through media and social campaigns [53,54], leading many patients with breast cancer to strongly identify with their diagnosis [55,56]. The most prominent theories of behavior change [57-59] stress that interventions that are perceived as personally relevant are most likely to succeed in changing people's behavior. Thus, to increase engagement with an app-delivered intervention for patients with breast cancer, it is important to tailor it in ways that are meaningful to those end users. For example, adding examples of cancer-related worrying thoughts (eg, "My cancer will never go away" and "I'm not strong enough to go through chemotherapy") to the Thought Challenger app may improve engagement with the app. Future work should also consider tailoring the app based on cancer stage and timing of treatment. For example, introducing the apps to patients right before starting chemotherapy may provide them with the needed coping skills during cancer treatment. Finally, although the patients with breast cancer generally found the coaching to be useful, none reported wanting more coaching calls, and a few participants found the coaching to be unnecessary. On the basis of this feedback, future studies may consider only providing coaching to a subset of patients with breast cancer who are in greatest need. For example, by leveraging a Sequential, Multiple Assignment, Randomized Trial [60], individuals who struggle to engage with the apps could be identified and provided with coaching. Providing support on an individual basis maximizes the scalability of app-based interventions by providing a more efficient use of resources.

Pilot studies are often conducted to obtain an effect size estimate to power a larger trial; therefore, this study's findings should not be overinterpreted in light of the relatively small sample. However, the results suggest that the IntelliCare apps have a moderate effect (based on Cohen *d*) in reducing mood and anxiety symptoms in patients recently diagnosed with breast cancer. Although the effect sizes obtained in this study are smaller than those reported in previous IntelliCare trials among the general population [32,42], they are comparable with the effect sizes of other mental health interventions (eg, mindfulness and in-person therapy) that have been tested among patients with breast cancer [61,62]. Achieving even a modest reduction of mental health symptoms may justify the expanded use of digital mental health interventions in patients with breast cancer, given their scalability, cost, and accessibility.

Limitations and Future Directions

The findings from this study should be interpreted in light of several limitations. Given the size and characteristics of the sample in this study, these findings may not be generalizable to other cancer populations (eg, pancreatic and lung). The findings related to the potential impact of IntelliCare on distress symptoms should be replicated in a larger sample of patients with breast cancer. As this was a single-arm trial, we cannot rule out the possibility that the observed improvements were because of factors other than IntelliCare, such as the natural course of the problems. It will be important to evaluate the IntelliCare apps in a randomized controlled trial among patients with breast cancer. Thus, it is important to not overinterpret the study's findings because of the absence of a control condition. As this study was conducted in a US National Cancer Institute–designated clinical cancer center, the findings regarding in-clinic recruitment feasibility have limited generalizability to other settings that may not possess as many resources. In addition, although the participants in this study were guided to download the apps during the informed consent session, future work should examine the benefits of providing more structure in teaching users how to navigate treatment apps. Finally, as there were more apps available to Android users than iOS users, it is hard to determine which apps were most efficacious in reducing distress symptoms. Future work should consider standardizing the order in which apps are tried, to allow for a better understanding of the effect of each app on psychosocial outcomes.

Finally, although the dropout rate of individuals in this study was generally at par with other app interventions, it was noticeably higher than that reported in previous IntelliCare studies in the general population. This may be attributed to the fact that individuals in this study were dealing with the stress of a recent breast cancer diagnosis. Similarly, the app usage rates were considerably lower than those reported in previous IntelliCare trials. This is consistent with research indicating that intervention impact and engagement generally decrease when moving from general to clinical samples [63]. Future studies should continue to explore the ways to address dropout in populations at high risk of dropout, such as providing added human support or connecting patients with additional resources in their community. Despite a higher dropout rate and a decrease in app usage in this study than those reported in previous IntelliCare trials in the general population, findings suggest that patients with breast cancer are still able to use, and benefit from, an app-delivered mental health program.

Conclusions

Mobile phone apps hold significant promise to overcome barriers in providing psychosocial care for patients with breast cancer [64-67]. However, relatively few publicly available apps have been empirically validated for treating mood symptoms [33,44], and those that have been validated have not been tested among patients with breast cancer [25]. IntelliCare, which has been rigorously studied in the general population [32,68,69], has the potential to make a significant public health impact by providing support to a large population of patients with breast cancer.

Acknowledgments

This project is funded by a seed grant from the University of Virginia Center for Engineering in Medicine. EL is supported by a research grant K08 MH112878 from the National Institute of Mental Health.

Conflicts of Interest

DM has equity ownership in and EL has received consulting fees from “Actualize Therapy,” a company developing and making available mobile technology products related to the research reported in this paper. DM and EL will not have direct access to the final raw dataset.

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Abbreviations

mHealth: mobile health
PHQ-4: Patient Health Questionnaire-4
PROMIS: Patient-Reported Outcomes Measurement Information System
RUCA: rural-urban commuting area

Edited by K Eddens; submitted 02.10.19; peer-reviewed by T McCall, N Guo; comments to author 02.12.19; revised version received 19.12.19; accepted 27.01.20; published 15.04.20.

Please cite as:
Chow PI, Showalter SL, Gerber M, Kennedy EM, Brenin D, Mohr DC, Lattie EG, Gupta A, Ocker G, Cohn WF
Use of Mental Health Apps by Patients With Breast Cancer in the United States: Pilot Pre-Post Study
JMIR Cancer 2020;6(1):e16476
URL: http://cancer.jmir.org/2020/1/e16476/
doi:10.2196/16476
PMID:32293570

Original Paper

Assessing Breast Cancer Survivors' Perceptions of Using Voice-Activated Technology to Address Insomnia: Feasibility Study Featuring Focus Groups and In-Depth Interviews

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Abstract

Background: Breast cancer survivors (BCSs) are a growing population with a higher prevalence of insomnia than women of the same age without a history of cancer. Cognitive behavioral therapy for insomnia (CBT-I) has been shown to be effective in this population, but it is not widely available to those who need it.

Objective: This study aimed to better understand BCSs' experiences with insomnia and to explore the feasibility and acceptability of delivering CBT-I using a virtual assistant (Amazon Alexa).

Methods: We first conducted a formative phase with 2 focus groups and 3 in-depth interviews to understand BCSs' perceptions of insomnia as well as their interest in and comfort with using a virtual assistant to learn about CBT-I. We then developed a prototype incorporating participant preferences and CBT-I components and demonstrated it in group and individual settings to BCSs to evaluate acceptability, interest, perceived feasibility, educational potential, and usability of the prototype. We also collected open-ended feedback on the content and used frequencies to describe the quantitative data.

Results: We recruited 11 BCSs with insomnia in the formative phase and 14 BCSs in the prototype demonstration. In formative work, anxiety, fear, and hot flashes were identified as causes of insomnia. After prototype demonstration, nearly 79% (11/14) of participants reported an interest in and perceived feasibility of using the virtual assistant to record sleep patterns. Approximately two-thirds of the participants thought lifestyle modification (9/14, 64%) and sleep restriction (9/14, 64%) would be feasible and were interested in this feature of the program (10/14, 71% and 9/14, 64%, respectively). Relaxation exercises were rated as interesting and feasible using the virtual assistant by 71% (10/14) of the participants. Usability was rated as better than average, and all women reported that they would recommend the program to friends and family.

Conclusions: This virtual assistant prototype delivering CBT-I components by using a smart speaker was rated as feasible and acceptable, suggesting that this prototype should be fully developed and tested for efficacy in the BCS population. If efficacy is shown in this population, the prototype should also be adapted for other high-risk populations.

(JMIR Cancer 2020;6(1):e15859) doi:10.2196/15859

KEYWORDS

artificial intelligence; breast neoplasms; survivors; insomnia; cognitive behavioral therapy; mobile phones

Introduction

Background

There were an estimated 3.6 million breast cancer survivors (BCSs) in the United States in 2016, and an estimated 30% to 50% of BCSs suffer from insomnia [1-3]. Insomnia, the most prevalent sleep disorder, has detrimental health consequences on cardiometabolic and immune system health, neurobehavioral function, depression, fatigue, and quality of life [4-7]. Poor sleep efficiency, duration, and quality have also been associated with an increased risk of mortality in BCSs [8,9]. Causes of insomnia may be multifaceted, including cancer-related physiological processes, iatrogenic effects of oncotherapies, menopause, and comorbid mood disorders associated with cancer diagnosis and psychosocial and economic stressors [10,11]. Insomnia after breast cancer treatment is often persistent, lasting multiple years, but is not frequently discussed with cancer care providers [12].

Cognitive behavioral therapy for insomnia (CBT-I) is recommended as the first-line treatment by the American College of Physicians and the National Comprehensive Cancer Network and has shown efficacy in a BCS population [13-15]. However, CBT-I–trained practitioners are scarce, it may not be covered by insurance, and scheduling multiple follow-up visits for insomnia can inhibit completion due to competing demands on time and finances [16]. Although automated therapies delivered via the internet have been developed and shown to be effective [17], there is still a need to reach more patients, underscoring the need to create more user-friendly experiences [18]. As screening and treatment for breast cancer improves and survivors live even longer, this growing population will increasingly need feasible options for accessible insomnia treatment [3].

Objectives

The aim of our study was to better understand BCSs' experiences with insomnia and to inform the development of a prototype through focus groups and in-depth interviews that explore how BCSs would perceive and use a screen-free, voice-activated program for CBT-I. We created a series of *metrics of success*, which we set out to meet before moving forward with fully developing the prototype and conducting efficacy testing. In this formative work, we solicited responses from survivors distinct from those who gave formative feedback. Our goals were to achieve that the majority of participants would report that they were *somewhat* to *very* interested in using the technology, that the majority of participants would report increased knowledge of CBT-I, and that participants would rate the concepts presented as *somewhat* to *very* important in addressing insomnia. We also set a target that a majority of participants would rate the perceived feasibility of using this prototype for the delivery of CBT-I components as moderate to high and that the prototype would show better than average system usability (score >68).

Methods

Study Participants

We recruited women through the George Washington University Medical Faculty Associates (GW MFA) in conjunction with the breast cancer team. We also advertised in the local newspaper, reached out to local breast cancer survivorship groups, and mailed flyers to GW MFA patients who met the basic eligibility criteria. BCSs were considered eligible if they had a history of stage I-III breast cancer and had completed active treatment (ie, surgery, radiation, and chemotherapy) at least three months prior. We used the Pittsburg sleep quality index, which has been validated in this population [19], to screen women for insomnia symptoms and severity. We used a previously established threshold of a score ≥5 (out of 21) to identify women eligible for participation [20]. In total, we reached out to 63 women; 25 women did not respond to contact, 2 women were stage 4 and thus not eligible, 3 women said they were not interested, 4 women were confirmed to participate but did not show up in focus groups, and 4 women had scheduling conflicts with the proposed dates. We sequentially enrolled women first in the formative, qualitative phase of the study until our target was reached and then in the prototype demonstration. In step 1 (formative), 11 women were included, and in step 2 (prototype demonstration), 14 women were included.

Formative Work

All formative data were gathered using focus groups in person or using in-depth interviews in person or by phone. The focus groups and in-depth interview guide questions are outlined in Table 1. These guides were semistructured, and facilitators were encouraged to probe participant responses. We were interested in perceptions of insomnia and how it might relate to breast cancer diagnosis, perceived triggers and symptoms of insomnia, anticipated barriers to CBT-I adherence, and comfort with using smart speaker technology. We, thus, inquired about participant experiences with insomnia, including the type of symptoms, timing of onset, and attempts to treat insomnia. We also asked women about their comfort level by using virtual assistants such as smart speakers like the Amazon Alexa or Google Home and smartphone-based assistants like Apple's Siri on the iPhone. Our questions were open-ended, with probes to better understand the current knowledge of both insomnia treatment options and smart speakers.

We conducted 2 focus groups. In group 1, 6 women participated. In group 2, only 2 women attended out of the 7 scheduled to attend. Last-minute conflicts came up with childcare (n=1), family emergencies (n=3), and rescheduling requests (n=1). Thus, we scheduled in-depth interviews with additional participants. We stopped focus groups and in-depth interviews when we found that responses did not generate any new information beyond what we had already collected.

Media Rez LLC, a Washington DC–based technology company, developed the prototype, which we called *Sleep Helper*. Media

Rez drew on multiple sources for developing the Sleep Helper program, using the standardized CBT-I protocol that has been evaluated in extensive scientific literature and has demonstrated efficacy in similar populations [15], input from research team members with experience in delivering CBT-I, and target population input. All coding was performed by HA and reviewed by the study team. Researchers used emergent themes from formative data to further frame content and create user appeal. The prototype included the following modules, based on CBT-I components: *morning*, consisting of recording time in bed and time sleeping, number of awakenings, and length of awakenings; *evening*, consisting of recording caffeine and alcohol intake, exercise, napping, and the ability to set reminders for the morning so as to help clear the mind; *education*, with short guidance about sleep hygiene; and *relaxation*, including an example meditation music and script. The scripts are shown in Table 2.

Some scripts are dependent on the participant's unique responses and only play when the participant provides a particular answer. For example, scripts might include suggestions for improved sleep hygiene based on the participants' answers. Extensive scripts allow a wide variety of answers, so they feel more natural and identify nonresponsive or unclear answers to be able to direct the participant back to the question.

Table 1. Focus group or interview discussion questions.

Theme	Questions
1. Perceptions and experiences regarding insomnia	• When did your insomnia start, and how would you describe it to others? • How has insomnia affected your cancer survivorship experience?
2. Perceived triggers and symptoms of insomnia	• Can you tell me about a specific thing that triggers your insomnia? • What strategies have you tried to overcome your insomnia? • What kinds of things do you do when you can't sleep?
3. Anticipated barriers to cognitive behavioral therapy for insomnia	• What are your thoughts on changing lifestyle, diet, and other habits to improve your sleeping patterns?
4. Current usage of Amazon's Echo/Dot, Google Home, or similar devices	• Do you use a home device that uses artificial intelligence at present, such as an Amazon Echo or Google Home? This can also include Apple's Siri or other mobile devices. • If you have ever seen or used one, can you describe that experience?
5. Comfort in interacting with voice-activated AI[a] assistants	• Tell me how you would feel about using voice technology at home to work on strategies to improve insomnia symptoms? • Have you used AI or other equivalent technology (cell phone or computer applications) for health or mood-related issues? • What were the strengths (frequency, reminders, interactive, etc) of using this technology? • What were the weaknesses?
6. General thoughts on using the smart speaker (Alexa) to address insomnia	• What are your hopes for insomnia treatment? • What frustrations do you foresee in using a device rather than speaking to a human being? • What are your thoughts on having Alexa control lighting and temperature in your bedroom? • How interested would you be in using a smart speaker to: learn about the stages of sleep, strategies to overcome insomnia, keep a sleep diary, connect with a specialist, or hear relaxation exercises? • How concerned would you be about using a smart speaker in regard to privacy? • How important are issues such as personalization and the ability for the smart speaker to meet your needs and answer questions?

[a]AI: artificial intelligence.

Table 2. Example scripts for Sleep Helper modules.

Module name	Cognitive behavioral therapy for insomnia component
Education	
Congratulations! You left the bed three times this week when you couldn't sleep, and listened to an audiobook until you were tired enough to sleep. This is good, because it helps you associate the bed only with sleep. In this case, sleep restriction could be helpful. Instead of going to bed at 10 pm, would you like to try going to bed at 10:30 for the next few nights?	Psychoeducation and stimulus control
(if yes) Good. I'll reset your alarms and lights for 10:30, and we'll see how that works out.	Sleep restriction
Morning	
I would like to ask you how easily you fell asleep last night, on a five-point scale, where one means it was very difficult to fall asleep, and five means you fell asleep easily.	Sleep hygiene
I'm curious to know how refreshed you feel now, on a scale from one, meaning fatigued, to five, meaning refreshed.	Sleep hygiene
How many times did you awaken last night?	Sleep hygiene
Night	
Sometimes it's hard to sleep because of unfinished business on our minds. I can help by remembering anything that's on your mind, and reminding you of it in the morning. Is there something you would like me to remember for you?	Psychoeducation and relaxation (reduce running thoughts or anxiety)
Did you exercise at least once today for more than 20 minutes?	Sleep hygiene
How many caffeinated drinks did you have between twelve o'clock noon, and bed time?	Sleep hygiene
Some people find that avoiding caffeine after twelve o'clock noon makes it easier to sleep at night. Would you be interested in trying to avoid caffeine after noon?	Psychoeducation
(if yes) Great! Going forward, I'll make recommendations to cut back on afternoon caffeine, and track your progress.	Sleep hygiene
Relaxation	
The last thing I can do for you tonight is to begin a relaxing meditation sequence. Would you like to begin this relaxation?	Relaxation exercises

Prototype Testing

After developing the prototype, we demonstrated the *Sleep Helper* program to 14 BCSs who had not shared formative input to measure interest, feasibility, and knowledge of the key components of CBT-I and smart speaker features. Demonstrations ranged from 60 to 90 min and included researcher prompts, observing participants engaging with the prototype, and soliciting feedback. Our objective was to determine the acceptability and teaching potential of the virtual assistant in delivering key CBT-I skills to BCSs. We completed 3 group demonstrations of the prototype (n=3, n=3, and n=6 participants) and additional individual presentations (n=2) to accommodate scheduling preferences. Our primary outcomes of interest, feasibility, and perceived importance were measured using a 5-point Likert scale at the end of the demonstration. We also measured usability of the prototype using the system usability scale (SUS), a 10-item scale with a 5-point Likert scale, with options ranging from strongly disagree to strongly agree for each item. Example items include *I would imagine that most people would learn to use this system very quickly* or *I thought that the system was easy to use*. The SUS is easy to administer, can be used in small sample sizes, and has shown validity in differentiating usable from unusable systems [21]. Previous research suggests that scores above 68 indicate better than average usability [22]. Finally, participants completed a written survey on whether their knowledge of CBT-I had improved from pre- to postdemonstration and whether they would recommend the prototype to friends or family, based on what they had seen.

This study was approved by the George Washington University's Institutional Review Board. All participants read the informed consent forms and agreed to participate before initiating focus groups or interviews.

Results

Participants

Our 25 participants were aged, on average, 58.5 (SD 9.8) years; 72% (18/25) of participants reported a history of stage I breast cancer, 24% (6/25) reported stage II breast cancer, and 4% (1/25) reported stage III breast cancer. Women reported completing curative treatment (surgery, radiation, and chemotherapy), on average, 57.1 months ago (SD 60.5 months). A total of 12 participants were self-reported as black or African American, 11 as non-Hispanic white, and 2 preferred not to answer.

Formative Work

For exploratory, open-ended qualitative interviews and focus groups, we recruited 11 BCSs with insomnia to describe their interest in and perceived feasibility of using voice-activated smart home technology for delivery of CBT-I components.

Open-ended questions about experiences with insomnia outlined the perceived causes and symptoms experienced by participants. Although the majority of participants had previously considered the relationship between their symptoms of insomnia and cancer diagnosis, 2 participants had not previously considered that insomnia might be related to breast cancer until they learned that other survivors in the focus group had similar experiences. Both focus groups reported similar experiences with insomnia, including a *new normal* of deficient sleep and low energy after either having trouble falling asleep or staying asleep (ie, being awake in the middle of the night). Common perceived triggers and symptoms of insomnia included anxiety, hot flashes, continuous need to go to the bathroom, and disruptive thoughts occurring during the intended sleep period. One woman described her trigger as:

> *Clearly anxiety. I'm just very, very anxious about something. Physically, something doesn't feel right, it's hard to sleep because it's on your mind.*

Other women attributed sleep disturbances to physical disruptions from hormonal therapies, for example:

> *It was practically the first night on tamoxifen, I was up every 2-3 hours having to go to the bathroom or having hot flashes. And this has been going [on] for 2 years. So, I have pretty much had 2 years of not having much sleep.*

The 2 most commonly mentioned strategies used to overcome insomnia included using technology such as a cell phone or television to distract themselves from anxious thoughts and keeping the room temperature cool and comfortable. Some women were familiar with strategies of restricting liquids before bedtime, avoiding alcohol and caffeine, and limiting naps, but participants also expressed difficulty in changing these behaviors.

Participants were eager to have customizable features to be able to personalize the program, but they also expressed a need for simplicity and straightforward use. As one woman expressed "one size does not fit all, you have to acknowledge that what works for one person may not work for someone else." Other women found the device "really attractive [in] that it's all put together in [one] package" but also "needs to offer, a kind of intuitive straightforward easy to use process."

Women largely had some, but not extensive, experience with using smart speakers. Most participants were not concerned about the security of sharing information about sleep with a smart home device, but they did want information about how data were going to be used. Other issues such as frustration using the device (based on prior voice-activated programs such as Siri not understanding commands) and concerns "if [the smart speaker] started talking randomly" were mentioned. Women also noted that they would not want it to disturb a bed partner (eg, having the device talk out loud at night).

Prototype Testing

We enrolled 14 women who received the prototype demonstration. We demonstrated the *morning*, *evening*, *education*, and *relaxation* modules, asking participants open-ended questions about what they thought of the content and how they might or might not want to incorporate it into their home routines. Participants responded that the *morning* and *evening* modules were of an appropriate length and that features such as querying on caffeine were good reminders about changing behaviors. "I've been trying to do that [note time of last caffeine intake] on my own but haven't been entirely successful." Some women suggested wanting encouragement and being congratulated for meeting goals (eg, if they went to sleep at the recommended time for a few days in a row). Participants found that the educational module was *surprisingly engaging*, but suggested that they might want a *menu* of choices to know what kind of things they might be able to listen to; this feature will be available on the app that accompanies the virtual assistant program. Most of the participants were happy with short lessons but liked the idea that they could ask the Sleep Helper program to tell them more about a given subject. Participants expressed concerns over privacy but thought that they would probably use the program anyway, saying that they share their data already with other programs and that as long as they knew how data were being used, they would be reassured. Others thought that the benefit of addressing sleep concerns outweighs the risk:

> *Because it is for a specific purpose...it is not to make my life easier it is to give me knowledge, data, and help me rather than just for entertainment purposes...*

When asked about how long they could imagine using the program for, some women stated that:

> *After 30 days everything becomes a routine...you would look forward to going in there and talking to it.*

This suggested that they envisioned continuing to use the program on an ongoing basis to record patterns even if sleep had improved. Others were skeptical about wanting to report sleep patterns daily but liked the idea that they could create default settings and then only update things that changed that day. Women also suggested allowing for customization for individual life events or vacations that may affect sleep patterns. "It should ask did something [that affected your sleep] happen today?" When women were asked how much guidance they needed to use the device, they said that a voice-activated setup guide would be sufficient, although a few women thought they might want to have a number to call if they needed support in using the program.

After the demonstration of the key prototype features, and open-ended discussion, participants completed questionnaires. On postdemonstration questionnaires, 79% (11/14) of the BCSs reported that knowledge of insomnia and CBT-I had increased after using the prototype compared with when they had arrived; the remaining participants said they had about the same knowledge after the demonstration. All 14 participants confirmed interest in using the program to treat insomnia symptoms at home, and all the participants reported that based

on the demonstration, they would recommend the program to friends or family.

All participants completed Likert scale questionnaires about interest, perceived feasibility, and importance of key CBT-I concepts that we had built into the initial prototype (Table 3). In short, nearly 79% (11/14) of participants thought it was both of interest and would be feasible to use the Sleep Helper program to record sleep patterns. Nearly two-thirds of the participants thought it would be feasible to tackle the difficult challenges of lifestyle modification (9/14, 64%) and sleep restriction (9/14, 64%) and were interested in this feature on the Sleep Helper program (10/14, 71% and 9/14, 64%, respectively). Using relaxation exercises on the Amazon Alexa were cited as of interest and feasible by 71% (10/14) of participants. More participants indicated that they had neutral feelings about the importance of using the bed only for sleep and sex, leaving the bed after 20 min of awake time, and keeping a regular schedule for getting in and out of bed, indicating potential educational opportunities to increase perceived salience.

Importantly, all participants said that they would recommend the prototype to friends or family, showing strong potential for future testing. The average SUS score was 82.3 (range 50-100), indicating success in meeting the target usability score of ≥68.

Table 3. Interest, perceived feasibility, and importance of prototype (N=14).

Interest, feasibility, and importance	Five-point Likert scale response, n (%)				
	Very	Somewhat	Neutral	Not very	Not at all
How interested would you be in using the Amazon Alexa to...					
Record your daily sleep pattern	11 (79)	3 (21)	0 (0)	0 (0)	0 (0)
Prompt you to change behaviors such as maintaining a regular schedule, avoiding stimulants, exercising, and avoiding screen time at night	10 (71)	2 (14)	2 (14)	0 (0)	0 (0)
Practice guided relaxation	10 (71)	3 (21)	0 (0)	1 (7)	0 (0)
Deliver a visual prompt to let you know that 20 min are up and you should leave the bed	9 (64)	2 (14)	1 (7)	1 (7)	1 (7)
Prompt you to restrict time spent in bed	9 (64)	2 (14)	1 (7)	0 (0)	1 (7)
How feasible do you think that it would be to...					
Tell Alexa when you went to sleep and nighttime awakenings when you wake up in the morning	11 (79)	2 (14)	0 (0)	0 (0)	1 (7)
Change behaviors such as having a regular schedule, avoiding stimulants, exercising, and avoiding screen time at night	9 (64)	5 (29)	1 (7)	0 (0)	0 (0)
Practice relaxation exercises to help your insomnia symptoms	10 (71)	3 (21)	1 (7)	0 (0)	0 (0)
Leave the bedroom if you do not fall asleep within 20 min	10 (71)	1 (7)	1 (7)	2 (14)	0 (0)
Restrict the amount of time you spend in bed	9 (64)	3 (21)	1 (7)	0 (0)	0 (0)
How important do you think that...is in avoiding insomnia					
Understanding the role of sleep in health	13 (93)	0 (0)	1 (7)	0 (0)	0 (0)
Behaviors such as having a regular schedule, avoiding stimulants, and avoiding exposure to screens at night	12 (86)	1 (7)	1 (7)	0 (0)	0 (0)
Relaxation exercise	12 (86)	2 (14)	0 (0)	0 (0)	0 (0)
Using the bed only for sleep and sex and leaving the bed if you cannot sleep for 20 min	7 (50)	3 (21)	3 (21)	1 (7)	0 (0)
Keeping a regular schedule for getting in and out of bed	8 (57)	3 (21)	3 (21)	0 (0)	0 (0)

Discussion

Principal Findings

In our formative work to understand BCSs' experiences with insomnia and smart home devices, we found that participants were interested in this technology, particularly if it could be personalized for ease of use. We reached our goal that the majority of participants would report that they were *somewhat* to *very* interested in using the technology, that participants would rate the program as feasible and highly usable, and that the majority of participants would report increased knowledge of CBT-I. In our demonstration, participants also reported that sleep logs (one of the key components of CBT-I that clinicians depend on to proscribe sleep recommendations) using the prototype was very feasible. This suggests that the data collected by the smart home device can be used by artificial intelligence programming to create personalized recommendations and schedules that go beyond simply presenting sleep hygiene education.

Comparison With Prior Work

Another qualitative study of cancer survivors similarly showed that insomnia may be exacerbated by anxiety, inability to relax,

and use of screen time before bed [23]. Each of these issues also surfaced in our interviews and focus groups and were considered in prototype development.

Previous studies have suggested a need for scalable methods to deliver CBT services, with self-administered CBT-I as a first step in a stepped care model [24]. Our study is not the first to use technology to offer components of CBT-I to cancer survivors. Researchers have previously delivered automated CBT-I to BCSs (n=255) via a web-based portal, showing improvements in sleep outcomes for wake after sleep onset and insomnia severity in a randomized controlled trial [25]. Another study among 18 BCSs and 10 other cancer survivors on average 4 years after diagnosis demonstrated the efficacy of web-based CBT-I on the overall insomnia severity index as well as using sleep diary measures [26]. A larger study of the same program including 303 adults with chronic insomnia (not specifically cancer survivors) supported the efficacy of this intervention in improving sleep outcomes [27]. These results suggest the promise of using an automated, technology-driven portal to deliver components of CBT-I to cancer survivors. Still, our approach of using voice-activated smart home technology differs from web- or video-based technologies, as it may have increased reach (eg, relaxation scripts could be delivered in the bed at the point of going to sleep using facemasks with built-in speakers), may have increased frequency of contact, and may eliminate screen time, which is one of the triggers for sleep disruption.

Strengths

The strengths of our study include formative work, development of an innovative technology, and early user testing to offer feedback on areas for improvement as the product is further developed. We triangulated data from the scientific literature and from formative data collection to frame messages around insomnia that were specific to our target population of BCSs.

Limitations

In this formative work, we gathered information from a limited number of participants, partly due to the short time frame of study funding. Yet, by the end of data collection, we were not observing additional themes that emerged, suggesting feedback saturation. We also demonstrated only a limited prototype, as the device was not fully programmed to incorporate feedback or be used in home testing. However, as our objective during this phase was only to assess perceived feasibility, this should not be considered a major limitation at this point in time. In future studies, we plan to further develop and test this prototype for actual feasibility and efficacy. Furthermore, we did not have demographic information such as income or education, which may have affected participant responses.

Conclusions

We anticipate that by using an iterative development process with end users to ensure high user satisfaction, we will be able to further develop a voice-activated program to deliver CBT-I components that will improve insomnia among our target population of BCSs. In the long term, we hope to increase the uptake of this effective therapy in the breast cancer population beyond what has been achieved with in-person visits, videos, or website-based programs. After demonstrating efficacy in the BCS population, we plan to adapt the technology for other high-risk populations.

Acknowledgments

The authors would like to acknowledge the participants who gave their time to participate in this project.

Conflicts of Interest

Media Rez is a for-profit company that seeks to commercialize an eventual product based on this technology, consistent with the Small Business Innovation Research program.

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Abbreviations

BCSs: breast cancer survivors
CBT-I: cognitive behavioral therapy for insomnia
GW MFA: George Washington University Medical Faculty Associates
SUS: system usability scale

Edited by H Wu; submitted 13.08.19; peer-reviewed by E de Bruin, Y Xiao, AW Kim, Y Vaizman; comments to author 22.10.19; revised version received 06.02.20; accepted 09.03.20; published 26.05.20.

Please cite as:
Arem H, Scott R, Greenberg D, Kaltman R, Lieberman D, Lewin D
Assessing Breast Cancer Survivors' Perceptions of Using Voice-Activated Technology to Address Insomnia: Feasibility Study Featuring Focus Groups and In-Depth Interviews
JMIR Cancer 2020;6(1):e15859
URL: http://cancer.jmir.org/2020/1/e15859/
doi:10.2196/15859
PMID:32348274

Original Paper

Use of an Abbreviated Geriatric Screening Tool in the Assessment of Older Cancer Patients' Functional Status, Dependency, and Comorbidities: Cross-Sectional Audit and Observations From a Regional Cancer Center in Australia

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Abstract

Background: Malignancies are the leading cause of disease burden in Australia, comprising 19% of total diseases. Approximately 1 in 4 men and 1 in 6 women die from malignancies by 85 years of age, with patients aged 65 years and older contributing to 58% of diagnoses and 76% of cancer mortality. In the context of malignancy-related disease and age-related degeneration, there is a need for comprehensive assessment of older patients to plan for appropriate management and predict prognosis. The utility of available comprehensive geriatric assessment tools has been limited in routine practice because of their time-consuming nature, despite their informing clearer understanding of patients' functional status, better clinical decision making, prevention of unpredictable admissions and emergency department overload, and support services planning. Though there are several promising tools available, there is a lack of literature on tools that can comprehensively assess functional status in an expedited fashion.

Objective: This study aimed to document functional status and comorbidities among a geriatric oncology patient cohort attending a regionally located, dedicated cancer care facility, using the completed Adelaide tool assessments. This study documents cohort characteristics, including sociodemographics, malignancy type, and comorbidities. Secondarily, we observed the utility of an abridged functional assessment in the multidisciplinary team (MDT) management of older cancer patients.

Methods: The study comprised a facility-based cross-sectional audit of results obtained from a screening tool administered to patients aged 65 years and older and attending an outpatient medical oncology clinic for management of cancer from late 2015 to 2017. Data relating to five domains were collected, including instrumental activities of daily living, activities of daily living, performance status, unintended weight loss, and exhaustion. Sociodemographic and disease-related factors were summarized as frequencies with percentages or mean with SD. Distribution of functional status based on sociodemographic characteristics, living status, disease-related factors, and comorbidities was analyzed using a chi-square test. Cumulative dependencies in the five domains were identified, and patients were classified as fit, vulnerable, or frail. Supplementary review of presentation notes for cases discussed at MDT meetings was undertaken to identify discrepancies.

Results: A majority of the study population showed poor functional status, with 88.7% (243/274) categorized as vulnerable and 8.4% (23/274) as frail. Exhaustion and unintended weight loss were identified as the most common contributors to dependency. Polypharmacy was strongly associated with decreased functional status.

Conclusions: The outcomes of this study are congruent with the existence of dependency in various domains, and with similar research in geriatric oncology. The Adelaide tool provided a useful basis for MDT discussion and management, where cases were

referred to the MDT. We recommend further examination of the tool's utility and impact in clinical decision making, and the distribution of dependencies in a rural cohort compared with metropolitan patients.

(JMIR Cancer 2020;6(1):e16408) doi:10.2196/16408

KEYWORDS

geriatric assessment; cancer; elderly; medical oncology; Australia

Introduction

Background

Globally, there are 962 million people aged 60 years or older, comprising 13% of the total population [1]. Advancements in medical sciences have led to an overall increase in life expectancy. According to the United Nations projections, the elderly population (>60 years) is estimated to reach 2.1 billion in 2050, or 22% of the projected world population [2]. The increase in life span is accompanied by challenges such as degenerative disorders, malnutrition, age-related disabilities, and increased risk of malignancies. Apart from physical illnesses, the elderly are also more vulnerable to social isolation, cognitive dysfunction, and emotional lability, with social isolation itself representing a significant risk factor for chronic noncommunicable conditions [3]. All these factors can culminate in a poor quality of life, and this recognition has catalyzed a strong global focus on the concept of healthy aging.

As per the recent Australian Burden of Disease Study (2011), malignancies are reported to be the leading cause of disease burden comprising 19% of total diseases. It has been estimated that 1 in 4 men and 1 in 6 women die because of malignancies by the age of 85, with patients aged 65 years and above contributing to more than half (58%) of diagnosed cases and three-quarters (76%) of cancer mortality in Australia [4]. Moreover, medical oncologists face the dual challenges of treating both the inherent problems associated with degenerative changes of aging and the malignancy-related disease itself [5]. As a result, there is a growing need identified among health care providers to access and use comprehensive geriatric assessments (CGAs) of patients to plan for the appropriate management and to predict prognosis [6]. The currently available CGA tools incorporate several domains such as nutrition, emotional wellbeing, cognition, social support, history of falls and injuries, comorbidities, polypharmacy, and disabilities [7-9]. However, although validated assessment is shown to have objective advantages over clinician judgment alone [10,11], the utility of these CGA tools and CGA-driven interventions has been limited in routine practice because of their time-consuming nature and consequent issues of completion rates and accuracy [12-14]. Hence, there is an imperative for many oncologists and multidisciplinary team (MDT) members to have access to an abridged tool to enable a clear understanding of elderly patients' functional status, thereby informing better clinical decision making [15,16]. A comprehensive understanding of functional status among the elderly can also facilitate the prevention of unpredictable admissions and overload in the emergency department. Further, it points to the need for and can inform the planning of required support services and bed occupancy [17]. Though there are several promising tools available in practice, there is a relative lack of literature on clinical tools that can comprehensively assess functional status and particularly those that do so in an expedited fashion [18].

Study Objectives

In this context, this study was designed to utilize a specific, abbreviated geriatric assessment (Adelaide tool) to document functional status and comorbidities among a geriatric oncology patient cohort attending a regionally located, dedicated cancer care facility. This was undertaken using existing patient- or proxy-completed Adelaide tool assessments. This study documents specific aspects of this cohort on the basis of sociodemographic characteristics, nature of malignancy, and coexisting morbidities, with the related aim of identifying patient characteristics that are associated with lower functional status scores. A secondary aim was to observe the utility of an abridged functional assessment in the MDT management of older cancer patients.

Methods

Study Design

This is a facility-based cross-sectional audit of results obtained from a screening tool administered among elderly patients aged 65 years or older who attended an outpatient medical oncology clinic for management and treatment of cancer.

Study Setting

This study was conducted in a dedicated cancer care facility located in a large regional center in Australia, providing medical oncology, radiation oncology, and hematology services. The facility is a part of a wider health district encompassing numerous smaller centers and communities. The study site is situated over 400 km road or air travel from the closest capital city, and almost 300 km from the nearest large metropolitan center. The cancer care service also operates a number of regular oncology clinics in small rural communities within the wider health district, and services a geographical area of around 106,000 km^2. The majority of patients from within the broader region and who are diagnosed with cancer are referred to this center for ongoing management and treatment if appropriate.

In the timeframe during which this study was conducted, patient visits and other interactions in the medical oncology and hematology areas of the center totaled around 26,000 inclusive of consultations, treatment visits, home nurse visits, and telephone follow-ups and telehealth appointments. The number of individual patients attending the center or its outreach clinics totaled 1255 in this period, with 689 (54.90%) of this cohort aged 65 years or older.

Of the 1255 patients attending the center in the study period, 557 (44.38%) presented to the medical oncology unit for a clinical consult. Of these 557 medical oncology patients, 350 (63.8%) patients were aged 65 or older, an increase in the proportion of older patients in the center overall and on the national estimates provided above—new medical oncology patients aged 65 years or older presenting in this period comprised 197 patients, or 56.3% (197/350) of all individual patients aged 65 years or older who attended the medical oncology clinic in the study timeframe.

In the wider hospital within which the oncology facility is situated, management of cancer and its treatment is provided by an MDT comprised of medical oncologists, radiation oncologists, hematologists, general and specialist surgeons involved in cancer-related procedures, pathologists, dieticians, social workers, and other allied health professionals who provide social, psychological, and nutritional support. The MDT meets fortnightly, and cases identified by clinicians on the basis of screening and assessment via methods such as the Adelaide tool or other means of selection by surgeons or other specialists are discussed. Recommendations regarding treatment, ongoing management, and/or any required referrals to allied health and support services such as community/home care are then determined and communicated to patients and their primary health care providers (eg, general practitioner). This approach aligns with current practice in the multidisciplinary management of oncology patients and incorporates recognition of geriatric assessment in such discussions and decision making [19,20].

Recruitment

This study included patients aged 65 years and over, diagnosed with any type of malignancy, and attending the study center during the period from November 2015 to November 2017. Each new patient aged 65 years or over and attending the medical oncology clinic during the reference period was invited to complete the Adelaide tool, a screening questionnaire for the assessment of older people with cancer. Existing patients aged ≥65 years and attending the medical oncology clinic, and who were identified for possible referral to an MDT meeting, were also invited to complete an assessment in most instances where they had not done so previously.

Study Tool and Data Collection

Initially, all new geriatric patients and some existing patients enrolled for cancer management were administered the screening questionnaire called the Adelaide tool screening questionnaire for the assessment of older people with cancer [21]. The Adelaide tool was developed by the Royal Adelaide Hospital Care Centre (Department of Health, South Australia) as a means of providing an abbreviated option for assessment of geriatric patients in clinical environments, and where time may not allow for initial extended and/or comprehensive assessments in all cases. A preliminary assessment of the validity of the Adelaide tool has been reported elsewhere [21].

Clinicians are able to use the tool to assess details related to self-rated health, medications use, memory, history of falls, hearing or vision impairment, activities of daily living (ADLs), instrumental activities of daily living (IADLs), social support, distress, pain, performance status, emotional wellbeing, and exhaustion. From this assessment, the Adelaide tool is used to classify functional status as fit, vulnerable, or frail.

This tool includes, in particular, the assessment of functional dependency in the following five domains referenced by other related studies [21]: (1) IADLs, (2) ADLs, (3) performance status (Karnofsky), (4) unintended weight loss, and (5) exhaustion [22,23].

Each new patient completed the Adelaide tool once, during an initial consultation at the medical oncology clinic before the commencement of treatment (where the treatment occurred). When required, assistance to complete the assessment was provided by an attending caregiver, friend, family member, or oncology nurse. In the small number of cases (n<5) where an assessment was mistakenly completed again at a later time, the later assessment was excluded from the analysis. On the basis of an examination of available records, all new patients (n=197) presenting to medical oncology in 2016 and 2017 were provided with a questionnaire and completed the questionnaire or were supported to do so as noted above. In addition, 77 existing patients who presented during this period and who had not previously completed the Adelaide tool also completed an assessment. Hence, a total of 274 assessments were completed and analyzed for this study.

In general, those patients who scored medium or high (vulnerable or frail) in the Adelaide tool were referred for consideration and discussion by the MDT. Owing to the retrospective nature of this study, however, this referral process to MDT was not always consistent. Therefore, on the basis of other factors, a patient who was classified as *fit* may have been referred for MDT discussion for other reasons. A patient who was classified as *vulnerable* may have been referred directly for treatment because of a number of factors, rather than referred to the MDT.

The data used in this study were therefore drawn from the Adelaide tool used for the screening of geriatric oncology patients (≥65 years), with the completed tool collected by an oncology nurse and maintained in the patient's clinical records. The screening results were also presented in around half the cases at the regular MDT meetings within the cancer center, at which—as specified above—discussions of patients take place to inform recommendations for treatments and other clinical decision making. A brief supplementary review of presentation notes for those cases discussed at MDT meetings was undertaken to confirm that those patients discussed at MDT meetings had completed an Adelaide tool assessment. This review also aimed to identify any significant discrepancies, such as obvious misclassification of functional status in MDT presentations. Such discrepancies were not identified in any case.

The Adelaide tool screening data collected during the period mentioned above were accessed, collated, and entered by a research assistant. All information was deidentified.

Statistical Analysis

Data were entered in Microsoft Excel with structured coding and analyzed using IBM SPSS, version 17.0. Patient sociodemographic and disease-related factors were summarized

either as frequencies with percentages or mean with standard deviation. On the basis of the Adelaide tool, cumulative dependencies in the specified five domains were identified. For this purpose, the Katz index of independence in ADLs, Lawton IADLs scale, the Karnofsky performance status (KPS), weight loss more than 5%, and exhaustion score were considered [22-25]. The ADL two-item scale (2 without help and 1 with help/completely unable to do) was used as reported by Katz et al [24]. Similarly, to assess IADL in/dependence, items relating to the ability to use the telephone, go out, do shopping, and handle money and medications were considered. If the person was not able to perform any activity in the IADL related activity, they were considered dependent in that domain.

A similar approach was used to classify dependency for ADL-related activities. The KPS was assessed using eight coded responses. Appropriate percentages for each response were identified from the standard tool. Unintended weight loss of more than 5% in the last 6 months was also considered as a factor of concern. The exhaustion score was taken as a factor of concern if the person felt that everything they did was an effort or if they could not get going for a moderate amount or most of the time [25]. Patients' functional status was classified as fit, vulnerable, or frail as per the categories reported by To et al [21]. Out of the five domains mentioned above, if there was no dependency in any domain, they were considered *fit*. Dependencies up to three factors were considered *vulnerable*, and 4 to 5 factors were deemed to be *frail*. Distribution of functional status on the basis of sociodemographic characteristics, living status, disease-related factors, and comorbidity status was analyzed using a chi-square test. Pain scores and distress scores across the three functional groupings were compared using the Kruskal Wallis (one-way analysis of variance) hypothesis test.

Data Exclusion

Patients who had incomplete data were excluded from the study. If any patient had missing data in any one of the five domains (ADL, IADL, performance status, exhaustion score, and weight loss), they were still included in the final analysis on the basis of the contribution to the final classification on functional status. As an example, a patient who is functional in three domains, nonfunctional in one domain, and missing data in one domain will fall into the vulnerable status category, irrespective of their functional status in the missing domain. Hence, such patients were not excluded from the final assessment of functional status even though they had missing information in one domain.

Research Ethics

This audit of screening tool data was approved by the local health district's Research Ethics and Governance Office as a non-research activity comprising a retrospective cross-sectional audit and analysis of an existing patient screening tool dataset. Patient names and all other identifying data were removed from the database.

Results

Demographic and Clinical Characteristics: Overview

A total of 274 patients were included in this study, representing all new patients aged 65 years or older who presented to the medical oncology facility in the study period, plus the additional existing patients noted above. Of the 274 patients, 110 (40.1%) had been subjected to the MDT assessment, and the rest (164/274, 59.9%) had undergone only Adelaide tool assessment. All patients ≥65 years whose cases were presented at an MDT meeting had completed an Adelaide tool assessment. Owing to the retrospective nature of the study, reasons for nonresponse were not comprehensively documented.

The demographic and clinical characteristics of patients are summarized in Table 1. The mean age of patients was 75.4 years (SD 7.0 years). A total of 52.2% (143/274) of patients were males, and 12.0% (33/274) were living alone. Distribution of patient-related factors among those who were discussed in MDT and those who were administered the Adelaide tool alone were not found to be significantly different. The authors of this study have retained the separation of the two participant cohorts in the below tables predominantly for ease of representing the data as they were collected and to link the data with later discussion of the degree to which referral of patients to MDT discussions might be useful in the management of those patients.

Among men, the most common site of cancer was colorectal cancer, followed by prostate cancer. Among women, the most common site of cancer was breast, followed by lung. Of the 274 patients, 18 (65.7%) had stage 4 carcinoma, and 20 (7.3%) had a family history of cancer.

About 12.0% (33/274) of patients had more than four existing comorbidities, and 18.7% (52/274) of patients reported a history of at least one fall in the last 6 months. Of those patients who had completed the Adelaide tool alone, and had not been referred for discussion at an MDT meeting, 100.0% (164/164) reported four or fewer comorbidities. About half of the study population (125/274, 45.6%) reported unintended weight loss in the recent past (Table 1). Over two-thirds of the patients (241/274, 77.8%) reported at least one comorbidity. Ischemic and other cardiovascular diseases (159/274, 58.0%), hypertension (135/274, 49.1%), musculoskeletal disorders (135/274, 49.1%), gastrointestinal tract–related diseases (98/274, 35.7%), dyslipidemia (88/274, 32.1%), and diabetes (49/274, 17.8%) were the most common comorbidities identified among the patients.

Table 1. Demographic and clinical characteristics of geriatric patients attending a regional cancer care center (N=274).

Factors and categories	Adelaide tool + MDT[a] (n=110)	Adelaide tool alone (n=164)
Age (years)		
Mean (SD)	75.7 (7.3)	75.2(6.8)
Median (IQR)	76 (69-81)	74(70-80)
Sex, n (%)		
Male	59 (53.6)	84 (51.2)
Female	51 (46.7)	80 (48.8)
Living status, n (%)		
Living with spouse	69 (62.7)	16 (9.8)
Living with children	7 (6.4)	100 (61.0)
Living alone	23 (20.9)	10 (6.1)
Living with others	11 (10.0)	38 (23.2)
Site of cancer, n (%)		
Breast	17 (15.2)	16 (9.8)
Colon or colorectal	22 (19.6)	23 (14.0)
Pancreas, stomach, esophagus, or biliary tract	15 (13.5)	13 (7.9)
Prostate	14 (12.5)	15 (9.1)
Lung	13 (11.6)	15 (9.1)
Female reproductive tract (uterus, ovary, or vagina)	7 (6.3)	6 (3.7)
Liver metastasis	6 (5.4)	10 (6.1)
Bone	3 (2.7)	1 (0.6)
Head and neck	3 (2.7)	3 (1.8)
Skin	2 (1.8)	2 (1.2)
Brain metastasis	2 (1.8)	2 (1.2)
Others	10 (8.9)	2 (1.2)
Comorbidities, n (%)		
0 to 4	77 (70.0)	164 (100)
More than 4	33 (30.0)	0 (0.0)
Functional problems, n (%)		
Memory problems	24 (23.1)	36 (22.1)
Vision problems (poor/blind)	101 (90.1)	156 (95.1)
Hearing problems	99 (88.4)	147 (89.6)
Weight loss	50 (50.5)	75 (47.2)
Fall	22 (19.6)	30 (18.3)

[a]MDT: multidisciplinary team.

Functional Status and Dependency in Functional Domains

Of the five functional domains included in the Adelaide tool, dependency because of exhaustion was the most commonly reported, followed by unintended weight loss. Dependency for household chores (31/274, 11.3%) and shopping (19/274, 6.9%) was found to be the maximum impaired IADL activity. Within the ADLs, continence (39/274, 14.3%) followed by bathing (24/274, 8.8%) were significantly impaired activities, making the elderly dependent for ADLs (see Table 2). Of 274 patients, 8 (2.9%) were identified as in the *fit* category of functional status, whereas a majority (243/274, 88.7%) belonged to the *vulnerable* status category (see Table 3).

Table 2. Distribution of dependency in various functional domains among geriatric patients attending a dedicated regional cancer care center (N=274).

Domain	Adelaide tool + MDT[a] (n=110), n (%)	Adelaide tool only (n=164), n (%)	Total (N=274), n (%)
IADL[b] dependent	16 (14.6)	24 (14.6)	40 (14.6)
ADL[c] dependent	20 (18.2)	32 (19.5)	52 (18.9)
Karnofsky performance score <70%	37 (33.6)	71 (43.3)	108 (39.4)
Unintended weight loss >5%	50 (45.5)	75 (45.7)	125 (45.6)
Exhaustion	76 (69.1)	116 (70.7)	192 (70.1)

[a]MDT: multidisciplinary team.

[b]IADL: instrumental activities of daily living.

[c]ADL: activities of daily living.

Functional status was found to be similar across different demographic, clinical, and social support structure elements. Though there was an increased proportion of frailty among male patients, increased comorbidities, memory disturbance, a history of falls, and the smaller sample size could have precluded the result from attaining statistical significance. However, a larger number of medications (6 or more) was found to be significantly associated with frail functional status among elderly patients. Similarly, patients with frail functional status had higher pain or distress scores compared with patients with fit or vulnerable status (see Table 3).

Table 3. Distribution of functional status across sociodemographic and clinical characteristics (N=274).

Factors and categories	Fit (n=8)[a]	Vulnerable (n=243)[b]	Frail (n=23)[c]	*P* value[d]
Age (years), n (%)				**.20**
<70	4 (3.0)	125 (92.6)	6 (4.4)	
70 to 75	2 (3.2)	52 (83.9)	8 (12.9)	
76 or more	2 (2.6)	66 (85.7)	9 (11.7)	
Sex, n (%)				**.56**
Male	5 (3.5)	124 (86.7)	14 (9.8)	
Female	3 (2.3)	119 (90.8)	9 (6.9)	
Living status, n (%)				**.30**
Living with spouse	5 (3.0)	21 (91.1)	5 (5.9)	
Living with children	0 (0.0)	154 (94.1)	10 (5.9)	
Living alone	2 (3.1)	16 (85.1)	1 (11.5)	
Living with others	1 (3.7)	52 (77.8)	7 (18.5)	
Comorbidities, n (%)				
0 to 4	6 (2.5)	215 (89.2)	20 (8.3)	.30
More than 4	2 (6.1)	28 (84.9)	3 (9.1)	.30
Presence of memory disturbances	2 (3.3)	44 (73.3)	14 (23.3)	.30
Fall >1 episode	1 (4.8)	16 (76.2)	4 (19.1)	.10
IADL[e] dependent	0 (0.0)	20 (50.0)	20 (50.0)	<.001
ADL[f] dependent	0 (0.0)	31 (59.6)	21 (40.4)	<.001
KPS[g] <70%	0 (0.0)	85 (78.7)	23 (21.3)	<.001
Weight loss >5%	0 (0.0)	105 (84.0)	20 (16.0)	<.001
Exhaustion	0 (0.0)	181 (94.3)	11 (5.7)	<.001
Type of assessment[h], n (%)				**.60**
Combined (Adelaide tool + MDT[i])	3 (2.7)	100 (90.9)	7 (6.4)	
Adelaide tool only	5 (3.1)	143 (87.2)	16 (9.8)	
Number of medications, n (%)				**.02**
Fewer than 6	4 (1.9)	193 (91.5)	14 (6.6)	
6 or more	4 (6.4)	50 (79.3)	9 (14.3)	
Distress score[j], median (IQR)	3 (0-5)	3 (0-5)	6 (0-7)	.02
Pain score[j], median (IQR)	3 (2-7)	5 (2-7)	5 (3-7)	.01

[a]2.9% (8/274).

[b]88.7% (243/274).

[c]8.4% (23/274).

[d]Chi-square test.

[e]IADL: instrumental activities of daily living.

[f]ADL: activities of daily living.

[g]KPS: Karnofsky performance status.

[h]For 7 patients–data on functional status are not available.

[i]MDT: multidisciplinary team.

[j]Kruskal-Wallis hypothesis test.

Discussion

Principal Findings

This study was carried out to assess the functional status of an elderly population diagnosed with malignancy and attending a dedicated cancer care center in a regional area using an abbreviated geriatric assessment tool (the Adelaide tool). It was found that a majority of the overall study population showed poor functional status, with 88.7% (243/274) of patients being categorized as having vulnerable functional status and 8.4% (23/274) as frail. Exhaustion and unintended weight loss were attributed as the highest contributors to dependency. Large proportions of this elderly population with malignancy were identified as having either vulnerable or frail functional status, and this reflects the existence of dependency in various domains.

Proportions of patients identified in this study with *fit* functional status (8/274, 2.9%) are less compared with the fit status (28%) reported in other studies involving the use of the Adelaide tool [21]. This could be explained by the differences in the distribution of types of cancers and a greater number of associated comorbidities in our study. However, the distribution of functional status across different sociodemographic and clinical factors was found to be similar in both the studies. Both studies identified the number of medications to have a positive association with poor functional status. Further, this study has also demonstrated the association of poor functional status with increased pain and distress scores. Considering that pain can directly limit various activities mentioned under IADL, ADL, and performance status, it is reasonable to assert that these attributes can lead to poor functional status.

An increased number of medications used was strongly associated with poor functional status in our study. This aligns with findings from other papers that show an association between polypharmacy in older patients with cancer and an increased risk of frailty and related complications [26-29]. It supports the importance of examining and discussing polypharmacy among older cancer patients as part of multidisciplinary oncology management, treatment decision making, and prognosis estimation [29-31].

Aside from the number of medications, however, several other factors such as the number of comorbidities, a history of one or more falls in the preceding 6 months, and memory loss associated with poor functional status did not achieve statistical significance. As this study aimed to identify the distribution of functional status among the study population, the small sample size addressing the primary objective may not have had enough statistical power to prove an association between these other factors and the functional status of older patients with cancer. Although it has been suggested in several studies that the associative and predictive value of many geriatric assessment domains is not always clear [32], there remains value in pursuing future research in regional, rural, and metropolitan cancer services to understand the utility of geriatric assessment domains in informing clinical decision making.

Additional Observed Results

The study was not specifically designed to assess the ways in and the degree to which the tool was utilized in clinical decision making. However, it was observed during this study that the functional status assessment on the basis of the Adelaide tool was incorporated in the presentations made at MDT meetings (as evidenced by MDT presentation copies) and was therefore used in clinicians' discussions around patient management and treatment decisions. In particular, the assessment informed clinicians' discussions at MDT meetings regarding whether a patient required management, treatment, and support by members of a wider MDT or whether management by the individual medical oncologist was sufficient. Similarly, the determination of treatment method for patients, such as systemic therapy, concurrent chemotherapy-radiation therapy, or observation-only, may also be influenced by the baseline comprehensive functional status and its incorporation in clinician discussion of individual cases.

At least subjectively, therefore, clinicians appeared to find the Adelaide tool useful as a basis for assessing the immediate and ongoing need for multidisciplinary discussion and management of patients, with a specific view to considering functional status as it relates to treatments such as chemotherapy. Further research would be required to better examine the relationship between Adelaide tool results, MDT discussion, and clinician decisions, and to more precisely assess the tool's relative ease of use for clinicians and patients. This supports the work and recommendations generated by recent research in relation to the use of geriatric assessment in the context of patient management and its potential impact on treatment decisions for older cancer patients [5,9,13,31].

Limitations

Considering that the 5 domains are part of the overall functional status, categories of functional status (fit, vulnerable, and frail) tested across domains such as ADLs and IADLs could lead to incorporation bias. The findings of this study should be interpreted against the background of the following limitations. Several records had missing observation on patient characteristics. In this study, compared with other domains, dependency based on exhaustion was found among 70% of the included patients. This might have reduced the discriminative ability of the Adelaide tool to assess the different functional status.

In addition, as noted above, the small sample size in the study may not have achieved sufficient statistical power to fully address the primary objective of identifying the distribution of functional status and its association with other factors such as comorbidities.

Further, although clinicians intended to refer all those patients classified as vulnerable or frail for discussion at the MDT meeting, the analysis of the above available data highlights that this did not occur in all cases. The retrospective nature of this study itself presents a limitation in this respect, as the rationale for not referring vulnerable or frail patients for MDT discussion is not always clear. There is an opportunity here to further investigate and suggest potential improvements to the clinical

process to optimize the utility of geriatric assessments in oncology patient management.

Contribution

This study expands on recent work in developing and trialing an abbreviated CGA tool, namely the Adelaide tool [21], in the MDT management of older cancer patients. In doing so, it contributes to existing research and confirms a specific association between a greater number of medications and poorer functional status (*vulnerable* or *frail*) in older people with cancer. Further, it goes some way to confirming the utility of the Adelaide tool in the broader context of MDT approaches to the management of geriatric oncology patients, albeit with a small sample size mitigating further extrapolation of results.

Conclusions

This study aimed to utilize the results of an abbreviated geriatric assessment tool to document functional status and comorbidities among a geriatric oncology patient cohort attending a regionally located, dedicated cancer care facility. This was undertaken using the existing Adelaide tool for geriatric patient assessments. This study documented specific aspects of this cohort, including sociodemographic characteristics, malignancy type, and comorbidities, and identified patient characteristics that are associated with lower functional status scores. In this patient cohort, it was found that a significant proportion of older patients were classified as vulnerable or frail. This outcome is congruent with the existence of dependency in various domains, and also reflects other research in the area of geriatric oncology and assessment. This has implications for future planning of oncology and related services in areas where there is a significant and increasing population aged 65 years and older.

Another secondary objective of the study was to examine the utility of an abridged functional assessment in the management of older cancer patients. The study confirmed the relative feasibility of integrating an abbreviated, comprehensive assessment of functional status in a clinical approach to the management of geriatric oncology patients, in particular using the Adelaide tool to achieve this. The functional status assessment on the basis of the Adelaide tool was used in clinicians' discussions and related decision making, for example, regarding whether a patient required management, treatment, and support by members of a wider MDT or whether management by the individual medical oncologist was sufficient.

Besides clinical decision making, this tool could also be used to inform prognosis prediction and to assess the need for further supportive care, reflecting recent work in the area of geriatric assessment and its provision of greater insights into survival and related decision making regarding treatment options for older patients with cancer [33]. This would require more in-depth research with clinicians and a larger sample size.

This study, therefore, suggests that the Adelaide tool provides a useful basis for multidisciplinary discussion and management of older patients with cancer and that resultant information helps to form a snapshot of a local patient subpopulation and the distribution of dependencies and range of functional status. However, it is recommended that further research is undertaken to examine the tool's impact on clinical decision making and MDT management of older cancer patients. Also, it is recommended that future attention be focused on the analysis of the distribution of dependencies in a rural cohort as compared with metropolitan patients, in addition to the incorporation of a larger sample size as means of extending the application of this work.

Acknowledgments

This project was supported by the Hunter New England Local Health District, NSW Health.

Conflicts of Interest

None declared.

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Abbreviations

ADL: activities of daily living
CGA: comprehensive geriatric assessment
IADL: instrumental activities of daily living
KPS: Karnofsky performance status
MDT: multidisciplinary team

Edited by H Wu, G Eysenbach; submitted 26.09.19; peer-reviewed by M Crichton, WF Tan, S Medlock; comments to author 28.10.19; revised version received 21.01.20; accepted 20.02.20; published 07.04.20.

Please cite as:
George M, Smith A
Use of an Abbreviated Geriatric Screening Tool in the Assessment of Older Cancer Patients' Functional Status, Dependency, and Comorbidities: Cross-Sectional Audit and Observations From a Regional Cancer Center in Australia
JMIR Cancer 2020;6(1):e16408
URL: http://cancer.jmir.org/2020/1/e16408/
doi:10.2196/16408
PMID:32255433

Original Paper

Facilitators and Barriers to Recruiting Ambulatory Oncology Practices Into a Large Multisite Study: Mixed Methods Study

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Abstract

Background: Practice-based research is essential to generate the data necessary to understand outcomes in ambulatory oncology care. Although there is an increased interest in studying ambulatory oncology care, given the rising patient volumes and complexity in those settings, little guidance is available on how best to recruit ambulatory oncology practices for research.

Objective: This paper aimed to describe the facilitators and barriers to recruiting ambulatory oncology practices into a large multisite study.

Methods: Using a mixed methods design, we sought to recruit 52 ambulatory oncology practices that have participated in a state-wide quality improvement collaborative for the quantitative phase. We used 4 domains of the Consolidated Framework for Implementation Research (CFIR) to describe facilitators and barriers to recruitment.

Results: We successfully recruited 28 of the 52 collaborative-affiliated practices, collecting survey data from 2223 patients and 297 clinicians. *Intervention attributes* included multimodal outreach and training activities to assure high fidelity to the data collection protocol. The *implementation process* was enhanced through interactive training and practice-assigned champions responsible for data collection. *External context* attributes that facilitated practice recruitment included partnership with a quality improvement collaborative and the inclusion of a staff member from the collaborative in our team. Key opinion leaders within each practice who could identify challenges to participation and propose flexible solutions represented *internal context* attributes. We also reported lessons learned during the recruitment process, which included navigating diverse approaches to human subjects protection policies and understanding that recruitment could be a negotiated process that took longer than anticipated, among others.

Conclusions: Our experience provides other researchers with challenges to anticipate and possible solutions for common issues. Using the CFIR as a guide, we identified numerous recruitment barriers and facilitators and devised strategies to enhance recruitment efforts. In conclusion, researchers and clinicians can partner effectively to design and implement research protocols that ultimately benefit patients who are increasingly seeking care in ambulatory practices.

(JMIR Cancer 2020;6(1):e14476) doi:10.2196/14476

KEYWORDS

recruitment activities; ambulatory care facilities; health services research

Introduction

Background

A growing proportion of health care is delivered in ambulatory practice settings, yet little information about ambulatory care quality and safety is available [1]. Ambulatory practice settings are diverse in scope and oversight and include those embedded in hospitals and health systems as well as free-standing buildings, where private, individual, or group practices deliver care to ambulatory patients. Increasingly, substantial amounts of complex care are delivered in ambulatory practice settings, where research has an important role in improving the quality and safety of patient care [2]. Given the rising patient volumes and complexity, researchers have an increased interest in studying ambulatory practice settings for descriptive, interventional, and implementational research. Conducting research in ambulatory practice settings can be a daunting task, posing unique challenges to recruitment. Recruiting ambulatory practices requires obtaining endorsement from the practices themselves before recruiting individual participants who can be patients, health care providers, and other staff. Researchers have identified barriers and facilitators to the successful recruitment of community health centers [3] and primary care practices [4] for example, but specialty practices such as ambulatory practice settings that provide care to oncology patients may have other recruitment challenges, and we know little about those.

Objectives

We sought to recruit ambulatory oncology practices that delivered chemotherapy to patients with cancer in our study. The purpose of our study was to understand health care delivery by characterizing clinician communication processes, communication technologies, and adverse patient outcomes in ambulatory oncology practices and to examine how these practices and technologies influence safe chemotherapy administration. Once practices agreed to participate, we recruited clinicians who worked in those practices and patients who were cared for at those sites. During the recruitment of practices into our study, we faced challenges mirroring what has already been reported in the literature [4-8]. For example, practice administrators frequently act as gatekeepers and make decisions about study participation on behalf of clinicians in the practice [4]. Clinicians have also reported difficulty in balancing the demands of research participation with patient care responsibilities [6].

Thus, the purpose of this paper was to report on the facilitators and barriers to the recruitment of ambulatory oncology practices in Michigan, United States, and share the lessons we learned.

Methods

Study Design

The overall study is using a mixed methods design. We began with a quantitative phase, by distributing questionnaires to all prescribers (ie, physicians, physician assistants, and nurse practitioners) and registered nurses who work in a sample of ambulatory oncology practices. In addition, for 6 weeks, site study coordinators completed a 1-page daily event log, and patients completed a 1-page self-reported symptom questionnaire. We then used the survey results to identify 8 practices for subsequent exploration via in-depth qualitative methods, and the analysis phase of the project is ongoing.

Setting

The study setting includes ambulatory oncology practices that belong to the Michigan Oncology Quality Consortium (MOQC). MOQC is an alliance of ambulatory oncology practices formed with the purpose of sharing and benchmarking their data to improve the quality of oncology care. As we were interested in targeting ambulatory oncology practices throughout the state of Michigan in the United States, we partnered with MOQC, which currently has 52 affiliated practices all over Michigan.

Procedures

We invited all MOQC-affiliated ambulatory oncology practices to participate in our study. We sought to recruit as many MOQC-affiliated practices as possible because we were interested in understanding the variation in clinician communication processes, communication technologies, and adverse patient outcomes in ambulatory oncology practices. The practices identified employees to serve as study coordinators who were responsible for distributing clinician questionnaires once, completing daily event logs, and distributing self-report questionnaires to patients daily for 6 weeks. Clinician questionnaires were about the usability of and satisfaction with the electronic medical record, communication among clinicians, perceptions of a safety climate, and perceptions of the work environment. The daily event logs summarized clinic activities and events related to chemotherapy (eg, the number of patients prescheduled and the number of patients who called the clinic for toxicity management). In the patient questionnaires, patients were asked to report symptoms related to their chemotherapy treatment. The survey procedures have been described elsewhere [9].

Data Collection and Analysis

By collaborating with MOQC, we had access to the latest information about the various practices to use for recruitment purposes (eg, name and contact information of the practice manager). Practice recruitment occurred on a rolling basis from April 2017 to November 2017. During that time, we held weekly meetings, where we reviewed practice enrollment and survey response data. KV maintained a tracking sheet of all MOQC sites that had tabulated information of when sites were initially contacted, the dates of follow-up, and the identified reasons for nonparticipation. Overall, 2 research team members (MM and KV) reviewed the notes taken during these meetings to identify barriers and facilitators to recruitment. The entire research team met regularly to discuss and confirm emerging barriers and facilitators.

We used the Consolidated Framework for Implementation Research (CFIR) to help identify facilitators and adapt barriers to successful recruitment and implementation of data collection. We followed the example set by Coronado et al [3] who also used CFIR to organize barriers and facilitators to participation in their study. CFIR is an organizing framework that assesses

potential factors that may influence implementation, grouping those factors into larger domains, which include intervention attributes, implementation process, external context, internal context, and characteristics of the individual involved [10]. We used all the CFIR domains, except for the characteristics of the individuals involved.

Results

Using the CFIR framework, we successfully recruited 28 of the 52 MOQC-affiliated practices to participate in our study (a recruitment rate of almost 54%). From those participating practices, survey data were collected from 297 clinicians (a 68% response rate) and 2223 patients (a 58.7% response rate).

Intervention Attributes

Intervention attributes refer to features of the intervention that can influence its execution, in our case, the characteristics surrounding data collection that could be customized to each practice without compromising the quality of data collected. Facilitators included involving physicians and ambulatory practice staff in the early stages of the project to get feedback on study materials and protocols. For example, 1 site developed a comprehensive, 1-page *helpful tips* sheet clarifying the data collection guidelines and patient eligibility criteria. The site gave us permission to distribute the tip sheet, acknowledging the original author, to all participating sites, and this also facilitated recruitment.

Implementation Process

Implementation processes are the strategies that affect the implementation of interventions. Although we are not conducting an intervention as a part of our study, the implementation process refers to the training and use of staff for data collection. Each facility designated a *practice champion* who was a staff member responsible for overseeing data collection, assuring that data were being collected as scheduled, and notifying the research team of any barriers to data collection. Rather than trying to identify such an individual ourselves, we facilitated recruitment by asking participating practices to assign a practice champion, usually someone with discretionary time and workflow flexibility. Each champion's primary role varied by the practice site. For example, in some sites, the practice manager acted as a champion and delegated data collection to a practice nurse, whereas in other practices, the nurse manager was the champion who collected all the data.

As we were asking sites to collect data from multiple sources, practice champions were required to attend a Web-based training session to learn about the study and assure that data would be collected uniformly at each site. Participating in the training was a mandatory requirement for engaging with us in the study, and training had to be completed before data collection could begin. We used PowerPoint slides (Microsoft Corporation, Redmond, Washington) [11] to present study information, and as the training was Web-based, we made it interactive by pausing during the presentation to ask for questions and input. We took the practice champions' suggestions for customization to facilitate data collection at each site. We used questions provided by the champions during each training session to edit and enhance the slides to promote greater clarification in subsequent training sessions.

To further facilitate data collection, we scheduled 15- to 20-min telephone conversations with practice administrators and physician leaders to describe the study in greater detail. Before each scheduled conversation, the study information consisting of a single-page overview of the study and a *frequently asked questions* (FAQ) sheet was sent. We also produced a 2-min video showing a high-level overview of the study. The 2-min video was essentially a *talking head* of one of the investigators (MM) who highlighted the benefits of study participation. The video was taken with a cell phone, edited using Camtasia (TechSmith Corporation, Okemos, Michigan) [12], and uploaded onto our secure box site. We also prepared a separate PowerPoint presentation that we shared with practices that were considering participation, again highlighting the benefits of participation to practices. In a few cases, we conducted in-person, informational site visits and distributed the aforementioned supplemental materials.

The External Context

The external context refers to environmental factors outside of each ambulatory practice, including MOQC practices throughout the state of Michigan and our efforts to recruit as many MOQC-affiliated practices as possible. Our recruitment efforts required several facilitative strategies, beginning with our presence at a MOQC biannual meeting that was attended by practice managers, physician leaders, and other MOQC stakeholders. The director of MOQC, who is a coinvestigator in the study, introduced the study to meeting attendees, highlighting how participation in the study would be relevant to the quality of care in individual practice settings. We provided attendees with a 1-page overview and study FAQ sheet. After the meeting, the MOQC director personally spoke with most physician leaders to remind them of the study and let them know that the study team would be contacting practices as a part of the recruitment process. In this way, the close professional relationships established by the director of MOQC with affiliated practices meant that we did not approach practices *cold*.

One of our earliest strategies to facilitate recruitment was to have a MOQC representative on the study team who was known to the practice staff. The MOQC representative served as a liaison to the MOQC director and as a point of contact for queries coming from MOQC-affiliated practices about the study. It was important that the study not fracture the practices' pre-existing relationships with the MOQC office and the director; therefore, having a MOQC representative on the study team was essential.

The Internal Context

The internal context refers to the characteristics of the implementing organization, specifically the unique characteristics and culture of each practice. Each practice differed both in terms of size and ownership as well as variation in patient populations served. The study team tailored procedures to the unique characteristics of each practice to facilitate recruitment. For example, some practices consisted of two or more physical locations. To develop a comprehensive

understanding of the overall practice, our goal was to recruit all locations of a single practice into the study, although some smaller locations saw patients only 2 or 3 days a week. We treated each physical location as an individual unit in recognition of the unique culture of each location.

We also acknowledged that the practice staff were in the best position to advise us on data collection procedures. We had conversations with the practice staff to clarify the inclusion criteria for patients in our study because in some practices, noncancer patients were treated with antineoplastic agents. Clarifying that the drug had to be delivered to a patient with cancer made it easier for practices to determine which patients to include.

The practice administrators were often gatekeepers who allowed access to stakeholders within each site so as to facilitate access, and the MOQC representative on our team sent periodic study updates to the practice administrators about the number of participating practices without identifying specific sites. Although the institutional review board (IRB) of our institution deemed our study to be exempt from an ongoing IRB review, we learned that this was insufficient for many practices that required separate IRB determination from their own home institutions. Upon request, we shared with practices the study protocol developed for our IRB.

Discussion

Principal Findings

To our knowledge, we are the first to report on ambulatory oncology practice recruitment, as the research to date has focused on recruiting primary care practices. Recruiting practices for research requires multiple strategies to succeed, both at the practice and individual levels, no matter the specialty. By framing our recruitment strategies according to CFIR domains of intervention attributes, implementation process, external context, and internal context [10], we overcame potential barriers and applied facilitators to recruitment and data collection. We also learned several important lessons as a result of our recruitment efforts.

Coronado et al [3] offered choices and flexibility to primary care clinics participating in their study to facilitate intervention implementation. Similarly, we took the advice of our practice champions to adapt some of our methods to the workflow and resources used by the ambulatory practices. Better aligning the research and workflow methods helped build a rapport and facilitate engagement. For example, the practice champions told us that faxing was the easiest way to return data. Setting up a fax line was not a part of our original research plan, but it made the practices feel more like partners in the study. Being flexible with structural aspects of data collection to mirror practices' processes enabled fluid implementation. The value of flexibility to practices' traits during implementation research has been noted elsewhere [3,13].

In recruiting ambulatory practices, it is important to enlist the support of more than the medical director of the practice, as he or she may have limited time to devote to research or not necessarily be a *leader* of a practice [14]. In these instances, other practice staff may be in charge of the day-to-day activities and become responsible for fulfilling the research needs. Therefore, we enlisted practice champions to lead the data collection and research protocol implementation as a part of the implementation process. As the staff may feel resentful of the extra work for participating if they are not consulted from the beginning, we had practices self-assign a practice champion to give them some control in the research process, which was key to getting buy-in for the project [14]. Studies have reported that a frequently mentioned reason for nonparticipation was not having enough time to engage in research studies or difficulties allocating staff for the research [4,7]. To address this potential barrier, we provided training and accessible support to those practice champions, which had the additional benefit of overcoming difficulties associated with incorporating and following study protocols [7].

A central facilitator that affected the external context focused on our collaboration with MOQC. There were many advantages to the collaboration that facilitated recruitment, including access to an established infrastructure and the latest information about each of the practices in the consortium to facilitate recruitment. Johnston et al [8] found that the lack of latest information was a tremendous barrier to recruiting primary care practices because of the additional time and effort researchers needed to invest to get that information. Another advantage of collaborating with MOQC was having a MOQC representative on the study team who could attend weekly meetings, a pivotal recruitment strategy. This is consistent with recommendations in the guidelines developed for researchers interested in conducting clinical trials in practice-based research networks [5] but has not been reported previously in ambulatory oncology research. We used the pre-existing relationship between the MOQC representative and the practices to increase the likelihood of getting favorable responses. Typically, unless a MOQC representative made the initial contact, the sites were either unwilling to talk with the study team members or denied knowledge of the study.

During the MOQC biannual meeting, and in individual phone calls, the MOQC director was careful to highlight how participation in the study would be relevant to the quality of care in individual practice settings to address barriers in the internal context. The director of MOQC, as well as the MOQC representative mentioned earlier, had a positive influence on site participation because of the professional networks built with physicians over the years. Such alliances are the foundation of practice-based research networks, which operate as loose coalitions of primary care practices to improve clinical practice and patient outcomes [15]. Developing a relationship with an established practice-based research network or quality collaborative, as was done in this study, would facilitate recruitment in many types of ambulatory practices. In addition, the FAQ sheet provided information on the relevance of the research topic to physicians' practices and monetary incentives. These strategies put the research into context for practices and align with research showing that distinguishing the individual benefits of research facilitates participation [3,16].

We also used many strategies to build a rapport with individual practices. Considering that practices function through the work

of many people, it was important to build a rapport with a variety of providers and staff. Our early strategies for building a rapport focused on communication that frequently flowed through the practice administrator, receptionist, and support staff. This, along with having the MOQC representative on the study team, counteracted the inability to build a rapport with a practice's receptionist, which has been identified as a barrier to recruitment [8]. In addition, by building a rapport with practice champions, providers, and medical directors, we were able to tap into multiple levels of leaders. Tapping into the power of opinion leaders or people considered to be likable, trustworthy, and influential has been shown to have a positive effect on promoting evidence-based practice, although the level of effectiveness does vary [17].

Another cited barrier to research participation is the lack of monetary incentives [7]. To overcome this, we offered a US $1000 incentive to each participating practice at the end of the 6-week data collection period, as an acknowledgment of the effort expended by the practice champion to collect data. The use of monetary incentives has been shown to increase the survey response rate compared with no use of incentives [18].

Lessons Learned

We learned 2 important lessons related to distributing monetary incentives, which have not previously been reported. First, university policy required that a current W-9 be on file for each practice before incentive disbursement. A W-9 is a form used in the US income tax system to confirm information for income-generating purposes. Completing this paperwork, even though required by the Internal Revenue Service in the US, added to the overall burden, especially for smaller practices. As we did not have the information to complete a W-9 on their behalf, we used email and telephone prompts to encourage practices to complete the W-9 paperwork. The second lesson was related to communication about the incentives. As some practices were spread across multiple physical locations, each participating location was eligible for the incentive. However, as the university sent out incentives addressed to the practice and not each location, confusion arose when one practice called to ask why they had received an honorarium check. As a result, we intercepted the outgoing mail so that we could insert a thank you note and an explanation for the enclosed check, before returning the letter to the mail.

We learned another lesson through our challenges with getting an IRB approval from multiple sites and navigating a complex IRB system. Our experience may no longer be relevant in the near future, at least for research conducted in the United States, as US researchers will face new challenges because of the changes in the IRB process. Specifically, the Federal Policy for the Protection of Human Subjects (also known as the Common Rule) in the United States changed in January 2019 [19], and the National Institutes of Health (NIH) will require a single IRB submission to NIH for multisite research proposals starting in January 2020. The barrier of having to obtain an IRB approval from multiple sites will no longer exist in US-based research. No matter where the research is conducted, building sufficient time for an IRB approval into the timeline is a good strategy. A couple of weeks elapsed between recruitment and data collection at each practice because of training requirements for the practice champion. During this time, the IRB process could have been initiated had we asked about practice-specific IRB requirements. Communicating with practices about their own policies should occur early on to mitigate other challenges that can pose significant barriers to research participation.

Recruiting practices took longer than anticipated, providing us with a final lesson learned. Recruitment took 9 months, a time frame reported in other studies [8]. In many cases, we entered into negotiations with practices that were considering participation but had not yet made a final decision. We tried to address practice concerns by allowing practices to deal with competing priorities to allow them more time to engage with us. We extended the recruitment timeline for some practices that told us about other conflicts of time, such as a practice champion on leave, staff illnesses, or other obligations (all cited as barriers to participating in research [7]). The goodwill engendered by our flexibility contributed to practice engagement.

Conclusions

Practice-based research in ambulatory care is essential to generate the data necessary to understand patterns of health care delivery, correlates, and outcomes in these diverse and understudied settings. Generating robust research data in ambulatory practice settings requires novel partnerships among researchers, coalitions, and a broad array of clinicians and practice administrators. Our experience provides other researchers with challenges to anticipate and possible solutions to common issues. Using CFIR as a guide, we devised strategies to facilitate recruitment efforts and minimize barriers. In conclusion, researchers and clinicians can partner effectively to design and implement research protocols that benefit not only researchers and providers but also the patients who are increasingly seeking care in ambulatory practices.

Acknowledgments

This project was supported by grant number R01HS024914 from the Agency for Healthcare Research and Quality. The content is solely the responsibility of the authors and does not necessarily represent the official views of the Agency for Healthcare Research and Quality.

Authors' Contributions

MM conceived the paper. LB, JG, MB, KV, and CF provided critical intellectual input.

Conflicts of Interest

None declared.

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Abbreviations

CFIR: Consolidated Framework for Implementation Research
FAQ: frequently asked questions

IRB: institutional review board
MOQC: Michigan Oncology Quality Consortium
NIH: National Institutes of Health

Edited by G Eysenbach; submitted 23.04.19; peer-reviewed by J Martin-Kerry, L McGoron; comments to author 03.10.19; revised version received 19.11.19; accepted 27.01.20; published 20.04.20.

Please cite as:
Manojlovich M, Bedard L, Griggs JJ, McBratnie M, Mendelsohn-Victor K, Friese CR
Facilitators and Barriers to Recruiting Ambulatory Oncology Practices Into a Large Multisite Study: Mixed Methods Study
JMIR Cancer 2020;6(1):e14476
URL: http://cancer.jmir.org/2020/1/e14476/
doi:10.2196/14476
PMID:32310140

Original Paper

Expression of Genes Related to Lipid Handling and the Obesity Paradox in Melanoma: Database Analysis

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Abstract

Background: Publicly available genomic and transcriptomic data in searchable databases allow researchers to investigate specific medical issues in thousands of patients. Many studies have highlighted the role lipids play in cancer initiation and progression and reported nutritional interventions aimed at improving prognosis and survival. Therefore, there is an increasing interest in the role that fat intake may play in cancer. It is known that there is a relationship between BMI and survival in patients with cancer, and that there is an association between a high-fat diet and increased cancer risk. In some cancers, such as colorectal cancer, obesity and high fat intake are known to increase the risk of cancer initiation and progression. On the contrary, in patients undergoing treatment for melanoma, a higher BMI unexpectedly acts as a protective factor rather than a risk factor; this phenomenon is known as the obesity paradox.

Objective: We aimed to identify the molecular mechanism underlying the obesity paradox, with the expectation that this could indicate new effective strategies to reduce risk factors and improve protective approaches.

Methods: In order to determine the genes potentially involved in this process, we investigated the expression values of lipid-related genes in patients with melanoma or colorectal cancer. We used available data from 2990 patients from 3 public databases (IST [In Silico Transcriptomics] Online, GEO [Gene Expression Omnibus], and Oncomine) in an analysis that involved 3 consecutive validation steps. Of this group, data from 1410 individuals were analyzed in the IST Online database (208 patients with melanoma and 147 healthy controls, as well as 991 patients with colorectal cancer and 64 healthy controls). In addition, 45 melanoma, 18 nevi, and 7 healthy skin biopsies were analyzed in another database, GEO, to validate the IST Online data. Finally, using the Oncomine database, 318 patients with melanoma (312 controls) and 435 patients with colorectal cancer (445 controls) were analyzed.

Results: In the first and second database investigated (IST Online and GEO, respectively), patients with melanoma consistently showed significantly (P<.001) lower expression levels of 4 genes compared to healthy controls: *CD36*, *MARCO*, *FABP4*, and *FABP7*. This strong reduction was not observed in patients with colorectal cancer. An additional analysis was carried out on a DNA-TCGA data set from the Oncomine database, further validating *CD36* and *FABP4*.

Conclusions: The observed lower expression of genes such as *CD36* and *FABP4* in melanoma may reduce the cellular internalization of fat and therefore make patients with melanoma less sensitive to a high dietary fat intake, explaining in part the obesity paradox observed in patients with melanoma.

(JMIR Cancer 2020;6(1):e16974) doi:10.2196/16974

KEYWORDS

gene expression; obesity paradox; melanoma, colorectal cancer; CD36; FABPs; transcriptomic analysis; public databases

Introduction

Genomic, transcriptomic, and proteomic data from several thousand patients and corresponding healthy controls are now publicly available on the internet, for many different pathologies, including different types of cancers. This allows researchers to investigate specific questions and medical hypotheses in silico, directly in the human context, without certain ethical concerns. We previously investigated expression data from several thousand patients, and identified novel potential markers useful for improving the diagnosis of melanoma and other solid cancers [1,2], as well as novel therapeutic approaches that were then validated in vitro by classical bench science [3,4]. In this study we aimed to determine the molecular mechanisms underlying the unexpected protective role of high fat intake in melanoma, given that obesity is a known risk factor in other cancers. The role fat plays in health maintenance as well as disease initiation and progression is being extensively investigated. There is particular interest in the protective role diet may have on cancer, since different cancer types are associated with being overweight or obese; furthermore, increased cancer mortality has been linked to dyslipidemia [5]. In patients with cancer, metabolic alterations impacting carbohydrate and lipid metabolism can activate phosphoinositide 3-kinase (PI3K) pathway–dependent oncogenic signaling, leading to an inflammatory state with increased expression of specific cytokines [6]. Omega-3 polyunsaturated fatty acids (PUFAs) have a beneficial effect by counteracting inflammation in cancer cells, which PUFAs easily diffuse into via the plasma membrane, by stimulating the production of anti-inflammatory metabolites [7]. PUFAs reduce plasma lipid levels and lipoproteins by modulating hepatic lipoprotein secretion [8] and likely by also mitigating dyslipidemia effects. How obesity and diet might impact melanoma onset and therapeutic efficacy has been discussed [9]. Although obesity and abnormal lipid levels in the blood represent established risk factors in other malignancies, they do not seem to impact cutaneous melanoma [10]. In fact, they are only slightly associated with an increased risk of cutaneous melanoma in men [11], although insulin resistance and dyslipidemia seem to promote the growth of uveal melanoma. Interestingly, obesity has been associated with a better prognosis and improved survival in patients undergoing treatment for metastatic melanoma. A higher BMI appears to be a protective factor in melanoma and this phenomenon has been named the obesity paradox [12]. In several other cancers, including colorectal cancer, being overweight and having a higher BMI are known risk factors, rather than protective conditions [13]. Fat metabolism might be differently controlled in different cancer cell types, thereby explaining why dyslipidemia may play divergent roles in different cancers. Scavenger receptors including macrophage receptor with collagenous structure (MARCO) and CD36 recognize and internalize lipoproteins, making them susceptible to degradation [14,15]. Furthermore, fatty acid–binding proteins (FABPs) play an important role in cancer progression and the intracellular transportation of long-chain fatty acids [16]. These molecules exert a pivotal role in regulating lipid metabolism.

The aim of this study was to investigate the expression of genes related to lipid-handling to analyze the molecular basis of the obesity paradox observed in melanoma.

Methods

Overview

The study was carried out in 3 steps: (1) a selection step was carried out on a public database, IST (In Silico Transcriptomics) Online, to identify genes of potential interest; (2) data collected in the initial selection step were validated in a first-round validation step with another database, GEO (Gene Expression Omnibus); and (3) data were further validated in a subsequent second-round validation step with a third database (Oncomine). Table 1 shows the databases used throughout the process and the types of patients investigated in each step.

First, in the selection step, the IST Online public database [17] was used to obtain gene expression data. It returns plots indicating the expression values of the given gene compared to the expression value of a second given reference gene. This can be carried out with several different cancer data sets and corresponding healthy controls. The analysis was performed with melanoma versus healthy skin and with colorectal cancer versus healthy control biopsies. In turn, we indicated our genes of interest (*CD36*, *MARCO*, *FABP1*, *FABP2*, *FABP3*, *FABP4*, *FABP6*, or *FABP7*) as the first gene and used a known housekeeping gene, beta-2 microglobulin (*B2M*), as the reference gene; it should be noted that the expression values of the first gene are independent from the reference gene and the values do not change if a different reference gene is chosen. We previously reported the methods used to study the expression of other molecules to identify relevant melanoma markers [2]. We analyzed data from 1410 individuals, including 208 patients with melanoma and 147 healthy controls, and 991 patients with colorectal cancer and 64 healthy controls. The first-round validation was carried out using the GEO public database [18]. The GDS1375 data set was used, which represents expression data from 45 melanoma biopsies, 18 nevi biopsies, and 7 heathy skin biopsies. The second-round validation was carried out on the DNA-TCGA data set in the Oncomine database [19]. In this case, 318 patients with melanoma were compared to 312 healthy controls, and 435 patients with colorectal cancer were compared to 445 healthy controls. The Human Protein Atlas public database was also interrogated [20].

Table 1. Schematic representation of the steps of this study.

Study phase and data set	Cancer type and subtype	Cancer samples, n	Control samples, n	Database
Selection				IST (In Silico Transcriptomics) Online
Melanoma and normal skin	Melanoma	208	147	
Colorectal cancer and controls	Colorectal cancer	991	64	
First validation round				GEO (Gene Expression Omnibus)
Melanoma and normal skin (GDS1375 data set)	Melanoma	45	25	
Second validation round				Oncomine
DNA-TCGA	Melanoma	318	312	
DNA-TCGA	**Colorectal cancer**			
	Colon adenocarcinoma	212	445	
	Rectal adenocarcinoma	90	445	
	Colon mucinous adenocarcinoma	37	445	
	Cecum adenocarcinoma	65	445	
	Rectal mucinous adenocarcinoma	7	445	
	Rectosigmoid adenocarcinoma	24	445	

Statistical Analysis

Within the scatterplots obtained from the IST Online database analysis, the number of patients falling above or below the chosen threshold were counted and analyzed according to the Fisher exact test using GraphPad Prism 5 (GraphPad Software, Inc).

Other statistical analyses were carried out on the expression values obtained by querying the GEO database. Data was analyzed with analysis of variance and analysis for the linear trend from healthy to nevi to melanoma samples was carried out, both with GraphPad Prism 5. The threshold for statistical significance was set at $P<.001$.

Results

Overview

Gene expression of *CD36*, *MARCO*, and various *FABP* isoforms in 355 patients (208 patients with melanoma versus 147 healthy skin controls) was analyzed, according to the transcriptome expression data reported in the IST Online database. Table 2 shows the results and indicates the statistical significance of distribution above or below the given threshold, according to the Fisher exact test, for both melanoma and colorectal cancer data for all 8 genes investigated. The threshold value was chosen as the value best discriminating the largest population within the controls. The following threshold values were used: *CD36*: 1000; *MARCO*: 150; *FABP1*: 100 in melanoma and 1000 in colorectal cancer; *FABP2*: 100; *FABP3*: 250; *FABP4*: 2000; *FABP6*: 200; *FABP7*: 500. *FABP5* does not appear in the IST Online database.

Interestingly, the 4 genes that had a significant difference in melanoma were not significantly different in patients with colorectal cancer versus healthy controls, indicating that the difference observed in melanoma appears to be cancer-specific.

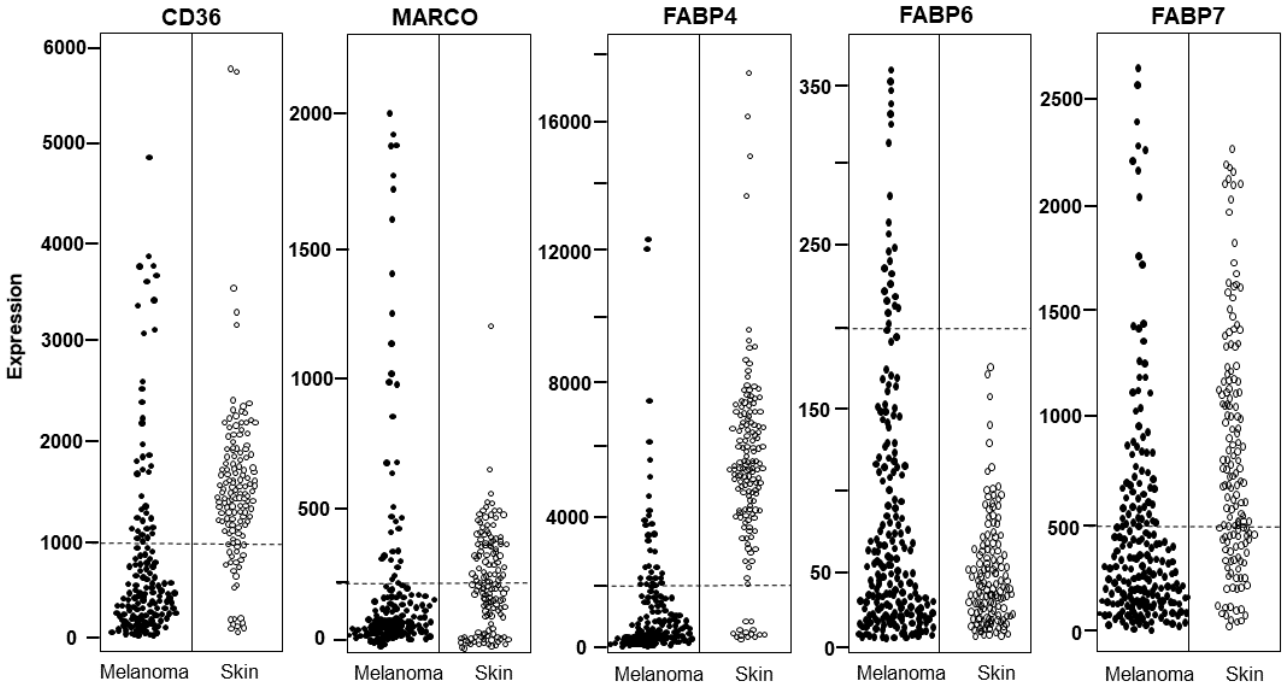
Figure 1 indicates the expression values of the 5 genes that had significant differences in melanoma versus healthy skin controls (*CD36*, *MARCO*, *FABP4*, *FABP6*, and *FABP7*). The significance of the distribution reported in Table 2 was computed by counting the number of individuals falling below or above the thresholds indicated by the dashed lines. The expression of *CD36*, *MARCO*, *FABP4*, *FABP6*, and *FABP7* in melanoma samples and healthy skin biopsies is visualized, according to data retrieved from the IST Online database.

These data indicate that melanoma samples show significantly lower expression of genes involved in fatty acid uptake (*CD36* and *MARCO*) and intracellular fatty acid binding (*FABP4* and *FABP7*) compared to healthy controls, and this phenomenon was not observed in a colorectal cancer data set.

Table 2. Expression in melanoma and colorectal cancer, according to the IST (In Silico Transcriptomics) Online database. Where *P* values are <.001, there was a statistically significant difference between the respective cancer values versus control values, evaluated as distribution above or below the given threshold, according to the Fisher exact test.

Gene	Regulation in melanoma versus controls	*P* value	Regulation in colorectal cancers versus controls	*P* value
CD36	Downregulation	<.001	No difference	.58
MARCO	Downregulation	<.001	No difference	.02
FABP1	No difference	.64	Downregulation	<.001
FABP2	No difference	.15	Downregulation	<.001
FABP3	No difference	.08	No difference	.07
FABP4	Downregulation	<.001	No difference	.60
FABP6	Upregulation	<.001	Upregulation	<.001
FABP7	Downregulation	<.001	No difference	>.99

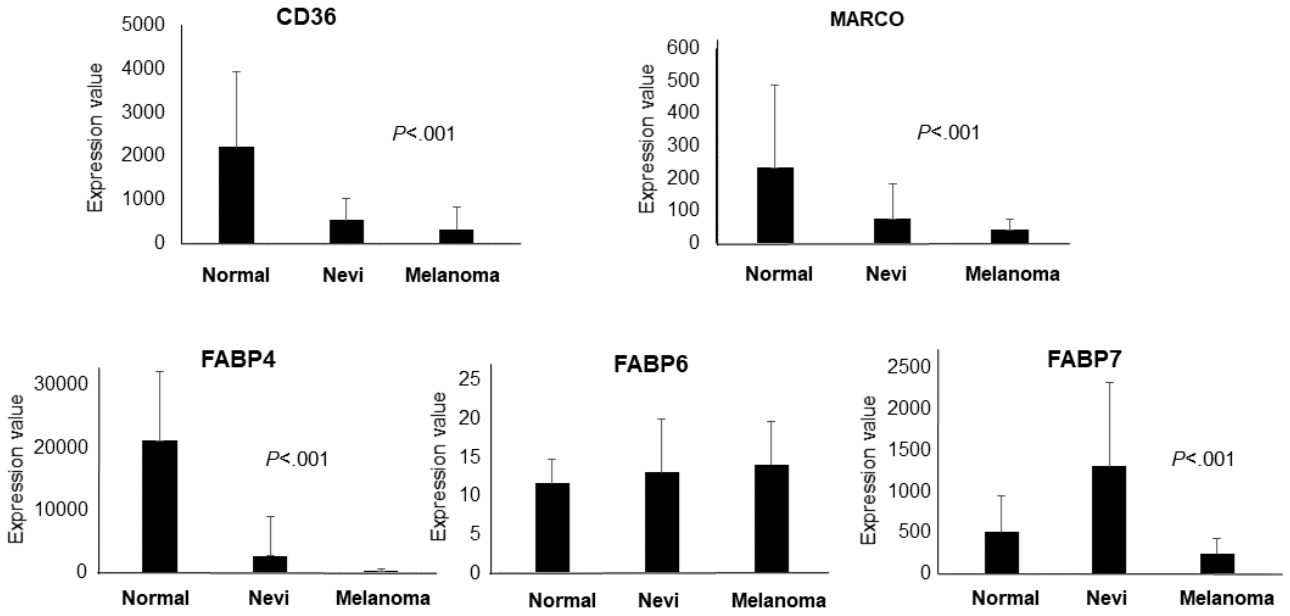
Figure 1. Expression of *CD36*, *MARCO*, *FABP4*, *FABP6*, and *FABP7* in melanoma and healthy skin samples from the IST (In Silico Transcriptomics) Online data set. Each dot indicates one individual and dashed lines indicate the threshold used to calculate the statistical significance of the distribution difference reported in Table 2. All reported genes show a significantly different distribution in melanoma versus controls according to the Fisher exact test (*P*<.001).



First Validation Round

Data collected from the IST Online database were then validated on a different database, GEO. Expression values in melanoma were obtained from the GDS1375 data set, as detailed in the Methods section. Figure 2 shows that the expression values of *CD36*, *MARCO*, *FABP4*, and *FABP7* are significantly decreased in melanoma samples (n=45) compared to nevi (n=18) and healthy skin (n=7) biopsies. A significant (*P*<.001) linear trend from healthy controls to nevi to melanoma biopsies was observed in *CD36*, *MARCO*, and *FABP4*. Therefore, the *CD36*, *MARCO*, *FABP4*, and *FABP7* data obtained from the IST Online database were validated on the GEO database. *FABP6*, which was increased in melanoma compared to control in the IST Online database (Table 2), showed a weak, nonsignificant increase in the GEO database (Figure 2).

Figure 2. Expression of *CD36*, *MARCO*, *FABP4*, *FABP6*, and *FABP7* in melanoma, nevi, and healthy skin biopsies from the GDS1375 data set on the GEO (Gene Expression Omnibus) database. Changes observed in the GEO database were in the same direction as observed in the IST (In Silico Transcriptomics) Online database for all genes except *FABP6*. Statistical significance was calculated by analysis of variance.



Second Validation Round

The 4 genes validated in GEO were further investigated in a third public database, Oncomine. Table 3 shows the statistical significance of the log2 copy number units change in the DNA-TCGA data set expression data from patients with melanoma and colorectal cancer compared to healthy controls, as analyzed in the Oncomine database. This analysis validated significant differences in *CD36* and *FABP4* expression in melanoma versus controls, and no significant difference in colorectal cancer.

Table 3. Gene expression in the DNA-TCGA data sets analyzed in the Oncomine database[a].

Gene	*P* values for the melanoma DNA-TCGA data set	*P* values for the colorectal cancer DNA-TCGA data set
CD36	<.001	>.99
MARCO	.58	>.99
FABP4	<.001	>.99
FABP7	>.99	.04

[a]The statistical significance of the differential log2 copy number in patients with melanoma or colorectal cancer versus controls is reported. The significance threshold was set to *P*<.001.

A final investigation was then carried out using the Human Protein Atlas public database. Although the potential roles of the genes investigated in this study were not verified in melanoma, their roles have been confirmed in other cancers. Specifically, increased *CD36* gene expression levels indicate an unfavorable prognostic value in 354 patients with stomach cancer (*P*<.001), and increased *FABP7* gene expression levels indicate an unfavorable prognostic value in 877 patients with renal cancer (*P*<.001), yet indicate a favorable prognostic value in 1075 patients with breast cancer.

Discussion

In this study we investigated the expression of different genes involved in lipid metabolism and found a significant difference in melanoma versus controls. This may explain part of the mechanism behind the obesity paradox observed in patients undergoing treatment for metastatic melanoma. The mechanisms underlying the association between dyslipidemia and melanoma remain controversial; this is due to the different metabolic controls within bulk melanoma cells and cancer stem cells or metastasis-initiating cells [21,22]. Metastasis-initiating cells display high *CD36* levels, which may indicate a crucial contribution of dietary lipids in the promotion of metastasis [23]. Furthermore, as we previously demonstrated, melanoma cancer stem cells show higher intracellular neutral lipids, higher lipogenesis activation, and lower autophagic flux [24]. This evidence indicates a complex molecular apparatus that allows melanoma cells to finely regulate fatty acid storage and mobilization depending on the metabolic environment and their differentiation level.

FABP4 and *FABP2* have recently been reported to have a significant association with cancer progression in patients with colorectal cancer [16] and several studies demonstrate that obesity and high fat intake are risk factors in colorectal cancer [13,25-28]. On the other hand, several studies highlight the

obesity paradox in melanoma, reporting significantly lower mortality in overweight patients undergoing treatment for melanoma [29], although a recent publication indicated that some caution is warranted [30]. Patients with melanoma or colorectal cancer appear to respond in opposite ways to high dietary fat intake or fat metabolism and may therefore be useful models to investigate how lipid-related gene expression may differentially regulate cancer initiation. For this reason, this study investigated lipid-related gene expression in patients with melanoma or colorectal cancer. Many genes have been identified as lipid modulators, although this field still remains poorly investigated. Genes controlling dyslipidemia in mice were recently reported [31], as well as other molecules that interfere with lipid storage [32,33], while a complete list of lipid-related genes in humans is currently lacking. In this work we investigated the expression of 8 genes (*FABPs* and other lipid-related genes) in melanoma and colorectal cancer biopsies, hypothesizing that differences in melanoma and colorectal cancer gene expression may partly explain the different role dietary fat plays in melanoma (ie, protective) and colorectal cancer (ie, detrimental). A significant reduction of the genes for scavenger receptors CD36 and MARCO (which are able to bind lipoproteins) and FABP4 and FABP7 translocases (which are able to bind and cell-internalize fatty acids) was found in melanoma biopsies compared to healthy controls, according to 2 independent databases, IST Online and GEO. We hypothesize that this reduced expression may lead to a reduced uptake of lipids and reduced cellular internalization. *CD36* and *FABP4* were also validated in a third database, Oncomine, using the DNA-TCGA data set. These genes showed no difference in control expression data compared to data from patients with colorectal cancer, for whom high fat dietary intake represents a negative prognostic factor. Therefore, we believe that the reduced gene expression observed in melanoma (571 patients and 484 controls, in 3 independent databases) might contribute to counteracting the detrimental effects of high fat intake.

More extensive analyses are ongoing in other cancers and on a larger list of relevant lipid-related genes; nevertheless, the results from this study may reveal some of the molecular mechanisms responsible for the obesity paradox observed in melanoma.

Acknowledgments

We thank Professor Eugenio Gaudio (Sapienza University) for the illuminating brainstorms rising our interest in molecular mechanisms linking cancer cell growth and lipid metabolism. This work was supported by an Italia-India Cooperation grant (Sapienza University) to CG and by RC 2018 from the Ministry of Health to AF.

Authors' Contributions

CG contributed to conceptualization and writing. LT and FS conducted data retrieval. FS analyzed data and LT wrote the initial draft. AF contributed to data interpretation and writing. CG and AF provided supervision.

Conflicts of Interest

None declared.

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Abbreviations

B2M: beta-2 microglobulin
FABP: fatty acid–binding protein
GEO: Gene Expression Omnibus
IST: In Silico Transcriptomics
MARCO: macrophage receptor with collagenous structure
PI3K: phosphoinositide 3-kinase
PUFA: polyunsaturated fatty acids

Edited by G Eysenbach; submitted 08.11.19; peer-reviewed by S Pesälä, J Fan; comments to author 17.03.20; revised version received 19.03.20; accepted 21.03.20; published 19.05.20.

Please cite as:
Giampietri C, Tomaipitinca L, Scatozza F, Facchiano A
Expression of Genes Related to Lipid Handling and the Obesity Paradox in Melanoma: Database Analysis
JMIR Cancer 2020;6(1):e16974
URL: http://cancer.jmir.org/2020/1/e16974/
doi:10.2196/16974
PMID:32209538

Original Paper

Awareness of the Signs, Symptoms, and Risk Factors of Cancer and the Barriers to Seeking Help in the UK: Comparison of Survey Data Collected Online and Face-to-Face

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Abstract

Background: Cancer is the second leading cause of death globally, causing an estimated 9.6 million deaths in 2018. Low cancer symptom awareness has been associated with poor cancer survival for all cancers combined. The Cancer Awareness Measure (CAM) is a validated, face-to-face survey used since 2008 to measure the UK public's awareness of the symptoms and risk factors of cancer as well as the barriers to seeking help.

Objective: The aim of this study is to explore whether online data collection can produce a representative sample of the UK population, compare awareness of cancer signs and risk factors and the barriers to seeking help between data collected online and face-to-face, and examine the relationships between awareness and demographic variables.

Methods: Differences in awareness of cancer signs, symptoms, and risk factors among samples were explored while adjusting for demographic differences (age, gender, ethnicity, educational level, marital status, and country of residence) to distinguish the effect of data collection method. Multivariate logistic regression models were used to calculate adjusted odds ratios for recall and recognition of signs and symptoms, risk factors, and barriers to seeking help.

Results: A total of 4075 participants completed the CAM, 20% (n=819) via face-to-face interviews and 80% online (n=3256; agency A: n=1190; agency B: n=2066). Comparisons of data collected using face-to-face interviews and online surveys revealed minor differences between samples. Both methods provided representative samples of the UK population with slight differences in awareness of signs, symptoms, and risk factors and frequency of help-seeking barriers reported.

Conclusions: These findings support a move to online data collection for the CAM. The flexibility afforded will enable the CAM to explore a wider range of issues related to the prevention, early diagnosis, and treatment of cancer.

(JMIR Cancer 2020;6(1):e14539) doi:10.2196/14539

KEYWORDS

neoplasms; surveys and questionnaires; cross-sectional study; awareness; help-seeking behavior; cancer

Introduction

Background

Cancer is the second leading cause of death globally, causing an estimated 9.6 million deaths in 2018 [1]. Half of the people diagnosed with cancer in England and Wales survive for 10 years or more, but approximately 4 in 10 cases of cancer in the UK could be prevented [2]. Cancer survival has consistently been reported to be lower in the UK than similar European countries [3,4].

Late-stage diagnosis contributes to excess deaths for bowel [5], breast [6], and lung cancer [7] in the UK. Late diagnosis could be related to low awareness of symptoms, leading to delays in seeking medical help. Low cancer symptom awareness has been

associated with delays in seeking medical help and poor cancer survival for all cancers combined [8].

Earlier detection can improve patient experience [9], costs to the National Health Service (NHS) [10], and cancer survival, but it relies partly on prompt presentation [11]. Understanding and potentially improving awareness of cancer signs is an important step in reducing the incidence of late-stage cancer and reducing cancer deaths in the UK.

In 2008, Cancer Research UK, in partnership with University College London, King's College London, and University of Oxford, developed the Cancer Awareness Measure (CAM) [12]. The CAM is a validated survey designed to measure awareness of signs, symptoms, and risk factors for cancer and potential barriers to seeing a doctor.

Cancer Research UK has used the CAM to collect data biannually from 2008 to 2014 from a representative sample of the UK population via the Office for National Statistics (ONS) Opinions and Lifestyle Survey. Questions in the survey are a combination of recall and recognition questions, designed to assess public awareness. Recall questions are open-ended questions, asking participants to list as many cancer warning signs and risk factors that they can think of. These are followed by recognition questions, where participants are given a list of warning signs and risk factors and asked yes/no do they think these are risk factors or warning signs of cancer.

Data from the CAM indicate that the average number of cancer warning signs recognized by representative samples of the UK population has increased from 6.4 (SD 1.9) in 2008 to 6.8 (SD 1.5) in 2014 out of a possible nine warning signs posed in the survey [13]. Recall of risk factors appears to have followed the opposite pattern, with recall decreasing from a mean 2.2 in 2008 to 2.0 in 2014 [13]. Awareness of cancer signs and risk factors has consistently been found to be lower among men [14,15], younger adults [14], and those from lower socioeconomic groups [14,16,17] or ethnic minorities [15,18].

Although CAM data have traditionally been collected via face-to-face interviews conducted by the ONS, the response rates have declined over the years (from 61% in 2008 to 47% in 2017). This study explores the viability of moving data collection online, a move seen in many large market research organizations. In Great Britain, 90% of households have access to the internet, and 73% of people have accessed the internet with a mobile phone [19]. The benefits of online data collection include lower costs [17], higher data quality [20], and a faster rate of return and lower data entry times [21]. Conversely, the limitations may include sampling issues [21] and differences in sampling methodologies [22].

Although the relationships among questionnaire modality, response rates, and accuracy have been described as complex [23], previous research exploring the impact of data collection method is encouraging. Socially desirable behaviors have been reported to be less likely to be disclosed in interviews than online questionnaires [24], and disease prevalence rates are much closer to known rates when using internet studies compared with data collected over the telephone or face-to-face [25].

Research Objectives

The primary aim of this study is to identify the extent to which public awareness of cancer and attitudes toward seeking help vary by data collection method (face-to-face vs online data) in adults (aged ≥18 years) in Great Britain. The research objectives are to (1) explore whether online data collection can produce a representative sample of the UK population (differences between samples); (2) compare the awareness of signs, symptoms, and risk factors for cancer, as well as the barriers to seeking help between data collected online and face-to-face (differences in levels of awareness); and (3) explore whether any relationships observed between awareness and demographic variables are consistent across samples (interactions between survey provider and demographic variables).

Methods

Participants and Recruitment

Face-to-Face Sample

Between January and March 2017, face-to-face data were collected by the ONS via the Opinions and Lifestyle survey. The ONS use stratified probability sampling to select sampling points from a database of 27 million private households in the UK. A random sample of addresses from each sampling point were selected, and interviewers invited one adult respondent from each household to complete the CAM using a face-to-face, computer-assisted interview.

Online Samples

Online samples were recruited by two market research agencies. Agency A recruited participants to their online panel via a face-to-face survey. Agency A used a probability-based approach for recruitment, which avoids in-built bias commonly found in online panel sampling methods. Agency B used "active sampling," in which a subsample of participants were selected from their more than 800,000-member panel based on their age, gender, social class, and education. Agency B panel members are recruited from standard advertising and strategic partnerships with a range of websites.

Great Britain Population Data

The Great Britain population statistics were taken from the ONS (midyear population estimates, Households and Individuals Internet Access survey), census data, and NHS Digital (Health Survey for England).

Outcome Measures

Variables collected in the CAM are outlined in Textbox 1. Details of the development and content of the CAM can be found elsewhere [12].

To reduce bias, open-ended questions about signs, symptoms, and risk factors were asked before closed questions. The number of warning signs endorsed or risk factors recognized were summed to produce total scores. Coding manuals were provided to all market research agencies regarding how to code recalled items to ensure consistency.

Textbox 1. Outcome measures.

Sociodemographic characteristics

- We amended the standard ONS demographic questions and adapted these for online samples where necessary: age, gender, educational attainment, ethnicity, country of residence marital status, internet use, and self-reported health status.

Awareness of signs and symptoms of cancer (recall and recognition)

- Recall: "There are many warning signs and symptoms of cancer, please name as many as you can think of."
- Recognition: "Could any of the following be signs of cancer?": lump or swelling, persistent unexplained pain, unexplained bleeding, persistent cough or hoarseness, persistent change in bowel or bladder habits, difficulty swallowing, change in the appearance of a mole, a sore that does not heal, and unexplained weight loss.

Awareness of cancer risk factors (recall and recognition)

- Recall: "What things do you think affect a person's chance of developing cancer?"
- Recognition: "Could any of the following increase a person's chance of developing cancer?": smoking, getting sunburned, exposure to another person's smoking, drinking alcohol, having a close relative with cancer, being overweight, being older, not eating many fruits and vegetables, not eating enough fiber, eating too much red or processed meat, not doing much physical activity, and infection with HPV (human papillomavirus).

Barriers to seeing a general practitioner

- "Which of the following might put you off going to the doctor?"
- Participants were asked to indicate whether any of a range of barriers might put them off seeing a doctor on a 5-point agreement scale from strongly agree to strongly disagree.

Statistical Analysis

Weighting and Sample Differences

Each market research agency provided their own weighting variable to ensure the sample was representative of the Great Britain population and to adjust for nonresponse where possible. Our analyses were carried out using the weighted variable provided by each agency. We did not create a bespoke weighting variable because of the lack of nonresponse data available. See Multimedia Appendix 1 for how each survey provider weighted their data.

Weighted sample demographics were compared between the surveys to explore any differences between the collected samples. Differences between survey responses and Great Britain population statistics were not tested for significance because confidence intervals for Great Britain data were not available.

Differences in Levels of Awareness

Differences in awareness of cancer signs and symptoms and risk factors between samples were explored while adjusting for demographic differences (age, gender, ethnicity, educational level, marital status, and country of residence) with the aim of determining the effect of data collection method.

Multivariate logistic regression models were used to calculate adjusted odds ratios for recall and recognition of signs and symptoms, risk factors, barriers to seeking help, and awareness of bowel screening. The outcome variable was binary to show if the responder did or did not recall or recognize signs and symptoms, risk factors, barriers to seeking help, and awareness of bowel screening. Only statistically significant variables were included in the final logistic regression models.

Interactions Between Outcomes and Demographic Variables

Interaction terms between survey provider and key demographics (gender, age, education level, marital status, ethnicity, country, long-term health, and internet usage) were added to the awareness models. Whether data collected by different methods varied by demographic variables, while controlling for any differences in sample characteristics between the surveys, was explored.

Results

Participants

In total, 4075 participants completed the CAM. Online participants made up 80% (n=3256) of the sample (agency A: n=1190; agency B: n=2066). The remaining 20% (n=819) of participants completed face-to-face interviews.

Differences Between Samples

The three weighted samples were generally representative of the Great Britain population (Table 1).

Table 1. Demographic characteristics by survey provider and compared with Great British population statistics (N=4075).

Demographic	Face-to-face, %	Online, %[a]		Great Britain population, %
	Office for National Statistics (n=819)	Agency A (n=1190)	Agency B (n=2066)	
Age groups				
18-24	10.2	8.4	12.0	15.1[b]
25-44	33.8	33.4	32.1	32.1
45-54	18.0	17.9	20.9	17.2
55-64	15.1	16.9	16.9	13.9
≥65	22.8	23.1	18.1	21.7
Missing	—	0.2	—	—
Gender				
Male	49.1	49.9	48.0	49.3
Female	50.9	50.1	52.0	50.7
Ethnicity				
White	87.9	87.5	92.7	86.0
Nonwhite	12.1	12.5	7.3	14.0
Country of residence				
England	86.6	84.7	86.3	86.5
Scotland	8.3	10.2	8.7	8.6
Wales	5.1	5.1	5.0	4.9
Higher education qualification				
Degree	30.5	26.4	32.2	27.1
Below degree	42.7	55.7	54.1	44.7
No qualifications	12.7	15.5	6.6	23.0
Other	14.1	2.3	5.5	5.2
Don’t know	—	—	1.6	—
Marital status				
Partner	50.5	62.6	61.7	50.9
No partner	49.5	37.4	38.3	49.1
Long-term illness				
Very good	37.0	20.1	15.6	Very good/good: 76
Good	42.0	48.5	47.4	—
Fair	15.9	23.7	28.3	—
Bad	3.6	6.4	7.1	Very bad/bad: 7
Very bad	1.3	1.3	1.6	—
Refused	0.3	0.1	—	—
Internet usage				
Several times a day	64.2	65.6	79.9	At least once a day: 80
Once a day	14.3	13.2	13.7	—
4-6 days a week	3.1	2.9	3.0	—
2-3 days a week	3.7	4.2	1.6	—
Once a week	2.1	2.4	0.6	At least weekly: 8
Less than once a week	1.3	2.2	0.4	Less than weekly: 2

Demographic	Face-to-face, %	Online, %[a]		Great Britain population, %
	Office for National Statistics (n=819)	Agency A (n=1190)	Agency B (n=2066)	
Never	9.2	9.5	0.8	Did not use in the last 3 months: 10
Don't know	0.9	—	—	—
Refused	1.3	—	—	—

[a]Percentages are weighted using the weighting variable provided by each survey agency; see Multimedia Appendix 1 for more information.
[b]Ages 15-24 years.

The gender split of all three samples largely matched the Great Britain population; however, both online samples were older than the ONS sample and the Great Britain population. Scottish participants were slightly overrepresented by agency A (10.2% vs 8.6% of Great Britain population).

All samples included a higher proportion of white participants than the Great Britain population (Great Britain population: 86%; agency A: 87.5%; agency B, 93%) and reported higher educational attainment. Both online samples had a larger proportion of participants with a partner (agency A: 63%; agency B: 62%) compared with the Great Britain population (50.9%) and were more likely to report being in good health (agency A: 48.5%; agency B: 47.4%; ONS: 42%). Face-to-face participants were less likely to report their health as bad (3.6%; agency A: 6.4%; agency B: 7.1%; Great Britain population: 7%). More than 90% of agency B participants reported using the internet more than once a day compared with 78.5% of face-to-face and 78.8% of agency A participants.

Differences in Levels of Awareness (Outcomes)

The number of cancer warning signs and risk factors recognized and recalled within each sample are included in Multimedia Appendix 2.

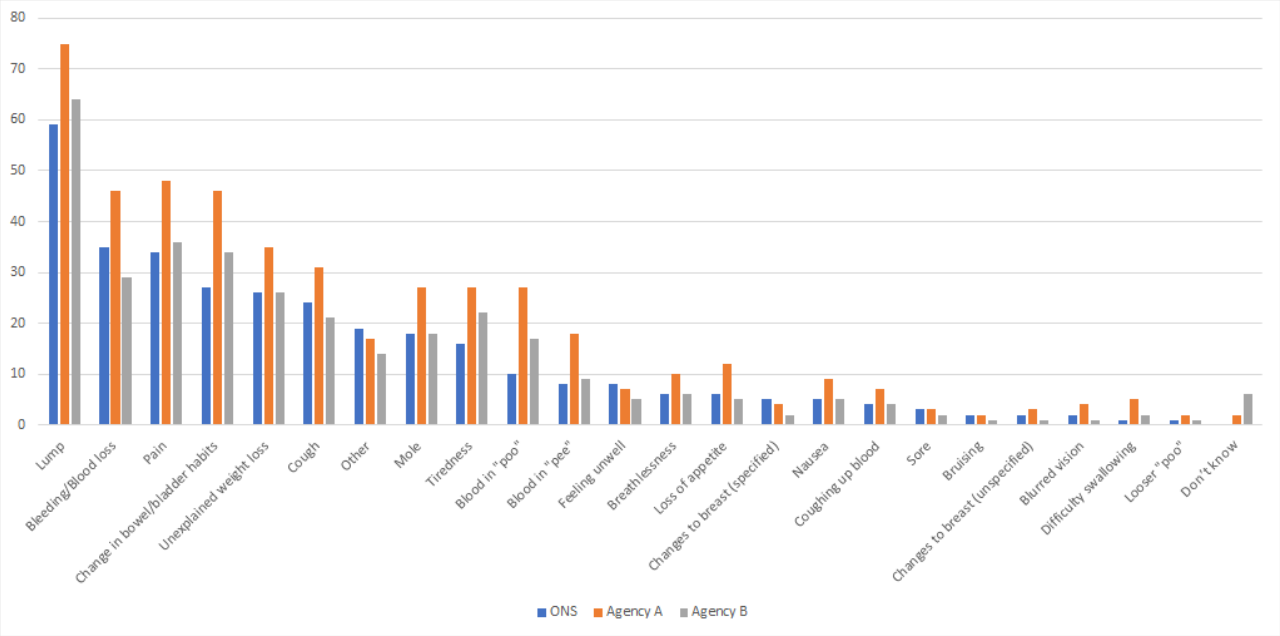
Cancer Warning Signs

Recall of Warning Signs

Agency A participants recalled significantly more signs of cancer than other participants, with a mean recall of five signs of cancer compared with three for both face-to-face and agency B participants. Figure 1 shows the percentage of participants recalling cancer warning signs.

A lump was the most frequently recalled sign in all three samples (agency A: 75.1%, agency B: 64.2%, face-to-face: 58.6%; Figure 1). Compared with face-to-face participants, agency B participants were less likely to recall bleeding or blood loss (29% vs 35%, $P<.001$, OR 0.7, 95% CI 0.6-0.8) and sores (1.5% vs 2.7%, $P=.003$, OR 0.4, 95% CI 0.2-0.8). Agency A participants were more likely than face-to-face participants to recall a lump (75% vs 59%, $P<.001$, OR 2.3, 95% CI 1.8-2.8), pain (48% vs 34%, $P<.001$, OR 1.9, 95% CI 1.6-2.3), bleeding or blood loss (46% vs 35%, $P<.001$, OR 1.5, 95% CI 1.3-1.8), and blood in urine (18% vs 8%, $P<.001$, OR 2.5, 95% CI 1.9-3.3). Participants from both online samples were more likely than face-to-face participants to recall change in bowel or bladder habits (agency A: 46%, $P<.001$, OR 2.9, 95% CI 2.4-3.5; agency B: 34%, $P<.001$, OR 1.5, 95% CI 1.2-1.8 vs face-to-face: 27%), blood in feces (agency A: 26%, $P<.001$, OR 4.2, 95% CI 3.3-5.6; agency B: 17%, $P<.001$, OR 2.1, 95% CI 1.6-2.7 vs face-to-face: 9.6%) and tiredness (agency A: 28%, $P<.001$, OR 2.1, 95% CI 1.7-2.7; agency B: 22%, $P=.04$, OR 1.3, 95% CI 1.0-1.6 vs face-to-face: 16%). Online samples were more likely to answer "don't know" when asked to recall warning signs for cancer than face-to-face responders (agency A: 1.8%, $P=.02$, OR 4.4, 95% CI 1.5-19.3; agency B: 6.1%, $P<.001$, OR 20.4, 95% CI 7.5-38.5; face-to-face: 0.2%).

Figure 1. Percentage of participants recalling cancer warning signs.



Recognition of Cancer Signs

Agency A participants demonstrated greater recognition of signs and symptoms, recognizing a mean of eight of nine presented signs and symptoms of cancer, compared with ONS and agency B participants who recognized a mean of seven.

An unexplained lump or swelling was the most commonly recognized sign in all samples (face-to-face: 94.7%; agency A: 98.4%; agency B: 94.7%; Table 2). Agency A participants were more likely than face-to-face participants to recognize a lump (98% vs 95%, *P*=.009, OR 2.4, 95% CI 1.3-4.6) and unexplained weight loss (96% vs 89%, *P*<.001, OR 3.5, 95% CI 2.3-5.5). For other signs, there were no significant differences between agency A and face-to-face responses.

Agency B participants were less likely than face-to-face participants to recognize a lump (94% vs 95%, *P*=.002, OR 0.4, 95% CI 0.3-0.7), changes in bowel habits (88% vs 90%, *P*<.001, OR 0.5, 95% CI 0.4-0.7), persistent cough (83% vs 84%, *P*=.01, OR 0.7, 95% CI 0.6-0.9), unexplained weight loss (87% vs 89%, *P*=.03, OR 0.7, 95% CI 0.5-0.9), persistent difficulty swallowing (76% vs 78%, *P*=.004, OR 0.7, 95% CI 0.6-0.9), and unexplained bleeding (86% vs 88%, *P*=.005, OR 0.7, 95% CI 0.4-0.9). Agency B participants were more likely to recognize a sore that does not heal as a sign or symptom of cancer (70% vs 63%, *P*=.01, OR 1.3, 95% CI 1.1-1.5).

Table 2. Percentage of participants from each sample who answered “yes” to the question “Do you think that the following could be a warning sign for cancer?” (N=4075).

Yes, it could	Face-to-face, %	Online			
	Office for National Statistics (n=819)	Agency A (n=1190)		Agency B (n=2066)	
		Participants, %	*P* value	Participants, %	*P* value
Unexplained lump or swelling	94.7	98.4	.009	94.7	.002
Change in appearance of a mole	92.9	95.9	.09	93.9	.006
Persistent change in bowel or bladder habits	89.8	91.4	.58	88.2	.001
Unexplained weight loss	89.1	96.4	<.001	86.5	.03
Unexplained bleeding	88.0	89.1	.93	86.3	.005
Persistent cough or hoarseness	83.7	86.7	.10	82.8	.01
Persistent unexplained pain	79.0	82.0	.05	83.8	.47
Persistent difficulty swallowing	78.3	76.3	.15	76.2	.004
Sore that does not heal	63.0	66.6	.18	70.0	.01

Awareness of Risk Factors for Cancer

Recall of Cancer Risk Factors

Agency A participants recalled a mean of five risk factors compared with both face-to-face and agency B participants who recalled a mean of three. Fewer agency A participants recalled zero risk factors (3.2%) than face-to-face (8.2%) or agency B (11.6%) participants (Multimedia Appendix 1).

The most frequently recalled risk factor within all samples was smoking, but recall was significantly lower in the agency B sample (*P*<.001, OR 0.4, 95% CI 0.3-0.5; Table 3). The same pattern was seen for alcohol (agency A: 55%, *P*=.07, OR 1.2, 95% CI 1.0-1.4; face-to-face: 54%; agency B: 43%, *P*<.001, OR 0.7, 95% CI 0.6-0.8). A higher proportion of agency B participants answered "don't know" to this recall question (5.4%, *P*<.001; face-to-face: 0.1%; agency A: 0.9%).

Table 3. Recall of risk factors for cancer from the three samples (N=4075).

Risk factor	Face-to-face, %	Online			
	Office for National Statistics (n=819)	Agency A (n=1190)		Agency B (n=2066)	
		Participants, %	*P* value	Participants, %	*P* value
Smoking	81.9	81.5	.96	68.6	.001
Alcohol	53.5	55.1	.07	43.3	.001
Diet (unspecified)	36.2	50.3	.001	40.0	.02
Sunburn	25.0	30.1	.001	21.1	.06
Being overweight	14.9	20.0	.04	25.6	.001
Exercise	13.8	24.1	.001	16.4	.06
Occupational exposure	13.7	12.2	.88	8.5	.001
Genes	11.5	23.8	.001	19.8	.001
Pollution	10.4	13.0	.002	7.8	.02
Family history	10.0	22.6	.001	15.2	.003
Lifestyle	9.6	18.1	.001	14.9	.02
Stress	8.4	11.7	.001	5.6	.02
Radiation	5.9	6.3	.19	4.7	.06
High-fat diet	4.6	2.1	.001	1.0	.001
Red meat	3.7	3.9	.51	3.3	.80
Sun beds	3.7	5.3	.09	2.0	.01
Passive smoking	2.7	3.1	.07	1.5	.001
Older age	2.3	6.1	.001	4.8	.009
Mobile phones	1.1	0.3	.60	0.2	.06
Many sexual partners	1.0	0.6	.98	1.5	.10
Other	12.9	24.5	.001	12.9	.61
Nothing	2.8	0.0	—	0.4	—
Refused	4.4	0.0	—	0.0	—
Don't know	0.1	0.9	.05	5.4	.001

Recall of sunburn (30%, *P*<.001, OR 1.7, 95% CI 1.3-2.0), genes (24%, *P*<.001, OR 2.4, 95% CI 1.8-3.0), and lack of exercise (24%, *P*<.001, OR 2.1, 95% CI 1.6-2.7) as risk factors was significantly higher in the agency A survey compared with the face-to-face survey (sunburn: 25%; genes: 12%; lack of exercise: 14%). Agency B participants were less likely than face-to-face participants to recall occupational exposure (9% vs 14%, *P*<.001, OR 0.6, 95% CI 0.5-0.8), stress (6% vs 8%, *P*=.02, OR 0.6, 95% CI 0.5-0.9), and high-fat diet (1% vs 5%, *P*<.001, OR 0.2, 95% CI 0.1-0.3). Participants from both online surveys were more likely than face-to-face participants to recall being overweight (agency A: 20%, *P*=.04, OR 1.4, 95% CI 1.1-1.8; agency B: 25%, *P*<.001, OR 1.8, 95% CI 1.4-2.2; face-to-face: 15%), family history (agency A: 23%, *P*<.001, OR 2.8, 95% CI 2.1-3.6; agency B: 15%, *P*=.003, OR 1.5, 95% CI 1.1-2.0; face-to-face: 10%), lifestyle (agency A: 18%, *P*<.001, OR 1.8, 95% CI 1.4-2.4; agency B: 15%, *P*=.02, OR 1.4, 95% CI 1.1-1.8; face-to-face: 10%), diet (agency A: 50%, *P*<.001 OR 2.2, 95% CI 1.8-2.7; agency B: 40%, *P*=.02, OR 1.2, 95% CI 1.0-1.4; face-to-face: 36%), and older age (agency A: 6%, *P*<.001, OR 3.4, 95% CI 2.1-5.9; agency B: 5%, *P*=.009, OR 2.0, 95% CI 1.2-3.5; face-to-face: 2%) as risk factors for

cancer. The only risk factor that face-to-face participants were more likely to recall was having a high-fat diet (face-to-face: 5%; agency A: 2%, *P*=.001, OR 0.4, 95% CI 0.3-0.7; agency B: 1%, *P*<.001, OR 0.2, 95% CI 0.1-0.3).

Recognition of Cancer Risk Factors

Online participants recognized more risk factors, a mean of 9 of 12 listed compared with 8 for face-to-face participants.

Participants recruited by online agencies were more likely than face-to-face participants to recognize being overweight (agency B: 74%, *P*<.001, OR 1.4, 95% CI 1.1-1.7; agency A: 73%, *P*=.004, OR 1.3, 95% CI 1.1-1.7; face-to-face: 67%), having a family history of cancer (agency B: 77%, *P*=.02, OR 1.3, 95% CI 1.0-1.5; agency A: 77%, *P*<.001, OR 1.5, 95% CI 1.2-1.9; face-to-face: 69%), eating too much red or processed meat (agency B: 61%, *P*<.001, OR 1.5, 95% CI 1.3-1.8; agency A: 58%, *P*<.001, OR 1.5, 95% CI 1.3-1.8; face-to-face: 52%), and infection with human papillomavirus (HPV) as risk factors of cancer (agency A: 41%, *P*<.001, OR 1.8, 95% CI 1.5-2.2 agency B: 49%, *P*<.001, OR 2.4, 95% CI 2.0-2.9; face-to-face: 29%). Agency B participants were more likely than face-to-face participants to recognize older age (68% vs 60%, *P*<.001, OR 1.4, 95% CI 1.2-1.7) but less likely to recognize smoking (95% vs 96%, *P*=.001, OR 0.4, 95% CI 0.2-0.7) as risk factors of cancer (Table 4).

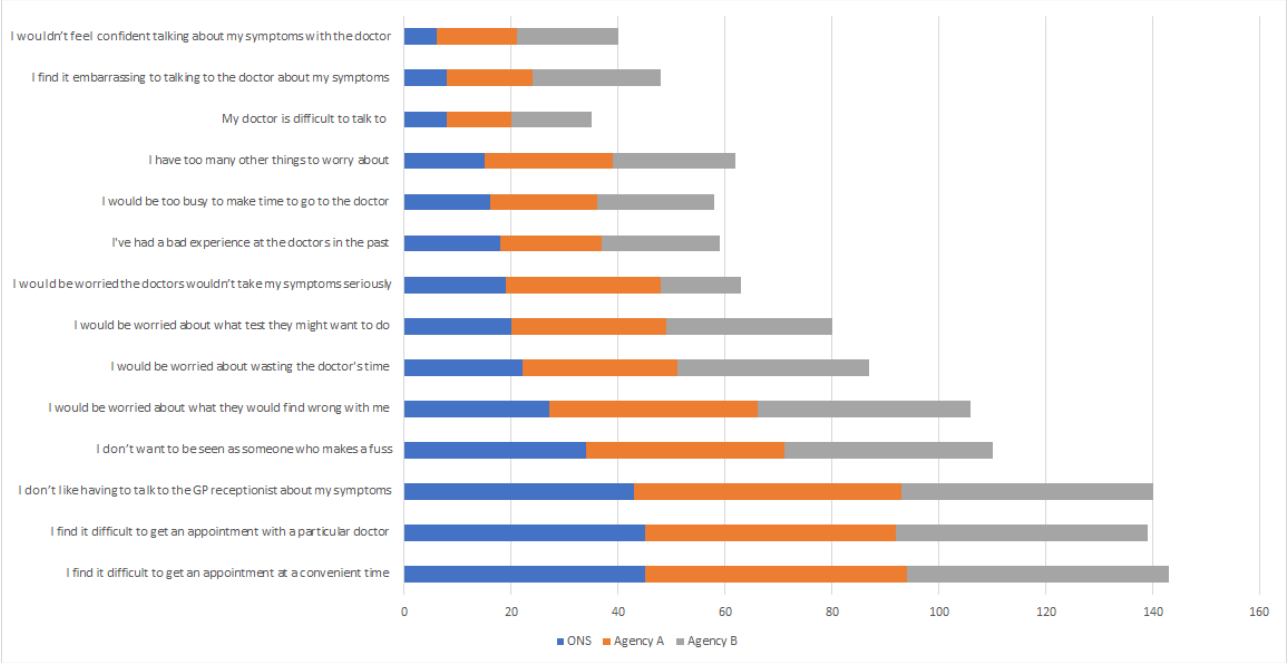
Table 4. Percentage of participants from each sample that recognized each risk factor for cancer (N=4075).

Risk factor	Face-to-face, %	Online			
	ONS (n=819)	Agency A (n=1190)		Agency B (n=2066)	
		Participants, %	*P* value	Participants, %	*P* value
Smoking	96.3	98.6	.24	95.4	.001
Getting sunburned	94.0	94.6	.40	93.7	.42
Exposure to another person's smoking	88.6	88.2	.77	86.1	.002
Drinking alcohol	78.9	78.6	.43	78.6	.93
Having a close relative with cancer	68.5	76.6	.001	76.6	.02
Being overweight	66.6	72.8	.004	74.1	.001
Being older	60.1	57.1	.16	67.8	.001
Not eating many fruits and vegetables	52.8	53.3	.95	53.6	.13
Not eating enough fiber	52.6	46.4	.10	49.1	.37
Eating too much red or processed meat	51.5	57.9	.001	61.0	.001
Not doing much physical activity	49.7	56.1	.002	55.1	.001
Infection with HPV (human papillomavirus)	29.2	41.3	.001	48.9	.001

Barriers to Seeing a General Practitioner

Online survey participants were significantly more likely to endorse 8 of 14 barriers to seeing a GP than face-to-face participants. The most frequently endorsed barrier for face-to-face and agency B participants was "I find it difficult to get an appointment at a convenient time"; for agency A participants, it was "I don't like having to talk to the GP receptionist." Agency B participants were more likely than face-to-face participants to endorse an additional barrier "my doctor is difficult to talk to" (*P*=.001, OR 1.6, 95% CI 1.2-2.1). Figure 2 shows the percentage of participants that endorsed barriers to going to the doctor.

Figure 2. Percentage of participants that endorsed barriers to going to the doctor.



Interactions Between Outcomes and Demographic Variables.

Recall of bleeding or blood loss, cough, and difficulty swallowing showed significant interactions between sex and survey provider. For participants living in Scotland, those recruited by agency B were significantly less likely to recall bleeding or blood loss as a sign of cancer compared with those recruited by agency A (P=.04).

Fewer females recognized family history as a risk factor of cancer when completing face-to-face interviews than in online surveys (agency A females: P=.006; agency B females: P<.001). Significantly fewer males recognized not doing enough physical exercise as a risk factor of cancer in the agency B survey compared with agency A (P=.02).

Discussion

Analysis

This analysis explored the viability of moving from face-to-face to online data collection for the Cancer Research UK's CAM.

Principal Results

Comparisons of data collected using face-to-face interviews and online surveys revealed minor differences between samples. Both methods provided broadly representative samples of the UK population with slight differences in awareness of signs, symptoms, and risk factors of cancer and frequency of help-seeking barriers reported, leading us to conclude that online data collection for the CAM is possible.

Recall of certain cancer signs and risk factors varied by demographic group. Recall of bleeding/blood loss, cough, and difficulty swallowing had significant interactions between sex and survey provider. Overall, recognition of risk factors was higher in the online surveys.

Recognition of risk factors varied by sex, education level, and country. Significantly fewer females recognized family history as a risk factor of cancer in the face-to-face survey compared with the online surveys. Significantly fewer males recognized not doing enough physical exercise as a risk factor of cancer in the online samples compared with the face-to-face sample. The reasons for these variations are unclear but provide avenues for further research and action.

Overall, online participants recruited by agency A were significantly more likely to recall cancer signs and risk factors compared with both agency B and face-to-face participants. This finding implies that agency A participants may be more engaged and knowledgeable than the other survey participants. Educational levels did not differ greatly among the three samples. Agency A participants may have been more engaged than other participants because they had previously taken part in a face-to-face survey, indicating that they may be a particularly motivated group.

Comparison With Prior Work

Previous research has found that levels of awareness of the HPV virus [26] and cholesterol [23] were higher among online than face-to-face or paper survey respondents. In this study, online participants recognized more risk factors than face-to-face participants, including being overweight, having a family history of cancer, eating too much red or processed meat, and infection with HPV (cholesterol was not assessed). However, only one of the online samples reported higher mean recall of risk factors compared with face-to-face participants. This particular panel, agency A, recruited participants after they had taken part in a paper survey, which may have resulted in a more engaged and knowledgeable sample.

Survey research within student populations has suggested that online participants are more likely to answer "don't know" than those completing the same survey face-to-face [7]. Other research suggests that nonresponse to open-ended questions can be reduced through online data collection [8]. In this study, face-to-face participants were less likely than online participants to respond to recall questions around signs, symptoms, and risk factors with "don't know."

Socially desirable behaviors have been found to be less likely to be disclosed in interviews than online questionnaires [27,28]. In this study, online participants were more likely than face-to-face participants to endorse barriers to seeking help. Participants may have found it easier to endorse barriers to visiting the doctor with the context of anonymity afforded by online data collection compared with face-to-face data collection.

Strengths and Limitations

Although this study provides insights into the possibility of using online data collection for a large representative sample of the UK, there are limitations that warrant consideration. Regarding recruitment, large differences exist in the size of samples recruited online and face-to-face, highlighting the comparative ease of online recruitment. Previous research indicates that online research may not be as representative as face-to-face interviewing [29], but this is often based on the type of recruitment procedures that precede data collection. In this study, both online samples were recruited through panels; however, there may be differences in the ways that panels are recruited and incentivized, which may have affected the results. To mitigate this, each agency employed procedures to ensure their samples were as representative as possible of the Great Britain population.

For the analysis, it was not possible to calculate unique weighting variables, and we relied on those provided by agencies. The questions within each survey were identical; however, there may have been small differences in the presentation of questions within each sample.

It was necessary to limit the demographic variables studied to control the length of the survey, meaning that unobserved differences may have contributed to the differences observed.

It was not possible to compare the samples collected by each survey agency with the Great Britain population data. The Great Britain population data used were publicly available, although confidence intervals were not provided, and statistically significant comparisons were not possible.

It was not possible to access information about response rates or completion times within each sample. This information may have been useful to explore the differences among samples in more depth.

Conclusions

The relationships between sampling, sample representativeness, survey modality, and subsequent responses are complex. Although sample representativeness varied a little between samples and there are likely unobserved differences, we were encouraged to see that these variations were small overall. This information will be useful in helping us to tailor our recruitment strategy to ensure that we recruit a sample that is as representative as possible of the Great Britain population in future CAM research.

We observed larger differences when looking at responses to the awareness questions themselves, even between the two online samples, which point to the fact that there may be differences in the sampling and running of these panels contributing to these differences.

Nevertheless, the flexibility and potential cost savings of online data collection will enable larger samples and greater variation in content at a lower cost, which will enable the CAM to explore a new and wider range of issues related to the early diagnosis, prevention, and treatment of cancer.

Acknowledgments

Many thanks to the agencies involved in the collection of data for this research. This research was funded by Cancer Research UK.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Survey Incentives and Survey Weighting Methodologies.
[DOCX File , 17 KB - cancer_v6i1e14539_app1.docx]

Multimedia Appendix 2
Number of cancer signs and risk factors recognised and recalled within each sample.
[DOCX File , 19 KB - cancer_v6i1e14539_app2.docx]

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Abbreviations

CAM: Cancer Awareness Measure
HPV: human papillomavirus
NHS: National Health Service
ONS: Office for National Statistics

Edited by D Vollmer Dahlke; submitted 30.04.19; peer-reviewed by S Lee, R Watson; comments to author 05.06.19; revised version received 29.07.19; accepted 20.09.19; published 17.01.20.

Please cite as:
Connor K, Hudson B, Power E
Awareness of the Signs, Symptoms, and Risk Factors of Cancer and the Barriers to Seeking Help in the UK: Comparison of Survey Data Collected Online and Face-to-Face
JMIR Cancer 2020;6(1):e14539
URL: http://cancer.jmir.org/2020/1/e14539/
doi:10.2196/14539
PMID:31951219

Original Paper

Perceptions of eHealth-Enabled Physical Activity Interventions Among Cancer Survivors: Mixed Methods Study

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Abstract

Background: Achieving adequate levels of physical activity (PA) is especially important for cancer survivors to mitigate the side effects of cancer and its treatment as well as for other health benefits. Electronic health (eHealth)-based PA interventions may offer feasible alternatives to traditionally delivered programs and optimize physical recovery after a cancer diagnosis, but perspectives of cancer survivors on this new delivery medium have not been extensively explored.

Objective: The overall aim was to explore participants' perspectives of eHealth-enabled PA interventions to inform the design of a future intervention among cancer survivors.

Methods: The study took place in a designated cancer center in Dublin, Ireland. A preceding questionnaire-based study was conducted primarily to establish interest in participating in subsequent eHealth-based studies. A follow-on focus group study was conducted to explore the concept of eHealth-based PA interventions for cancer survivors. The data were analyzed using thematic analysis.

Results: The questionnaire-based study (N=102) indicated that participants had a high level of interest in participating in follow-on eHealth-based studies. The focus group study (n=23) indicated that, despite some trepidation, overall positivity was expressed by participants toward the concept of eHealth-based PA interventions. Four themes were generated: (1) Health impact, including PA as a barrier and as a motivating factor, (2) Education needs, which emphasized the need for integrated information about PA and to increase technical literacy, (3) Goal setting, which should be integrated within the technical specification as a motivating factor, and (4) Support needs, as well as the importance of personalized human interaction, in tandem with technology.

Conclusions: Qualitative research at the pretrial phase adds value to the design of a complex intervention and is especially useful in an area such as eHealth. The findings highlighted an interest in participating in eHealth-focused research as well as barriers, training needs, and key design features that can be applied to optimize the design of future eHealth-based PA interventions in cancer.

(JMIR Cancer 2020;6(1):e16469) doi:10.2196/16469

KEYWORDS

cancer; eHealth; exercise; focus group; physical activity; qualitative; mobile phone

Introduction

The benefits of physical activity (PA) in cancer patients are well known, including improvements in quality of life, improvement in function, and a possible reduction in risk of recurrence in some cancer types [1]. Despite those known benefits, uptake of PA by cancer survivors is low from the time of diagnosis through to survivorship [2,3]. The challenge remains to elucidate the optimal type of intervention for increasing PA levels in cancer survivors. The majority of PA interventions in cancer survivors are low-tech and delivered face-to-face in a group setting which is time- and resource-intensive, and accessibility can be limited [4,5]. Alternative models of delivery are warranted. The emergence of increasingly sophisticated technologies, with the potential to enhance the delivery of PA interventions, may provide a feasible and scalable alternative to traditional interventions [6].

Usage of electronic technologies in the general population is high. The number of smartphone users worldwide currently exceeds three billion and is predicted to increase further over the coming years. China, India, and the United States have the highest number of smartphone users with each country exceeding the 100 million user mark [7]. In the United Kingdom, 45.1 million people used the internet on a daily basis in 2019 according to the UK Office for National Statistics, beating the record set in 2016 [8]. Despite the ubiquity of smartphones and their high usage, harnessing their benefits for health benefits is relatively new.

There is emergent systematic review-level evidence in favor of the health benefits of electronic health (eHealth) interventions. eHealth is a concept in health care that may present opportunities to improve PA in cancer survivors. eHealth has been defined as “health services and information delivered or enhanced through the Internet and related technologies” and eHealth “characterizes not only a technical development, but also a state-of-mind, a way of thinking, an attitude, and a commitment for networked, global thinking, to improve health care locally, regionally, and worldwide by using information and communication technology” [9].

A systematic review including almost 5000 participants indicated the promise of using mobile apps and SMS text messaging as mobile health (mHealth) interventions, with studies showing an improvement in physical health and significant reductions of anxiety, stress, and depression [10]. Similarly, a further systematic review indicated the potential of apps in improving symptom management through self-management interventions in long-term conditions [11], although little is known about their economic benefit and long-term sustainability.

Only a small number of studies have integrated eHealth as a delivery medium for PA interventions in cancer survivors [12]. New types of health service interventions can be complex [13] and difficult to integrate into practice. The Medical Research Council (MRC) has proposed a framework for the development of complex interventions [14]. This phased approach of health service evaluation begins with a theoretical element, then integrates a series of preliminary studies to inform the design of an intervention element. Integrating qualitative research can optimize the robustness of interventions [15], and this approach has been utilized within a number of complex interventions in the pretrial design phase [13,16,17].

Aligned to the recommendations of the MRC framework [14], we first conducted a systematic review of eHealth-based PA interventions [12]. This review identified only 10 studies, which included eHealth-based PA programs across a diversity of platforms. We found that consensus is lacking in terms of the optimal eHealth-based intervention design in the cancer setting.

Although previous studies have explored perspectives of cancer survivors toward exercise, these studies have mainly been conducted after completion of a structured exercise program [18-21]. One of the disadvantages of gaining participant perspectives after completion of an intervention are that preferences are influenced by their direct experience of the program itself [18]. Also, these studies related to traditionally delivered exercise regimes and did not specifically focus on newer technology-based alternatives.

A survey-based study evaluated technology-based health behavior interventions versus traditional modalities [22] in cancer survivors. This indicated a receptivity to using Web apps as a technological delivery medium. An online questionnaire-based study in cancer survivors evaluated preferences for technology-supported exercise interventions and indicated they may be feasible and acceptable [23]. It would appear that no prior study has integrated in-depth personalized insights of eHealth-based PA interventions at the pretrial phase to inform the design of such an intervention in cancer survivors. The overall aim of this study was to explore perspectives of cancer survivors toward the concept of an eHealth-based PA program. To address this aim, a phased approach was taken.

This paper will briefly describe a preliminary questionnaire-based study to ascertain basic information pertaining to self-reported PA levels, knowledge of PA guidelines, smartphone use, as well as interest in a follow-on focus group study. The main focus of the paper will be a focus group study that qualitatively explores perspectives of cancer survivors toward the concept of an eHealth-based PA program.

Methods

Overview

The preceding questionnaire-based study will be described first, followed by the follow-on focus group study. Both studies took place in St. James’s Hospital, Dublin, Ireland, an acute-care hospital that is one of the largest designated cancer centers in Ireland. Written informed consent was obtained separately for each study. Inclusion criteria were as follows: over 18 years of age, attending oncology outpatient clinics, absence of cognitive disabilities that may hinder following instructions, and patients who had received chemotherapy or radiation therapy for malignancy and had finished a course of treatment or were anticipated to finish their treatment within 3 months. Ethical approval was granted by St. James’s Hospital, Tallaght University Hospital Research Ethics Committee (reference: 2015-05).

Recruitment

Due to the heterogeneous nature of cancer and its treatment, there were a large number of cancer clinics in St. James's Hospital Oncology service, including breast, gynecological, colorectal, and lung cancer clinics. The lead investigator liaised with the relevant medical and nursing staff in advance of both studies. The treating physician performed initial eligibility screening and advised whether each patient could be approached for study participation. The lead investigator then approached the patient, provided information about the study, and, if appropriate, obtained written informed consent.

Preceding Questionnaire-Based Study

Preceding the main focus group study, a cross-sectional study was conducted in mixed cancer outpatient clinics to ascertain possible interest in participating in subsequent eHealth-related studies. Participants filled out this 5-minute paper-based questionnaire (see Multimedia Appendix 1) while waiting for hospital-based cancer-related outpatient appointments. As this was such a new area of focus, a short questionnaire was specifically designed to scope out the following information: (1) knowledge of, and adherence to, PA guidelines as well as quantification of sedentary behavior, (2) smartphone ownership and usage of mobile phone app technology, and (3) willingness to participate in further eHealth-related studies. No prior questionnaire existed that explored the use of technology in PA interventions for cancer survivors; therefore, the questionnaire that was developed was based on an existing PA assessment questionnaire [24] and the specific objectives of this study. Willing participants were subsequently contacted for inclusion in the focus group study.

Follow-On Focus Group Study

Focus groups were employed in this qualitative study, chosen for their strength in generating new ideas and diverse opinions in a way that would be less accessible in a one-to-one interview [25]. A further advantage of focus group design is that participants can develop ideas through facilitated group-based discussion [26]. The design and reporting of research methods used in this study was informed by the COREQ (COnsolidated criteria for REporting Qualitative research) standardized reporting guidelines [27]. Participants were chosen from the pool of participants in the preceding questionnaire-based study who indicated a willingness to participate in a focus group study. A convenience sampling method was adopted in this study, with participants included being the first who responded and were available for participation.

Data Collection

Focus groups were conducted by the lead investigator who was also group moderator (CH). CH was a doctoral student with a background as a physiotherapist, who was not involved in the clinical care of participants. He had additional training in qualitative methodology and focus group facilitation. The assistant facilitator varied between two people, depending on availability, and was either an academic (JB) or a postdoctoral researcher (JM), both trained in qualitative methodology. No repeat interviews took place and transcripts were not returned to participants for accuracy.

All interviews were recorded using a Voice Tracer DVT2000 digital recorder (Philips). CH facilitated the discussion and JB or JM took field notes, including observations during the interviews. These field notes assisted in identifying potential themes that emerged that the lead moderator may have missed, as well as recording general observations that assisted in data analysis.

At the start of each focus group, brief study information was provided regarding goals and reasons for conducting this research, and ground rules were agreed upon. An interview guide (see Multimedia Appendix 2) was developed based on prestated study objectives, results of a previous systematic review [12], and relevant qualitative literature [28]. The interview guide was semistructured to encourage a free flow of conversation [29]. The interview guide was not pilot-tested prior to the first focus group. Data collection continued until saturation was reached, a stage where no new ideas or themes emerged [30].

Data Analysis

Questionnaire data from the first study was analyzed descriptively. In the focus group study, to optimize rigor, a synopsis of the main points was given at the conclusion of each focus group, whereby participants were questioned regarding whether it was an accurate portrayal of what had been discussed.

In view of the emergent nature of this area, data analysis was performed using thematic analysis following the phased approach outlined by Braun and Clarke [31]. Recordings were transcribed verbatim by CH and double-checked for accuracy by JB. Focus group transcripts were coded into meaningful clusters using NVivo 9 (QSR International) qualitative data analysis software. Two independent researchers (CH and JM) performed this inductive coding and produced a collection of codes that they deemed to have meaning in the context of the stated objectives of the focus groups. The data were examined to establish recurring patterns of meaning. Codes and themes were discussed, refined, and agreed upon by authors and then checked and compared to ensure grouped data were contextually meaningful. Any differences in coding were discussed by researchers until a consensus was achieved.

Results

Results of Preceding Questionnaire-Based Study

This study took place between August 2015 and January 2016 and included 102 participants. Due to the nature of our method of recruitment, there were no refusals to participate once the patients were referred to the lead investigator from their treating physicians. There were slightly more female participants included in the study (54/102, 52.9%). The mean age of the participants was 65.5 years (SD 14.3).

Participants had a range of cancer diagnoses, with the highest number having colorectal cancer (52/102, 51.0%). Results indicated that almost half (46/102, 45.1%) of all participants reported to be achieving or exceeding guideline PA levels. A total of 63.7% (65/102) of participants overestimated the recommended weekly PA, while 18.6% (19/102) underestimated the guideline for weekly PA.

The number of smartphone users was 59.8% (61/102), with lower numbers noted in those over 65 year of age. It was also identified that 89% (54/61) of those that had access to smartphones used smartphone apps. The most frequently specified mobile apps were Facebook (14/61, 23%) and WhatsApp (9/61, 15%). Only 16% (10/61) of participants reported using PA or exercise apps on their smartphones.

Interest in participating in a follow-on focus group was expressed by 61% (37/61) of participants who owned or had access to a smartphone. Interest in participating in a future eHealth PA intervention was also high (47/61, 77%) among participants in this study.

Results of the Focus Group Study

Seven focus groups were conducted between November 2015 and April 2016. In total, six focus groups had 3 participants present, with one focus group having 5 participants present. Data saturation was reached following analysis of the sixth and seventh focus groups. This resulted in conclusion of the study after the seventh focus group, with a final sample size of 23 participants. The remaining 14 participants who expressed interest in participating in the focus groups could not attend after they were recontacted; reasons given were mostly due to weather, being unwell on the day of the focus group, lack of interest, and having difficulty accessing the center due to travel distance.

Focus Group Participant Characteristics

Demographic details of the participants are collated in Table 1. The focus groups ranged from 23 to 34 minutes in length and the mean duration of the focus groups was 28.7 minutes (SD 3.4). Out of 23 participants, 17 were female (74%) and 6 were male (26%), and they had a mix of cancer diagnoses. The age range was 34-82 years. Out of 23 participants, 12 were over 65 years of age (52%) and 11 were 64 years of age or under (48%).

Table 1. Demographic details of focus group participants.

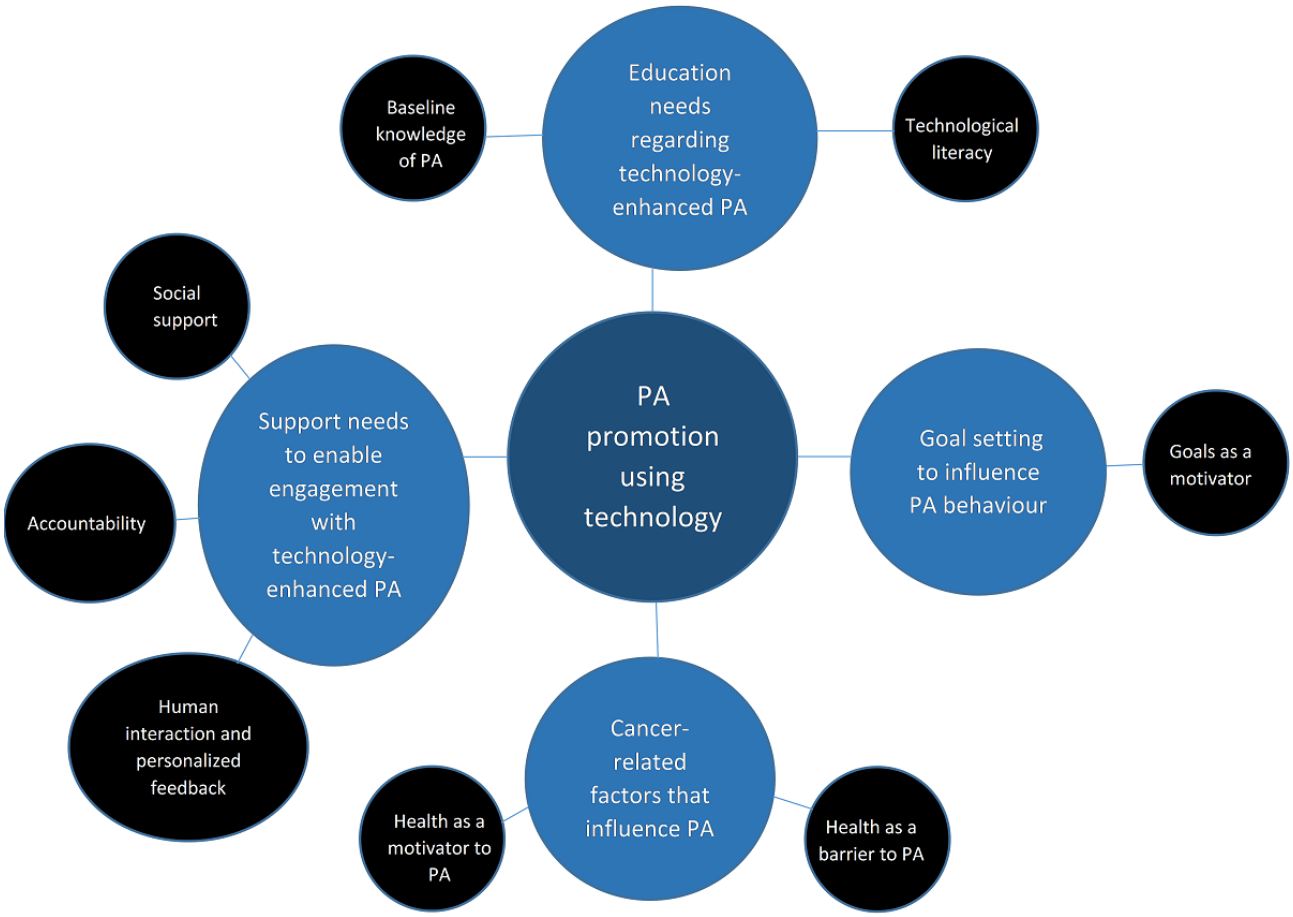
Variable	Value (n=23)
Gender, n (%)	
Male	6 (26)
Female	17 (74)
Age at study enrollment (years), mean (SD)	61.34 (12.60)
Cancer type, n (%)	
Breast	4 (17)
Colorectal	6 (26)
Ovarian	5 (22)
Testicular	2 (9)
Endometrial	3 (13)
Other	3 (13)
Treatment, n (%)	
Chemotherapy only	15 (65)
Chemotherapy and radiotherapy	8 (35)
Surgery	23 (100)
Marital status, n (%)	
Married	14 (61)
Single	9 (39)

Results of Thematic Analysis of Focus Groups

Overview

Following analysis and coding of the transcripts, a number of themes and subthemes were generated from the data and are detailed in Figure 1. There were four main themes—*health impact*, *education needs*, *support needs*, and *goal setting*—with accompanying subthemes. The role of technology was embedded throughout these themes.

Figure 1. Themes and subthemes following analysis and coding of focus group transcripts. PA: physical activity.



Theme 1: Health Impact

Overview

The initial opening question "What motivates you to exercise?" generated discussion around general PA-related factors. A strong generic theme that was generated was the topic of *health impact*. Two distinct subthemes generated from this main theme were the role of health as a barrier to PA and, conversely, its role as a facilitating factor or motivator for PA.

Subtheme 1: Health as a Barrier to Physical Activity

There were a number of participants who signaled that side effects of cancer treatment or general health were primary barriers to PA, with fatigue frequently referenced.

> *Ever since the chemo I've lost interest ... got so tired.* [Participant #80, female, 76 years, ovarian cancer]

Subtheme 2: Health as a Motivator to Increase Physical Activity

Some participants remarked that good health and feeling better were motivating factors to increase PA.

> *When I was going through the treatment I felt like going out for a walk, no matter how tired I was ... and I think it helped me through the treatment ... and helped me overall.* [Participant #19, female, 65 years, ovarian cancer]

Losing weight and improving general fitness served as motivation for a number of participants.

> *Well mine is to lose weight, and to get a bit fitter.* [Participant #85, female, 58 years, breast cancer]
>
> *I felt that walking before I got sick helped me, kinda get strong you know, helped me you know, physically, helped me through the treatment as well, you know.* [Participant #19, female, 65 years, ovarian cancer]

Theme 2: Education Needs

Overview

The theme of education featured prominently in terms of knowledge about PA, technical literacy, and the need for a PA program that features human interaction in tandem with eHealth.

Subtheme 3: Baseline Knowledge of Physical Activity

Throughout the focus groups, the absence of education about the importance of PA following a cancer diagnosis was frequently discussed.

> *After the treatment I was never really told exercise was important.* [Participant #56, female, 53 years, colon cancer]
>
> *I didn't hear anything about it at all, until I met you [speaking to lead investigator].* [Participant #57, female, 60 years, breast cancer]

> *Even if you got a leaflet, even if there was something, or the book recommend, a book to read, but there was nothing.* [Participant #69, male, 76 years, rectal cancer]

Subtheme 4: Technical Literacy

Education about technology and technological literacy also presented under the umbrella of education. Many participants indicated that for technology to be introduced, they would require education or training on how to use it first.

> *Someone just to sit there with you, for just a certain amount of time, till you sort of grasp it.* [Participant #87, female, 74 years, ovarian cancer]

There was also an awareness among some participants that they were not entirely comfortable using technology currently, but they similarly agreed that support and education would make it possible to try using technology.

> *There's no point saying to somebody that's ... never used an app before, "switch on that app and away you go," you know it's not as easy as that.* [Participant #12, female, 54 years, ovarian cancer]

Subtheme 5: Built-In Personalization and Feedback

The focus groups highlighted the importance of direction and feedback throughout the program.

> *I think I'd want a bit of feedback from the like of you [speaking to CH], somebody like you, you know even to keep contact maybe every two weeks.* [Participant #38, female, 69 years, rectal cancer]

Personalization and the provision of PA prescription specific to each individual participant also became evident.

> *I think each person is an individual, so no one app, do you know, it has to be adaptable to every single person not just one type of person, so like [Participant #11] said, you input your information there and ... it's specifically for you, so I think that's important.* [Participant #01, male, 34 years, testicular cancer]

Theme 3: Goal Setting

Overview

One of the main themes to be generated from the data extracted from the focus groups was the concept of goals.

Subtheme 6: Goals as Motivation

The importance of goals was expressed in a number of different ways; however, the role of goal setting as a factor for motivation was particularly prevalent. Implicit in this theme was the concept of self-monitoring.

> *I'll say, "hey that's not good enough now ... I'm definitely going to go 2 km and then I'll get to 2," and I'll think, "ah sure I'm at 2 now, I don't feel so bad, maybe I'll go to 3," and then it actually motivated me every day to beat my previous record.* [Participant #12, female, 54 years, ovarian cancer]

When participants were asked whether having a smartphone app could help improve PA, one participant who had been using an app agreed that it did, again highlighting the presence of a target or goal as a motivator.

> *Yeah, it did, because I had a target, tell you exactly what you've done, if you've hit that target, well not every day, but maybe once a week, trying to beat that target.* [Participant #81, male, 57 years, esophageal cancer]

Theme 4: Support Needs

Overview

The theme of support featured prominently and was heavily discussed. It took the form of two subthemes that resulted from the analysis: accountability and social support.

Subtheme 7: Accountability

The importance of accountability, so participants would be *answerable* to an individual, was evident.

> *Well even just to sit, and talk to somebody like yourself, and to feel like there is somebody there, that you care if we do exercise or not.* [Participant #87, female, 74 years, ovarian cancer]

Subtheme 8: Social Support

In contrast to the professional, prescriptive support that participants mentioned as important, the majority of participants also described motivation stemming from family, friends, and peers.

> *My friends and family more so, kind of influence in a way, they say, "I'm going for a walk, do you want to go for a walk?" I'll say, "yeah, sure why not."* [Participant #01, male, 34, testicular cancer]

Application of Findings to Intervention Design

A summary of the technological features from the themes and subthemes to be integrated into the eHealth PA-based intervention are listed in Textbox 1.

Textbox 1. Key design features of eHealth-based physical activity interventions.

- Personalized instruction to upskill technical literacy
- Integrated education about physical activity
- Integrated goal setting
- Integrate peer support where possible
- Tailored program—individually prescribed
- Blended program, including technology and human interaction and personalized professional guidance throughout the program
- Supervision for initial session
- Feedback on behavior
- User friendly

Discussion

Principal Findings

eHealth-based PA interventions are an emerging type of intervention for cancer survivors. The aim of this study was to explore perspectives of cancer survivors toward the concept of an eHealth-based PA program. The initial scoping study highlighted the lack of knowledge of PA guidelines, which echoes the focus group findings. PA levels were likely to be overestimated due to the crude self-report method of quantification [32]. The majority of participants were familiar with and used mobile apps, but usage of health-focused apps was low. This questionnaire-based study provided useful preparatory research for the design of the subsequent focus group study, and a high level of interest to participate in future eHealth-based studies was shown in this sample.

This focus group study delved much deeper into this topic and showed that while receptivity to the concept of an eHealth-based intervention was positive, participants need integrated education about the role of PA, technological upskilling to enable engagement with this medium, and some face-to-face interaction with a health professional in tandem with the remotely delivered aspect of an eHealth program.

This study highlighted the need for face-to-face support to initialize patients at the start of an eHealth program. The value of a trusted patient–health care provider relationship has been highlighted in a study that evaluated perspectives of mHealth interventions (ie, health interventions supported by a mobile device) in cancer survivors [33] and in patients with rheumatoid arthritis [34]. Our study showed that instead of a fully automated eHealth program, a blended program with personalized and formalized face-to-face human interaction integrated with eHealth would be optimal, which echoes previously identified program preferences [34].

Perspectives from this study indicated that an important technical specification to incorporate is personalized goal setting. Goal setting has previously been identified in a focus group study of cancer survivors as important in helping promote increased PA levels [35] and is underpinned by a well-recognized theoretical framework [36]. Further behavior change techniques that should be incorporated are feedback on behavior—automated and personalized—as well as self-monitoring, mirroring work from a recent study [33].

Peer support as an important element of group-based interventions was also referenced in this study, which mirrors previous research [37-39]. It has been suggested that the group dynamic enables better emotional support and coping skills than mediums that are not face-to-face, such as websites or books [38]. Conversely, a large qualitative study of cancer survivors' perspectives of a cancer rehabilitation program indicated that participants were not motivated by the group aspect per se and risked dependency [39], so transitioning to "real life" outside the intervention can be difficult. Notably, practical challenges of integrating group-based exercise outside the home setting, such as travel and scheduling challenges [39], are overcome by eHealth-based interventions. Nonetheless, as peer support came across as an important motivational element from the perspective of cancer survivors in this study, we suggest integrating this into eHealth programs where possible (see Textbox 1).

Several participants identified a technological training need to upskill sufficiently to enable engagement with eHealth-based interventions due to low confidence in their computer literacy. This lack of knowledge of technology was not the only deficit highlighted by this study, with results from the preceding questionnaire study highlighting a lack of knowledge of optimum PA, with only 17.6% (18/102) of participants correctly identifying recommended PA guidelines as identified by the American Cancer Society [40]. Creating an opportunity for health professionals to bring up the benefits of PA and methods to improve PA behaviors is needed. Exercise preferences were not explored in this study, but it was implicitly stated throughout that walking was the most preferable form of exercise, which mirrors similar research in cancer survivors [33]. Building strength and flexibility in cancer survivors is also valuable [40], and it would be important to incorporate other modes of exercise in an eHealth-based PA program.

A number of strengths pertained to these two studies. The initial questionnaire-based study indicated a receptivity to further eHealth-based studies, which is likely important to establish in a new area of focus such as this. In the focus group study, participants were not biased by a predetermined program. This study involved identifying end users' needs and preferences to inspire and influence the technological aspects of the intervention, which can be applied to the design of future

interventions. This study provided valuable information on acceptability and intervention components [15].

Focus groups conducted at the pretrial phase have an added value that can optimize the design of the intervention and trial procedures [15]. Employing focus groups provided the opportunity to drill down and generate a depth of information not found in the preceding cross-sectional questionnaire-based study. There was a small number of participants in each focus group, which we observed to be less intimidating [6] and encouraged interaction, although it may potentially have limited diversity of views.

Study Limitations

Resource constraints meant the research could be conducted in only one center, although a geographical spread of participants was noted. The generalizability of results to other settings is not known, although we have no evidence to suggest perspectives of this cohort are at odds with other locations. It should also be noted that sample size for the questionnaire study was small and may not be representative of the cancer survivor population. The mean age was over 60 years and participants were predominately female (74%) which may have influenced the results of the focus group. Naturally, in a heterogeneous disease such as cancer, it is likely that design of an eHealth intervention should be nuanced with a need for different considerations, such as increased supervision for people with advanced and metastatic diseases [33] and for those with a range of comorbidities. Ideally, a suite of PA options should be available to cancer survivors, of which eHealth appears to be an acceptable option. Also, an inherent limitation of this pretrial focus group study is that a hypothetical PA program was discussed, which may have given rise to overly positive comments due to social desirability bias [41].

Clinical Implications

An important consideration in the design of eHealth-based interventions for people with cancer is to consider that technological upskilling may be necessary to bridge the knowledge gap and ease initial trepidations to optimally harness the potential of this medium. Opportunities for interaction with a health care provider need to be built into the program. The program should be individualized, and essential behavior change elements to integrate into the program are goal setting and feedback on behavior.

Future Directions

Future qualitative work should include other stakeholder perspectives and evaluation of user experience after completion of the eHealth interventions. There was a notable absence of issues relating to privacy and data security in the focus groups. Other behavioral change techniques, such as prompts and cues to be more physically active as well as incentives, rewards, and gamification, were not raised by participants but response to these behavioral change techniques may be mixed [33]. Future studies should nonetheless explore these pertinent topics.

Stakeholder perspectives gleaned from this study have informed key design features of the IMPETUS (IMproving Physical activity and Exercise with Technology Use in cancer Survivors) trial (ClinicalTrials.gov registration: NCT03036436), which we have recently conducted in our center. The intervention was based on intervention elements summarized in Textbox 1 and underpinned by sound behavioral change theory [36], which included aspects of goal setting, prompts, self-monitoring, and encouragement of independent exercise. Findings reported in this paper will help design and reconfigure future interventions incorporating this new and exciting medium.

Conclusions

Given recent advancements that offer more technologically enhanced programs, this type of research is warranted to tailor design features and optimize their acceptability to cancer survivors. Even though low levels of technological literacy were reported among some participants, it would appear that there is an initial receptivity to the concept of eHealth-based PA interventions. However, these interventions should not be delivered in isolation, but with technological upskilling, built-in human interaction, and integrated behavioral change techniques in tandem. This study will add to the body of literature to ensure that eHealth interventions are user informed and tailored to suit the unique needs of cancer survivors.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Questionnaire.
[PDF File (Adobe PDF File), 323 KB - cancer_v6i1e16469_app1.pdf]

Multimedia Appendix 2
Interview guide for focus groups.
[DOCX File , 22 KB - cancer_v6i1e16469_app2.docx]

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Abbreviations

COREQ: COnsolidated criteria for REporting Qualitative research
eHealth: electronic health
IMPETUS: IMproving Physical activity and Exercise with Technology Use in cancer Survivors
mHealth: mobile health
MRC: Medical Research Council
PA: physical activity

Edited by G Eysenbach; submitted 07.10.19; peer-reviewed by A Roberts, H Quirk; comments to author 06.12.19; revised version received 31.01.20; accepted 28.02.20; published 28.04.20.

Please cite as:
Haberlin C, O' Donnell DM, Moran J, Broderick J
Perceptions of eHealth-Enabled Physical Activity Interventions Among Cancer Survivors: Mixed Methods Study
JMIR Cancer 2020;6(1):e16469
URL: http://cancer.jmir.org/2020/1/e16469/
doi:10.2196/16469
PMID:32343259

Original Paper

Usability of a Mobile Phone App Aimed at Adolescents and Young Adults During and After Cancer Treatment: Qualitative Study

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Abstract

Background: Adolescent and young adult (AYA) cancer patients are seldom involved in the process of testing cancer-related apps. As such, knowledge about youth-specific content, functionalities, and design is sparse. As a part of a co-creation process of developing the mobile phone app Kræftværket, AYAs in treatment for cancer and in follow-up participated in a usability think-aloud test of a prototype of the app. Thus, the app was initiated, created, and evaluated by AYAs with cancer experience.

Objective: The aim of this study was to explore the results of a think-aloud test administered to see how the prototype of the app Kræftværket was used by AYAs in treatment for cancer and in follow-up, and to investigate the strengths and weaknesses of the app.

Methods: A total of 20 AYA cancer patients aged 16 to 29 years (n=10 on treatment, n=10 in follow-up) were provided with the first version of the co-created mobile phone app Kræftværket during a 6-week test period (April-May 2018). After the test period, 15 participated in individual usability think-aloud tests. The tests were video-recorded, transcribed verbatim, and analyzed using a thematic analysis approach.

Results: The thematic analysis led to the following themes and subthemes: navigation (subthemes: intuition, features, buttons, home page, profile), visual and graphic design (subthemes: overview, text and colors, photos, videos, YouTube), and usefulness (subthemes: notifications, posts, adding). The analysis identified gender differences in app utilization—female participants seemed to be more familiar with parts of the app. The app seemed to be more relevant to AYAs receiving treatment due to app functions such as tracking symptoms and searching for relevant information. Lack of notifications and incorrect counting of posts were perceived as barriers to using the app.

Conclusions: Usability testing is crucial to meet the needs of the AYA target audience. AYA cancer apps should preferably be relevant, targeted, and unique, and include a tracking function and AYA-produced videos. Notifications and correct marking and ordering of posts are critical to make apps engaging and dynamic. Further research is recommended to evaluate the Kræftværket app with the input of more AYAs.

(JMIR Cancer 2020;6(1):e15008) doi:10.2196/15008

KEYWORDS

AYA; adolescent and young adult; app; cancer; co-creation; mHealth; mobile phone; think-aloud test; usability

Introduction

In Denmark, approximately 500 adolescents and young adults (AYAs) aged 15 to 29 years are diagnosed with cancer each year. Worldwide, there has been an increased focus on AYA cancer patients as a group with special treatment and support needs, addressing problems such as social maturity, identity-forming, health concerns, romantic relationships, friendships, fertility, mood changes, and risk of depression and anxiety [1,2]. Mobile health (mHealth) apps have demonstrated benefits in addressing some of these needs of AYAs, including connecting with peers and health care teams, accessing information, and health care tracking [3-5]. For AYA cancer patients, networking with peers, information seeking, and tracking of symptoms are found to be most relevant at diagnosis onset and during the initial treatment period [6,7], and the motivation to use health apps often decreases over time [8,9]. Differences in the supportive care needs for AYAs in treatment and off treatment are common, particularly regarding information about the disease, treatment, and side effects versus information about risks of recurrence and potential late effects [10].

Internationally, several apps have been developed for AYAs with cancer, but AYAs have rarely been involved in the development process [11,12] despite research indicating that user involvement in the development of mHealth solutions is necessary to ensure relevant content and functionality [13,14]. Moreover, it is important to involve AYAs during app development and evaluation because they are a target group highly familiar with mobile technology [15], and they are discerning and critical users of digital health technologies [16]. Research suggests that patient-oriented apps may strengthen patients' empowerment [17] and that apps are effective tools for enhancing self-management in both younger and older patients [18,19]. Additionally, digital health intervention apps have been shown to address unmet psychosocial and health information needs of AYA [20]. Research also points out that support from friends, family, and other cancer patients, as well as access to information on illness and diagnosis, may increase the quality of life of cancer patients [21,22].

Unfortunately, many apps have not been evaluated by AYAs through processes including usability testing [23,24], which may affect the app's quality and appeal for its intended target audience [25]. Additionally, experts in the field seldom evaluate health apps according to the quality and validity of the provided information, which could potentially endanger patient safety [11,23]. This study seeks to address these concerns by investigating the results of a usability think-aloud test of an app, which was created on the basis of initiative and ideas from AYAs with cancer, developed in a co-creation process with an eHealth solution company, and validated by experts. The app is intended to strengthen the quality of life and empowerment in AYAs with cancer [26]

The aim of this study was to explore how the app Kræftværket was used by AYAs who were either on treatment for cancer or in follow-up as well as to investigate the strengths and weaknesses of the app. The results from this study will contribute to the improvement of the Kræftværket app, so that it may serve as a tool that Danish AYA cancer patients will benefit from in the future. Additionally, the study may inspire the development of future apps in other countries aimed at AYAs with cancer.

Methods

The Kræftværket App

This study is based on a project located at Kræftværket, a youth support center and social organization for AYAs (aged 15-29 years) with cancer at the Copenhagen University Hospital Rigshospitalet in Denmark. The name of both this center and the mobile phone app described in this study—Kræftværket—is composed of the Danish words for "cancer" (kræft) and "power plant" (kraftværk), evoking empowerment throughout the time of cancer treatment and recovery. The idea of creating an app arose from AYAs at Kræftværket, who saw the need for a tool to strengthen the quality of life and empowerment in AYAs with cancer. Therefore, health professionals from Kræftværket decided to host a series of workshops in which current and former AYA cancer patients could assist in the development of the app in a co-creation process partnered with an eHealth solution company. The app development process was divided into three phases, with this study describing the usability testing of the prototype app as part of phase II (Table 1). The co-creation process is described in its entirety in Elsbernd et al (2018b) [27], and the three phases are described in detail in Elsbernd et al (2018a) [28].

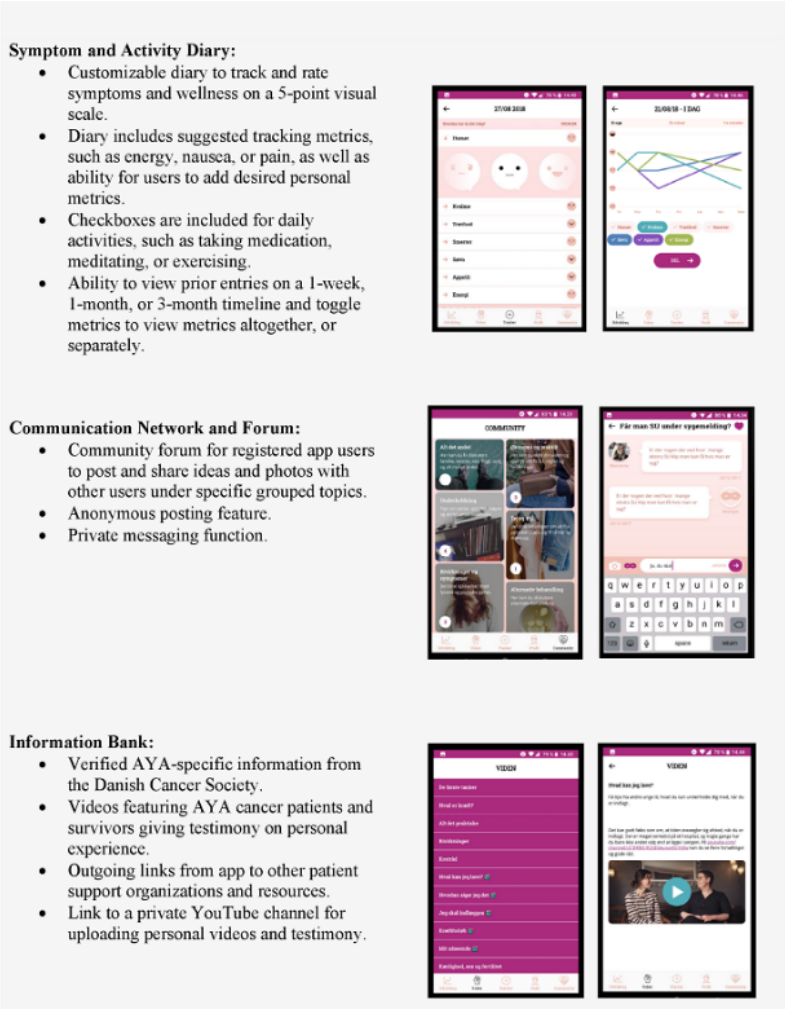
The first version of the Kræftværket app was ready for usability testing in April 2018. It contained a symptom and activity diary, a communication network and forum, and an information bank (presented in Figure 1). The app's community forum was intended to connect and build a community for AYAs with cancer, and the symptom tracker was intended to strengthen the understanding and management of the illness and its symptoms. The app would additionally serve as an information bank with relevant information about cancer diagnosis and implications on youth life. Lastly, the app may serve as a tool for collecting data and knowledge for research.

Table 1. Kræftværket app development phases.

Phases, content	Participants, N
Phase I: initial work (2017/18)	17
Literature review and research protocol [28]	
Initial technology workshop	
Co-creation workshop and ad hoc meetings [27]	
Phase II: pilot-testing the prototype (2018/19)	20
EORTC QLQ-C30 [26]	
Think-aloud test[a]	
Focus group interviews	
Phase III: implementing and testing the final app (2020)	50
EORTC QLQ-C30	
Focus group interviews (funding achieved)	

[a]Current study.

Figure 1. Version 1 content and design of the Kræftværket app. Text from Elsbernd et al [<xref ref-type="bibr" rid="9ref28">28</xref>].



Participants and Recruitment

The participants for phase II—pilot-testing of the app—were recruited in the youth support center Kræftværket by a youth coordinator (MH). The pilot testing involved participation in usability testing via think-aloud testing, focus group interviews, and health-related quality of life questionnaires, such as the European Organization for Research and Treatment of Cancer quality of life questionnaire (EORTC QLQ-C30; Table 1). The results of the EORTC QLQ-C30 health-related quality of life testing are described in Taarnhøj et al [26]. The results from

the focus group interviews will be published separately. Phase II inclusion criteria were users of Kræftværket, AYAs between 15 and 29 years of age with access to a mobile phone and the internet, including cellular data or Wi-Fi. Exclusion criteria were AYAs who had participated in the co-creation process for the development of the app, and those unable to read and write in Danish. A total of 20 AYAs were recruited: 10 AYA currently receiving cancer treatment and 10 AYA who had completed cancer treatment and were in follow-up. In total, 15 AYA participated in the think-aloud test because five persons dropped out for various reasons, including acute illness on the day of the test (Table 2).

Table 2. Demographic and clinical information of participants.

Demographic	All participants (N=20)	Participants who attended think-aloud test (n=15)	Participants who dropped out (did not attend think-aloud test) (n=5)
Gender, n			
Male	6	4	2
Female	14	11	3
Age (years), mean (range)	25 (16-29)	25 (16-29)	21 (18-29)
Treatment, n			
On treatment	10	8	2
Off treatment	10	7	3
Cancer type, n			
Lymphoma	9	6	3
Breast	4	3	1
Head and Neck	2	2	0
Leukemia	1	1	0
Testicular	1	1	0
Ventricular	1	1	0
Thyroid	1	1	0
Brain	1	0	1

Setting

The usability test consisted of a 6-week test period (April-May 2018) in which the participants were given access to the app prototype. They were instructed to use the app according to their needs; however, they were not given any specific instructions on the frequency with which to use the app. After the test period, the participants arrived and were asked to participate in the think-aloud test, which was administered by the eHealth solution company associated with the co-creation process. The test took place in the youth support center Kræftværket at Copenhagen University Hospital, Rigshospitalet, in May 2018. The test was performed individually with one participant at a time, and each test lasted 10 minutes on average (range 7-13 minutes). All tests were video-recorded.

Think-Aloud Test

Usability was evaluated using the think-aloud method to test the app's functionalities as well as opinions, comments, and concerns among users [29]. The think-aloud test provided an overview of which functionalities (eg, understanding navigating paths and use of buttons) were causing the greatest difficulties and which functionalities were best received by the users. The test assessed how participants perceived icons, menus, and navigation paths. As part of the evaluation, participants were given minor tasks using the app, which the participants were asked to complete while describing their thought processes aloud along the way with questions such as:

- What do you think you can do on this page?
- How do you track your side effects?
- How do you do to add a symptom to the tracking feature?
- How do you find the community?
- How do you write an answer to a question in the community?
- How do you upload a new profile picture?

SH performed the transcriptions of the think-aloud tests. Verbal statements were transcribed verbatim with physical actions incorporated into the transcript and identified with square brackets ([]), which are included in the quotations. All physical actions were included in the transcript, including the exact functionalities or features of the app that were used when the participants scrolled, pressed buttons, took pictures, and more.

Data Analysis

Data were analyzed using a thematic analysis approach inspired by Braun and Clarke's 6-step model [30]. Coding of text involved reading and re-reading the transcriptions to identify and categorize concepts across data relevant to the research question. Concepts were highlighted in the margin of the transcriptions. The authors SH, MH, KAB, and HP completed this initial coding separately to ensure an independent coding process. They subsequently met to discuss and sort the concepts

into themes and subthemes, and each author presented their coding. In a joint process, the researchers came up with suggestions for themes and subthemes, which were written on sticky notes and placed on a table to create a good overview. There was an immediate agreement on themes; subthemes were arranged and rearranged during constructive discussions until agreement was reached.

Ethical Considerations

The study was approved by the Danish Data Protection Agency (VD-2018-27). Ethical approval is not necessary for this kind of study in Denmark; however, the principles stated in the Helsinki II Declaration were followed. All informants received oral and written information before the think-aloud test and were provided written informed consent to participate. All informants were given the opportunity to withdraw their consent without any consequences for the treatment at the hospital. The video-recordings consisted solely of recordings of the participants' hands and mobile phones. Participants' faces and other identifying characteristics were not recorded.

Results

Data Analysis

Data analysis yielded results on how the app was used, including the relation to gender and treatment status, as well as strengths and weaknesses of the prototype app and suggestions for improvements. The following themes were identified: navigation, visual and graphic design, and usefulness (Textbox 1).

Textbox 1. Themes and subthemes consisting of strengths, weaknesses, and suggestions for improvements.

1. Navigation
   - Intuition
   - Features
   - Buttons
   - Home page
   - Profile
2. Visual and graphic design
   - Overview
   - Text and colors
   - Photos
   - Videos
   - YouTube
3. Usefulness
   - Notifications
   - Posts
   - Adding

Navigation

Intuition

Many of the participants assessed navigation paths and whether they were intuitive in nature. Navigation was determined to be intuitive if it imitated the navigation paths used in other media, such as existing apps and text message systems, and if it seemed clear, simple, and user-friendly: "It is very simple, it seems very intuitive, it works very similar to other media" (female participant). For example, the buttons in the symptom and activity diary, liking conversations in the community with hearts, and the creation of conversation threads in the community were perceived to be intuitive.

Features

Tracking and Scale

A key feature of the app was a symptom and activity diary with patient-provided tracking features. It consisted of a scale containing five smileys to track the following symptoms: mood, nausea, fatigue, pain, sleep, appetite, and energy. Additionally, it included an activity diary to record activities such as running, cycling, yoga, social activities, and alcohol consumption. After tracking, it was possible to view the statistics over time for periods of one week, one month, and three months. Tracking of symptoms was the feature most frequently used during the test period, and most participants were very excited about it. It helped them remember daily events and symptoms, which one participant noticed could be a challenge during chemotherapy. Additionally, it could be referred to when visiting the doctor, and it provided a good overview of symptom progression. The participants found it easy and straightforward to use. However,

the think-aloud test led to some suggestions for changes. When choosing a symptom, it was not possible to proceed without first rating the symptom, although it might not be relevant at all. Also, several of the participants had difficulty interpreting the smileys. For example, they did not know if "being very nauseous" should be rated with a happy or a dissatisfied smiley. Some participants suggested replacing the smileys with a number:

> *I don't know if I'm so much a supporter of smileys. Perhaps I'm more a supporter of numbers, because now I'm suffering from a lot of headaches [presses on "headaches"], and I have chosen to say if I don't have a headache, then it is a happy smiley [presses on the happiest smiley], and there I would have preferred numbers instead.* [Female participant]

Not all participants were able to find the first and last smiley on the scale because they did not notice they had to scroll sideways to see them. Also, it was suggested to place the tracker and statistics next to each other in the menu because they were linked features. Notably, many of the participants stated that using the tracker was most relevant during their treatment course, and the tracker was perceived to be the main reason to use the app; as such, the app was determined to be a stronger tool for patients in treatment rather than after treatment.

Notes

In the symptom and activity diary, it was possible to write notes for a specific day. The user was encouraged to write a note with the following app-provided teaser: "What have you been particularly aware of? Write here." Most participants thought it was a good idea to make room for notes because they had the opportunity to elaborate on why they might be particularly tired one day or what made a given day particularly good. Unfortunately, most of the participants were unable to find old notes because old notes could only be found by clicking back to the day they were written: "It was a very long time ago, I don't know when I wrote it [scrolls up and down and press the back button (the arrow) at the top—repeats this action 5-6 times but finds no notes]" (female participant). Because of this, one could risk having to click 30 times back if notes were written one month ago. One participant suggested adding notes as an element of the statistics, which remained constant. This could then increase the overview and minimize clicks.

Buttons

Edit

In the symptom and activity diary, it was possible to press the button to edit and add a new symptom or a new activity to the tracker. Many of the participants were happy about adding new features because it could tailor the app to their individual needs during their cancer course. The participants did, among other things, add Kræftværket (number of visits), menstruation, fertility, sexual health, bloating, and headache to the symptom tracker and walks, work, studies, and treatment dates to the activity tracker. During the think-aloud test, it became clear that the female participants were more familiar with the edit button than the male participants, as only women had added new symptoms and activities during the six-week test period. None of the male participants had noticed the edit button for adding new activities. One male participant explained that he had misinterpreted the wording of edit: "I haven't seen it before, but now I can see that I can even add...I wouldn't call it 'edit,' something with 'add' maybe" (male participant).

Back Arrow

Several of the participants had difficulty using and figuring out the use of the back arrow button, designed to return to the previous page. The main problem was that previously entered data disappeared when the arrow was pressed: "I have repeatedly pressed the arrow up here, because I wanted to return [pointing to the arrow in the upper left corner], because everywhere else this is a back function, but then it erases it all, and then I can start over" (male participant). Some suggested inserting a save button, which could be used when new information had been entered (eg, in the tracker). This could increase the feeling of security with data entered because many were in doubt about what would happen to their data when they pressed the arrow.

Share

In the symptom and activity diary, it was possible to see one week, one month, or three months' timeline and toggle metrics to view statistics. Under the statistics, there was a button called "share." When pressing the share button, it was possible to attach the statistics to a text message or an email by selecting from the phone book. Some participants were not concerned with sharing their statistics and could see an advantage to sharing with others, such as a doctor or a nurse, with prior arrangement. However, most participants were unsure of who to share the statistics with: "I can't quite imagine who to share it with, if I have to be honest" (female participant). A single participant did not choose to touch the button at all because he was afraid and unsure of who would receive the statistics when sharing. He did not know that the button was associated with his own address book.

Icons

The participants evaluated the following icon buttons: Anonymous (a masked face), Knowledge (a clenched fist), Videos (a clapboard), Upload Photo (camera), and Upload Text (arrow). The participants found the icons to be user-friendly, and most participants recognized them from other social media, such as Messenger, which aided in their understanding. The only icon they could not associate with its contents was the clenched fist—the icon for knowledge—which was used to link to the information bank. One suggested a book icon instead: "It is a very nice icon and a little like, 'We stand together,' that is good, but I don't know if it is so much related to knowledge, I might have thought of a book or something like that" (female participant).

Home Page

The symptom and activity diary served as the home page when opening the app, with the mood tab open and available for ranking. Three smileys were visible under mood: a sad smiley, a dissatisfied smiley, and a happy smiley. Some participants thought it was a bad idea to be met by an open tracker if they did not intend to use the tracker on that given day, whereas others thought it was inconvenient to be met by non-happy

smileys: ”When you go into it you just see some smileys, and the first is the ‘I’m not so happy.’ Here I just really think it should be closed” (female participant). More participants called for a visible home page with an overview of the app content to get a better insight regarding the content and an idea of how to navigate.

Profile

The profile consisted of a place for users to provide and manage their personal app information, including a photo, name, city, email, password, day of birth, cancer type, and gender. Additionally, a logout button was provided. Most profile settings were optional except for name, email, and password. Several participants were doubtful about what the profile should be used for and why it was there at all. More participants were concerned about whether others could see their profile settings because these were private. Conversely, one participant thought it was smart to have the opportunity to see other app user’s profile information (eg, city). With that information, it would be possible to contact others to meet in real life. The password was marked with 18 dots, which confused all participants who were asked to recall their password and reprint it. No one could remember if they had ever logged in with a password, and found it confusing that the number of dots did not match the number of characters in the correct password: “It looks like I have a really long password—[clicks on it and it doesn’t respond] I don’t think I have, and I can’t change it either” (female participant). It was also possible to change the day of birth in the profile, which one participant questioned because this never changes. Additionally, it was possible to choose a day of birth later than today’s date.

Visual and Graphic Design

Overview

Some participants called for a better overview of the information bank, the tracking statistics, and community threads. Additionally, some participants lost the overview of the subpages in the information bank, as all the headings were named “knowledge,” which did not reflect the content of each page. However, it was noted that the order of information in the information bank followed the chronology of a cancer course, which was considered an advantage: “I think the topics make really good sense, also the sequence they follow, because it is usually in the order that things actually happen” (female participant). A few participants lost the overview in the tracker when all symptoms were shown simultaneously in the statistics. However, most participants thought the statistics were easy to understand because each symptom had its own color in the curve and could be clicked on and off as needed. Moreover, some participants found it difficult to get an overview of replies in the community, especially if there were many replies in the same thread, as they appeared in one long vertical row requiring scrolling down the page.

Text and Colors

Most participants were satisfied with the amount of text on the pages, even though opinions differed whether the information bank was too text-heavy or not. However, the information bank was welcomed by all participants because it could replace the many paper flyers the AYAs had received at the time of diagnosis and it was targeted toward AYA, unlike some of the flyers and handouts. The participants additionally found that the colors in the app supported the features: “I think the color coordination makes sense” (female participant). One participant noted that the color scale was very pink and a little too distracting.

Photos

It was possible to upload photos in two different places in the app: profile photos and photos for posts in the community. The participants found it easy and straightforward to upload photos, but it was considered a problem that profile photos could not be deleted: “I have no desire to have a picture in there, so now I have problems, I think” (female participant). When a profile picture was uploaded, it was not possible to remove it, but only to replace it with another photo. This was concerning for those who wanted to remain anonymous.

Videos

In the app’s information bank, approximately half the topics were accompanied by a short video, in which AYAs from Kræftværket spoke about their personal experiences with a given topic. Several participants thought the videos were easy to find and play. Additionally, they were excited about the videos because it was nice to identify with real people and it increased the feeling of normalcy during the cancer course. It was suggested to link videos with all the available information bank topics: “It is a pity that there are not videos on all of them actually...It could be nice if there was also a face on...So that you can think okay, I’m not completely abnormal” (female participant).

YouTube

In the app’s information bank there was a link to a private YouTube channel for uploading personal videos and testimonies. Two participants were asked about their use of YouTube, but they had not found this feature during the test period. One of the participants thought it was difficult and confusing to upload videos, and the other participant thought that YouTube was an inappropriate medium for the users of the app and she could not imagine speaking about herself and her cancer course on YouTube because it was too personal: “For me Kræftværket does not belong to YouTube, there are some other platforms...I can’t even see myself using it” (female participant).

Usefulness

Notifications

Most participants missed notifications because they were not getting reminders of new posts in the community, and they did not know whether their own posts were commented on by others. As a consequence, they often forgot to use the app. They pointed out that if the app was to become a useful tool to them, notifications should work to serve as a reminder: “Notifications, I really, REALLY think are missing. It’s probably 70% of the reason why I do not use this app” (female participant). Furthermore, notifications could make the app more dynamic as they would create visible activity.

Posts

In the community, there were several problems with posting, which had an impact on the credibility and desire to use the app. First, the participants pointed out that the number of posts were not counted correctly on the community page, so the actual number of posts did not match the visible number: "My posts don't pop up on the front page [the speech bubbles show '0' on the front of the community despite of her post]" (female participant). In addition, it was unclear whether the system counted every single post or the number of responses related to each post. It was possible to give likes to posts using a heart icon, but it was unclear whether likes were given to a full conversation thread or only a single post. Moreover, dates for each individual post were missing, so it was impossible to distinguish between new and old ones. It was mentioned that posting in the community was mostly relevant during the cancer treatment period where concerns and questions about issues related to life with cancer were urgent.

Adding

Several participants mentioned that the app could work better by connecting with other apps and media, so the users did not have to switch between many different apps. It was suggested to link to relevant Facebook pages, the Epic system (electronic health records), the Peak app (training of cognitive skills), and health apps (eg, running and cycling): "It could be smart if you could get something to pull data from your health app because...I forget (the Kræftværket app) a little" (male participant). It was additionally suggested that the app should register attendance in the youth support center Kræftværket. The app could also be made more dynamic by having the opportunity to add new main topics to the community as opposed to using preset topics, which would further customize the app to the needs of the individual.

Discussion

Principal Findings

This qualitative study of a think-aloud test highlighted the strengths and weaknesses of a prototype of a mHealth app aimed at AYAs during and after cancer treatment. The study is among a limited number of usability studies evaluating health apps [31]. Additionally, there is a lack of studies that actively involve cancer patients, including AYAs, in usability testing of apps, which this study seeks to address [24,32]. Many studies focus on testing the outcome and effectiveness of cancer apps in terms of self-management and adherence to treatment [12,33,34]. These studies are highly beneficial and are necessary to understand the utility of these apps; however, lack of usability testing may lead to the development of unsuitable navigation paths as well as content and design that does not appeal to AYA with cancer, which may limit their use.

The results of our study discuss two of the main functionalities in the app—the tracker and the information bank—which were perceived as strengths by most participants. AYAs were particularly excited about the app's tracking function, where they could track activities and symptoms such as mood, energy, and sleep, and get statistics on the tracking for one week, one month, and three months. The tracking was found to be a strong tool for recalling activities, events, moods, and symptoms, which could be used at hospital visits or consultations. This tool could also be tailored to the individual needs of AYAs during treatment. In line with this, research has shown that personalization of apps may better adjust to the needs of young adults, which provides a positive user experience [35]. Adolescents often perceive tracking of personal health data as a benefit [36]. However, in contrast to a study on adolescents with asthma who welcomed sharing health data with email recipients [37], the participants in our study were generally more skeptical about sharing health data, and more were in doubt about who they should even share data with.

In our study, some participants suggested using a numerical scale to rank symptoms instead of using smileys. This is in line with suggestions raised by adolescents with cancer testing a pain app [32]. The information bank was perceived as a strong reference tool for seeking information during the cancer treatment course. Topics containing short videos were especially well received because it was possible to identify with the stories of other AYAs, which increased the feeling of normalcy. The use of videos has also been perceived as useful in other app-testing studies [38]. Video cancer narratives have demonstrated a significant therapeutic effect for those AYA who create the narrative [39], but few studies describe the effect of watching other's cancer video narratives. However, studies on narrative communication in adult cancer prevention and control point to the importance of parasocial connections between the storyteller and the audience [40], because authentic narratives impact recipients emotionally and thus both benefit and inspire the audience [41].

As found in other studies, the participants in our study wanted a clear, concise presentation of information, which should not be too text-heavy [35,42]. The think-aloud test also led to several suggestions for improvement of the app, which should be taken into consideration when developing apps for AYA cancer patients. For improved navigation, the wording and design of buttons and icons should be very precise for correct understanding. As such, the wording of "edit" was ambiguous, and it was not clear what happened when using the back arrow button. Moreover, some had difficulties scrolling sideways. Difficulty in managing navigation levels, including relying on the back button as a safe option, as well as difficulty in scrolling and performing swipe gestures have been found on app usability [35,43,44]. Additionally, an overview of content should be very clear. A suggestion to accomplish this was the creation of a home page presenting all content of the app, which is in line with the idea to have a dashboard that brings together all the features that the app provides [45].

We found that anonymity should be a very high priority; as such, it should be possible to delete uploaded photos, and the app should be transparent about who personal information was available to. In contrast to our study, other research has found that young people with asthma were interested in allowing the upload of pictures to make the profile more interactive, with less concern regarding anonymity [46]. In line with the need for anonymity, we found that YouTube may not be a relevant media in relation to the app, as information regarding illness and cancer is a private matter for some AYAs. As such, not all

AYAs were interested in telling about their illness publicly. The linked YouTube channel was set to be private, but it seemed this was not sufficiently clarified because the participant who reflected on it found it too personal to post a video. The need for privacy contrasts with studies on adult cancer survivors using YouTube for their personal narratives [47,48]. Reasons for posting personal videos on YouTube were, for example, to provide support and advice for others in the same situation and raise awareness of aspects of the diagnosis [48]. Keeping illness a private matter is a general theme among adolescents with chronic illness. Illness is often associated with abnormality and being old and dependent on others, in contrast to the normal, healthy identities AYAs wish to create [49]. Visible body changes, which are known side effects of cancer treatment, highly affect body image and identity formation [50] and may be another detractor to the use of YouTube in this app.

Notifications were found to be one of the most necessary features for participants to use the app at all. The app did not contain a notification system; therefore, the participants missed reminders when their posts were commented on by others, which made the app static and less user-friendly. Also, problems with posting in the community were associated with reduced use of the app; it was suggested that it had to be more transparent how posts were counted in the community. A better understanding of the ordering and interaction on posts could make the app more dynamic and engaging. Previous research on adolescents' use of apps has shown that reminders could improve usability [35]. In line with other research, we found that the Kræftværket app was perceived to be most relevant during a cancer course in which most AYA lacked knowledge about diagnosis and treatment. Tracking of symptoms, information seeking, and asking other AYAs for advice seem to be most relevant at diagnosis onset [6]. In our study, we also found some gender differences in the use of tracking as few male participants had used the edit button in tracking of symptoms. One male misunderstood the wording of "edit," and none of the young men had noticed the possibility of adding new activities in the activity tracker. Existing research confirms gender differences in the usability testing of apps as female cancer patients have shown to be more persistent test users by using apps continuously and generally more frequently during test periods than males [51,52].

Limitations

Some limitations should be taken into consideration. The duration of the think-aloud test was only approximately 10 minutes per person; therefore, the participants were each assigned different tasks and questions to uncover all aspects of the app. As a result, some of the app's functionalities were tested more thoroughly than others, which may be reflected in the emphasis of various themes in the study. The app was developed for two target groups: AYAs during and after active treatment. Approximately half the test users noticed that the app was primarily relevant during cancer treatment, which is an aspect that earns more attention in the forthcoming evaluation of the app. At present, it is not known how the app will be used by AYAs who get access to it during treatment and then continue using it during follow-up. This study highlighted how a cancer app, which was developed in a co-creation process involving AYAs, was received by other AYA test users. Even though the app was developed in a co-creation process, the test users had several suggestions for improvement, reflecting that AYAs have individual needs and opinions about apps that cannot all be met.

Conclusion

The think-aloud test of the Kræftværket app has led to some conclusions relevant for the general development of youth-specific cancer apps. Usability testing is crucial during the app development process to improve the app according to the needs of the target audience. Additionally, cancer apps aimed at AYAs should contain relevant, targeted, and unique content, preferably including a symptom and activity tracker and videos presenting relevant advice from other AYAs with cancer experience. Notifications are necessary to remind AYAs to use the app, and ordering and interaction of the posts should be transparent and precise to satisfactorily create a dynamic and engaging app. Further research is recommended to evaluate the Kræftværket app with the input of more AYAs in other hospital settings and for a longer test period covering the trajectory of the participant's illness and recovery.

Acknowledgments

We acknowledge all participants in the study and The Danish Cancer Society for funding of the project (grant number R224-A13480).

Conflicts of Interest

None declared.

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Abbreviations

AYA: adolescent and young adult

Edited by K Eddens; submitted 19.06.19; peer-reviewed by S Baptista, X Skrabal Ross; comments to author 26.07.19; revised version received 22.08.19; accepted 17.10.19; published 02.01.20.

Please cite as:
Hanghøj S, Boisen KA, Hjerming M, Elsbernd A, Pappot H
Usability of a Mobile Phone App Aimed at Adolescents and Young Adults During and After Cancer Treatment: Qualitative Study
JMIR Cancer 2020;6(1):e15008
URL: https://cancer.jmir.org/2020/1/e15008
doi:10.2196/15008
PMID:31895046

Original Paper

Cancer Patients' and Survivors' Perceptions of the Calm App: Cross-Sectional Descriptive Study

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Abstract

Background: There is a need for tools to decrease cancer patients' and survivors' long-term symptom burden. Complementary strategies, such as meditation, can accompany pharmacologic therapy to improve symptoms. Although support programs with targeted content have wider reach, higher adherence, and greater impact, there are no consumer-based meditation apps designed specifically for cancer.

Objective: This study aimed to gather information to advise the development of a cancer-specific meditation app in a small convenience sample of cancer patients and survivors who currently use the Calm app.

Methods: Adult cancer patients and survivors who are Calm users (N=82) were recruited through the Daily Calm Facebook page. Participants completed a Web-based survey related to Calm app use and satisfaction, interest in and ideas for a cancer-specific Calm app, and demographic characteristics. Open-ended responses were inductively coded.

Results: Participants were aged between 18 and 72 years (mean 48.60 years, SD 15.20), mostly female (77/82, 94%), white (65/79, 82%), and non-Hispanic (70/75, 93%), and reported using Calm at least 5 times per week (49/82, 60%). Although rates of satisfaction with current Calm components were high (between 65/82, 79% and 51/81, 63%), only 49% (40/82) of participants used guided meditations that they felt specifically helped with their cancer-related symptoms and survivorship, and 40% (33/82) would prefer more cancer-related content, with guided meditations for cancer-specific anxieties (eg, fear of recurrence; n=15) and coping with strong emotions (n=12) being the most common suggestions. A majority of participants (51/82, 62%) reported that they would be interested in becoming a member of a Calm cancer community (eg, in-app discussion boards: 41/46, 89%; and social media communities: 35/42, 83%). Almost half of the participants (37/82, 45%) reported that they would benefit from features that tracked symptoms in concurrence with app usage, but respondents were divided on whether this information should be shared with health care providers through the app (49/82, 60% would share).

Conclusions: Responses suggest ways in which the current Calm app could be adapted to better fit cancer patients' and survivors' needs and preferences, including adding cancer-specific content, increasing the amount of content focusing on coping with strong emotions, developing communities for Calm users who are cancer patients and survivors, and including features that track cancer-related symptoms. Given differences in opinions about which features were desirable or would be useful, there is a clear need for future cancer-specific apps to be customizable (eg, ability to turn different features on or off). Although future research should address these topics in larger, more diverse samples, these data will serve as a starting point for the development of cancer-specific meditation apps and provide a framework for evaluating their effects.

(JMIR Cancer 2020;6(1):e16926) doi:10.2196/16926

KEYWORDS

cancer; cancer survivors; mindfulness; meditation; consumer behavior; mobile apps; health; mental health

Introduction

Meditation and Cancer Symptoms

In 2018, approximately 1.7 million people were diagnosed with cancer in the United States [1]. Although therapeutic advances have increased cancer survivorship rates from 49% to 69%, the burden of long-term symptoms arising from cancer and cancer therapy among patients and survivors, such as fatigue, depression, pain, and sleep disturbance, is high [2,3]. There is an urgent need for tools that are engaging and easily accessible for cancer patients and survivors that can help to decrease this burden [3]. The growing population of cancer patients and survivors can benefit from complementary strategies to accompany pharmacologic therapy and better manage symptoms [4].

According to a systematic review of surveys conducted in 18 countries across Europe, North America, and Oceania, meditation is the most common complementary strategy for symptom management among cancer survivors [5]. Meditation can be classified as a mindfulness-based strategy, comprising purposeful focus on the present moment without judgment [6]. Findings indicate that mindfulness-based interventions can improve mood, attitude toward one's ability to cope with pain, fatigue, sleep disturbance, and anxiety related to cancer symptoms [7]. These interventions are typically delivered through in-person visits with trained providers, which can be time consuming and costly [8-12]. Even programs that allow at-home participation often involve regular meetings that can be difficult to manage alongside fatigue and pain [13]. Simplifying access for cancer patients and survivors may decrease symptom burden.

Smartphone-Based Meditation

Smartphone-based meditation apps are a resourceful and novel way of delivering meditation practices for symptom management to cancer patients and survivors [14]. Smartphone use is virtually universal among cancer patients and survivors [15,16], and this population reports willingness to use app-based guided meditation [17]. A systematic review published in 2016 found that there were 539 mobile apps related to oncology, 117 of which were targeted toward patients, but few (<6%) were explicitly supported by industry [18]. The use of mobile health (mHealth) tools has been suggested as a means of increasing the scalability of behavioral interventions, thereby allowing a wider reach than possible with in-person interventions [19]. One study recommended Web-based mindfulness-based guided meditation to provide an opportunity for participation in meditation that is otherwise unavailable to many underserved cancer patients and survivors [20].

Despite the growth and promise in using mobile apps to deliver interventions, most empirically supported apps have been developed by the investigator within the context of specific research [21]. Generally, these research-specific apps are not widely available or set up for planned commercial dissemination. A focus on commercially available apps with a broad client base, adapted for specific cancer patients' and survivors' needs, may allow for easier dissemination. However, there is a lack of evidence for using consumer-based mobile apps to improve symptoms in cancer patients.

A recent review found that there were approximately 150 mobile apps for cancer patients and survivors offering mostly educational content and information [22]. Only 5 apps that targeted cancer patients and survivors included some form of meditation content, and to our knowledge, none of them has been empirically evaluated to support their potential feasibility or effects on cancer patients and survivors [22-24]. A systematic review by Jongerius et al [25] identified only 2 meditation studies for cancer patients delivered via mobile apps, both focusing on breast cancer patients. One study used a consumer-based app, Headspace, but did not track app utilization [26]. The other study was not specifically a mobile app, instead adapting Mindfulness-Based Stress Reduction for iPad delivery, and was conducted only over 6 weeks without any follow-up [27].

There are more than 500 mindfulness-based mobile apps available to the consumer (eg, multiple types of meditation, breathing exercises, music and sounds, and movement) [28-30]. Calm is the most popular health and fitness app in the United States (more than 50 million downloads and 1.8 million subscribers), with more than 100 guided meditations to teach users the basics of meditation and how to incorporate meditation into one's life, and also includes hundreds of programs for intermediate and advanced meditators [17,31]. The Seven Days of Calm (ie, introductory course) introduces the user to mindfulness meditation and meditation practices. Users also have access to a library of meditation content, with 3- to 35-min guided meditations addressing a wide range of topics, including coping with negative emotions, increasing compassion and gratitude, and living in the present moment. Users also receive a new 10-min guided meditation every day (ie, The Daily Calm). Beyond basic guided meditations, Calm also offers a variety of other features, including relaxing, soothing music and nature sounds (Calm music), narrated fictional stories for sleep (Sleep Stories), breathing training exercises (Breathe Bubble), in-depth audio series providing education about living mindfully (Calm Masterclass), and video lessons on slow, mindful movement routines (Calm Body).

Despite the variety of content offered and a basis in scientifically validated clinical stress reduction theories [32-34], Calm was designed for the general population, not specifically targeted for cancer patients and survivors. Research suggests that programs targeted to specific patient groups have wider reach, higher adherence rates, and greater impacts on health behaviors [35,36]. The Center for eHealth Research and Disease Management recommends that to improve the uptake of electronic health (eHealth) on patient populations (eg, cancer), the patient or user feedback should be incorporated to help facilitate the development of interventions to be targeted for

end users [37]. Targeting content and features in an app such as Calm provides researchers and clinicians with an established platform to disseminate smartphone-based meditation practices to cancer patients and survivors. The large reach and sustainability (ie, low cost, easy to access, and convenience to use any time or place) of consumer-based apps, such as Calm, may prove a viable and effective solution for patient and survivor symptom management if adapted using patient feedback. There is a need to explore cancer patients' and survivors' perceptions of consumer-based meditation apps and use this information to inform future content and features, making it possible for these apps to help improve the lives of those afflicted by cancer.

This Study

The purpose of this study was to conduct formative research in a small convenience sample of cancer patients and survivors who use Calm to gather information (ie, perceptions, satisfaction, and suggestions) to advise the development of content and features that would better meet the needs and preferences of this population. Data from this study may inform future design for consumer-based apps that want to target specific populations and provide a framework for evaluating their effects within those populations.

Methods

Ethics Approval

The Institutional Review Board at Arizona State University (STUDY00010456) approved the study. All participants provided electronic consent before participating in the survey. The dataset generated or analyzed during the study is available from the corresponding author upon request.

Study Design and Recruitment

This was a cross-sectional descriptive study. Participants were recruited from August 1 to 12, 2019, using a post on the Calm Facebook Community page asking users who had a past or current cancer diagnosis to participate in a survey. If interested, potential participants were provided a link to complete an eligibility screening confirming that they currently or previously had a cancer diagnosis and their age. Eligibility criteria were (1) having had a cancer diagnosis and (2) aged 18 years or older. Those who were eligible were able to move on to the survey questions (see Textbox 1). Before beginning the survey, participants were informed that their participation was voluntary, that they could stop the survey at any time, and that their responses were anonymous and would only be reported in aggregate. They were given the option to consent to participate in the study by clicking to continue to the survey questions on the next page.

Survey

The survey was developed by 3 doctoral-level researchers and a master's-level trained public health data analyst. The survey was Web-based and delivered via Research Electronic Data Capture (REDCap) and took approximately 15 min to complete. All responses were anonymous. Participants completed 21 questions developed by the research team to learn about usage of and satisfaction with the current version of Calm, interest in and ideas for a cancer-specific version of Calm, clinical and cancer characteristics (ie, current treatment status, cancer stage, type of cancer, and type of treatments received), and demographic characteristics. Survey questions are listed in Textbox 1; the complete survey, including response options for each question, is provided in Multimedia Appendix 1.

Statistical Analysis

Quantitative data were analyzed using IBM SPSS version 25.0. Responses to open-ended questions were combined and categorized by first reviewing all responses, and the categories were developed inductively based on recurrent content within responses, defined and named, and then applied to responses [38]. Responses were individually coded by a master's-level data analyst. To capture the breadth of participants' feedback, themes were specific and reflected verbatim from participants' responses. Responses that included content fitting multiple categories were assigned to all relevant themes. For example, referring to the types of new meditation content that could be created specifically for cancer patients and survivors that responded "Concentrating on gratitude and the positive things in your life, and also meditations dealing with anxiety when scheduled for follow-up testing" would be coded as *positive focus, gratitude* and *acute worrying about treatment sessions, scans, or appointments*. Not all participants completed every question; as such, the sample size differs across questions.

Textbox 1. Survey questions.

Calm usage characteristics

1. How often do you use Calm?
2. For each component of Calm, please rank your level of satisfaction.
3. Are there any meditations in Calm that have been or were specifically helpful for your cancer-related symptoms or cancer survivorship?
4. Are there any meditations that were specifically not helpful for your cancer-related symptoms or cancer survivorship?
5. How do you feel about Calm's content overall?

Interest in Calm specifically for cancer

1. Would you be more likely to use Calm if it was specifically made for cancer patients and survivors (ie, Calm for Cancer)?
2. Do you believe there could be components of Calm, other than what is already available, that could be specific for cancer patients and cancer survivors?
3. How useful do you find (Mindfulness Reminders, Tracking, and Share your Stats)?
4. What tools could Calm provide that would be useful to you, specifically related to having cancer or being a cancer survivor?
5. Calm currently has a Calm Community Facebook (FB) group. Are you a member of this group?
6. Would you be interested in being a member of a Calm Cancer Community or connecting with other cancer patients and cancer survivors, specifically?
7. If you could share your progress with managing symptoms (eg, fatigue, pain, and stress) with your doctor through Calm, would you use this feature?
8. Is there anything else you would like to share with us?

Clinical characteristics

1. When were you first diagnosed with cancer?
2. What specific type of cancer are or were you diagnosed with?
3. What stage is your cancer in currently?
4. (i) Are you currently in treatment for cancer or have you received cancer treatment in the past?

   (ii) What treatment(s) are you currently receiving/did you receive?

   (iii) When did you start treatment or for how long did you receive treatment?

Demographic characteristics

1. What is your birthdate?
2. How would you describe yourself (with regard to race)?
3. Do you identify as Hispanic or Latinx?
4. What gender do you identify with the most?

Results

Demographic Characteristics

A total of 82 Calm users with a current or past diagnosis of cancer (ie, cancer patients and survivors) participated in the survey. Participants were aged between 18 and 72 years (mean age 48.60 years, SD 15.20). The majority of respondents identified as female (78/82, 94%), white (65/79, 82%), and non-Hispanic (70/75, 93%; see Table 1).

Multimedia Appendix 2 presents information about participants' types of cancer diagnoses and treatments received. Breast cancer was the most common type of cancer (35/82, 43%). The average age at diagnosis was 44.91 years (SD 4.78; minimum 18 and maximum 69 years). Approximately half of the participants (40/78, 51%) reported that their cancer was in remission or that they were cancer free. At the time of the survey, approximately one-third of the sample was receiving treatment for cancer (29/82, 35%).

Table 1. Demographic characteristics of the sample.

Category	Value, n (%)
Race[a] (N=79)	
White	65 (82)
Asian or Asian American	4 (5)
Black, African American, or Native African	3 (4)
Native Caribbean or Afro-Caribbean Islander	2 (3)
Biracial or multiracial	2 (3)
American Indian or Alaskan Native	1 (1)
Other	3 (4)
Ethnicity (N=75)	
Non-Hispanic or Non-Latinx	70 (93)
Hispanic or Latinx	5 (7)
Gender (N=82)	
Female	77 (94)
Male	5 (6)

[a]For race, participants were given the option of selecting multiple responses, such that the total number of responses does not sum to 79.

Usage of and Satisfaction With Calm's Components

More than half of participants reported that they used Calm at least five times per week (49/82, 58%), and rates of satisfaction with Calm components were generally high (see Tables 2 and 3). The Daily Calm was the most popular component, with only 1 (1%) of 82 respondents reporting that they did not use it. When asked to rank their level of satisfaction, the Daily Calm also had the highest satisfaction rate, with 95% (78/82) of respondents reporting that they were *satisfied* or *very satisfied* with this component. Calm Body and Masterclass were the least used components, with 49% (38/78) and 44% (34/78) of respondents, respectively, reporting that they did not use them. Calm music had the lowest satisfaction rates, with 4 (5%) of 81 respondents reporting that they were either *dissatisfied* or *very dissatisfied*, and an additional 13 (16%) of respondents reporting that they were *neither satisfied nor dissatisfied*.

Table 2. Participants' self-reported frequency of using Calm (N=82).

Frequency	Value, n (%)
Less than 1 time per week	5 (6)
1-2 times per week	13 (16)
3-4 times per week	15 (18)
5 or more times per week	49 (60)

Table 3. Participants' satisfaction with current Calm components and content.

Component	Very dissatisfied, n (%)	Dissatisfied, n (%)	Neither satisfied nor dissatisfied, n (%)	Satisfied, n (%)	Very satisfied, n (%)	I do not use this component, n (%)
Daily Calm (N=82)	1 (1)	0 (0)	3 (4)	24 (29)	54 (66)	1 (1)
Meditations (N=82)	1 (1)	0 (0)	6 (7)	21 (26)	45 (55)	9 (11)
Calm Music (N=81)	1 (1)	3 (4)	13 (16)	22 (27)	29 (36)	13 (16)
Sleep Stories (N=82)	1 (1)	0 (0)	5 (6)	26 (32)	31 (38)	19 (23)
Breathe Bubble (N=79)	1 (1)	1 (1)	6 (8)	13 (16)	27 (34)	31 (39)
Calm Masterclass (N=78)	1 (1)	0 (0)	8 (10)	16 (21)	19 (24)	34 (44)
Calm Body (N=78)	1 (1)	0 (0)	9 (12)	16 (21)	14 (18)	38 (49)

Almost half (40/82, 49%) of the respondents reported that there were meditation options in Calm that were helpful for their cancer-related symptoms or survivorship. When asked to describe the meditation programs that were specifically helpful and explain how they helped, participants reported that guided meditation that focused on anxiety, gratitude, and stress were

most helpful for cancer symptoms and survivorship (see Table 4). Participants reported that guided meditations about anxiety and stress helped them to decrease reactivity in acutely stressful or anxiety-provoking situations, such as before scans, doctor's appointments, or treatment sessions. They expressed that these meditations helped them to notice their feelings (eg, worry and pain) during these stressful moments and redirect their attention to the present, focusing on their breath, which helped them feel more centered and grounded. Participants reported that guided meditations about gratitude also helped them move their attention away from their cancer and focus on positive things in their lives right now. Several participants noted that guided meditations about gratitude also helped them to appreciate the difficulties of others and brought about a sense of peace, reminding them that they are not alone.

Table 4. Participants' reports of guided meditation content specifically helpful for cancer-related symptoms or survivorship (N=40).

Meditation content	Value, n
Anxiety	12
Gratitude	6
Stress	5
Letting go (eg, of fears and control)	5
Breathing meditation	3
Pain	3
Sleep meditation	2
Living in the moment	1
Grief	1

When asked to report whether participants enjoyed Calm's current content overall and if they would prefer that there was more content related to cancer, 79% (65/82) of respondents reported that they enjoyed Calm's current content. However, 40% (33/82) of participants reported that they would prefer additional cancer-related content, such as topics related to being a cancer patient (19/82, 23%), topics related to being a cancer survivor (25/82, 30%), or other topics related to cancer (22/82, 27%). Some of the participants who reported that they would prefer other cancer-related topics provided a description of the topics they would like to see (see Table 5). The most commonly described topics were strong emotions that arise during or after cancer (especially fear, shock, uncertainty, and isolation) and life after surviving cancer (eg, healing, trauma, and lifelong worry).

Table 5. Descriptions of other cancer-related guided meditation content that participants would prefer for inclusion in Calm (N=22).

Meditation content	Value, n
Strong emotions during or after cancer	6
Life after cancer	5
Acceptance and letting go	4
Positive focus and gratitude	4
Chronic illness	3
Acute worrying about treatment sessions, scans, or appointments	3
Visualizations about staying strong (eg, mountain in a storm)	2
Bereavement	1
Narrators who are cancer patients and survivors	1
Cancer and pets	1

Interest in Cancer-Related Calm Content

More than one-third (31/82, 38%) of the participants reported that they would be more likely to use Calm if it were specifically made for cancer patients and survivors, and 73% (60/82) believed that there could be components of the app modified specifically for cancer patients and survivors, beyond what is currently offered. When asked about what kinds of meditation content could be developed specifically for cancer patients and survivors, what they would like to see, and how it would be different from what is currently available, guided meditations for cancer-specific worries or anxieties were the most common suggestions (see Table 6). In particular, 7 participants shared fear of cancer recurrence as an important topic. Other cancer-specific worries included waiting for scan results, going into treatment or surgery, anxiety about potential side effects, terminating treatment, and fear of death. After cancer-specific worries, the next most common suggestion was guided

meditations for dealing with strong emotions that arise during cancer, especially fear and anxiety.

When asked what participants would like to see and how it would be different from what is currently available on Calm, the most common response was the inclusion of cancer-specific content while maintaining the structure of the current Calm app (see Table 7). The second most common response was to change the emphasis of the app to focus more on topics that are relevant to being a cancer patient or survivor (eg, strong emotions, focus on the present moment, and positivity) or to curate existing Calm content to create cancer-relevant compilations within the current app (eg, as a series or Masterclass).

Table 6. Participants' suggestions for new guided meditation content for cancer patients and survivors (N=51).

Meditation content	Value, n
Fears and anxieties specifically related to cancer	15
Managing difficult and strong emotions	12
Short guided meditations to use before or during treatment or scans	7
Similar to current content but specifically addressed to cancer patients and survivors	7
Hope for the future	7
Loving and knowing your body	7
Noninternally focused (eg, focus on surroundings, not on the breath or body)	7
Coping with side effects of cancer and treatment	5
Healing	5
Living in the present	5
Life after cancer	4
Interactions with others and accepting their reactions	4
Grief and mourning	4
Positive self-image	3
Visualizations	3
Remaining positive	2
Breathing	2
Movement and getting outdoors	2
Guilt	2
Trust	2

Table 7. Participants' suggestions for cancer-specific guided meditation content and app components (N=30).

Meditation content	Value, n
Including cancer-specific content	16
Emphasizing different topics (eg, strong negative emotions and focus on present)	9
Curating current Calm content into cancer-relevant series	7
Reformatting content (eg, shorter guided meditations and interactive components)	6
Including content that is more personal or personalized	5
Validation of differences in cancer experiences	5
Content and format that reflects the chronological *Cancer Journey*	3
Including content related to pain management	3
Including spiritual content	2

Interest in Connecting With Other Cancer Patients and Survivors

When asked if they would be interested in becoming a member of a Calm cancer community or in connecting with other cancer patients and survivors who used Calm, almost two-thirds (51/82, 62%) of participants agreed. Respondents who showed interest were asked to select from a list of different forums or types of communities in which they would be interested in participating. Discussion boards (eg, blogs or chat rooms available through the app) and communities on social media (eg, Facebook and

Instagram) were the most popular suggestions, with 89% (41/46) and 83% (35/42) of respondents reporting that they would be interested in these types of communities, respectively. The majority of these respondents showed interest in communities integrated into the Calm app, such as group meditation programs that allowed multiple users to meditate at the same time (33/47, 70%) and the ability to contact other users individually via app-based direct messaging (24/38, 63%).

When asked if they would be interested in other types of communities, 6 (27%) of 22 respondents responded positively. Of the 4 respondents who provided additional open-ended descriptions of other types of potential communities that they might be interested in joining, all expressed a desire for communities with a narrower target audience. Specifically, they proposed that there might be different communities for different types of cancer, such as communities focused on chronic pain; communities for friends, family members, and caregivers; and communities specifically focused on staying positive.

Interest in Cancer-Related Tools or Features to Support App Engagement

Participants were asked about the usefulness of Calm's in-app tools designed to support user engagement (see Table 8). Responses indicate that more than 80% of participants used the tracking features and mindfulness reminders (15/82, 18%, and 16/81, 20%, reported that they did not use and pay attention to the tracking features and the mindfulness reminders, respectively), and more than half of the respondents reported that these features were either *mostly* or *very useful*. Most participants reported that they did not use or pay attention to the Share your Stats feature (48/82, 59%), which allows users to post meditation progress on social media, and only 20% (16/82) found this feature to be useful.

Table 8. Participants' reports of usefulness of in-app tools to support app engagement (N=82).

Tool	Not at all useful, n (%)	Mostly not useful, n (%)	Sometimes useful and sometimes not, n (%)	Mostly useful, n (%)	Very useful, n (%)	I do not use or pay attention to this tool, n (%)
Tracking	2 (2)	2 (2)	10 (12)	19 (23)	35 (43)	15 (18)
Mindfulness Reminders	1 (1)	1 (1)	11 (13)	23 (28)	31 (38)	16 (20)
Share your Stats	9 (11)	5 (6)	5 (6)	9 (11)	7 (9)	48 (59)

Participants were asked to select from a list of possible new features to indicate which tools Calm could provide that would be useful to them, specifically related to having cancer or being a cancer survivor (see Table 9). The most popular response was creating a cancer community within the Calm app (59/82, 72%), followed by the sending of text messages via Calm with charts or graphs that concurrently present data on their cancer-related symptoms and Calm usage that week (37/82, 45%). There was modest support for tools for tracking symptoms or Calm usage exclusively or sharing symptom or usage reports with health care providers.

Participants who selected *Other tools* were given the option to describe additional tools that were not listed but might be useful for cancer patients and survivors. A total of 3 respondents expressed a desire for notifications with positive affirmations, encouraging words, or inspirational quotes. Another participant noted that it could be beneficial if tools in which cancer patients and survivors shared information with their health care providers also allowed providers to respond with feedback. In addition, 3 respondents who were currently undergoing cancer treatment expressed concern about receiving notifications with information about their cancer symptoms, suggesting that this would bring additional, unnecessary attention to difficulties that they are already highly aware of.

Table 9. Participants' reports about potential app-related tools specifically useful for cancer patients and survivors (N=82).

Tool	Reported helpful, n (%)
Calm Cancer Community (ie, engagement with others through the Calm app)	59 (72)
Weekly text messages with a report (ie, graph or chart) about your use of the app and how you are feeling (ie, you track your cancer specific symptoms in Calm)	37 (45)
Daily text messages with feedback related to how you are feeling (ie, you track your cancer-specific symptoms in Calm) with a weekly report (ie, graph or chart)	27 (33)
Share your weekly symptom report with your health care provider	21 (26)
Daily text messages with feedback related to the use of the app (ie, time spent using, etc)	17 (21)
Share your stats (ie, time spent using) with your health care provider	14 (17)
Other tools	6 (7)

Interest in Symptom-Tracking Features

When participants were specifically asked if they would use a feature that allowed them to share progress with managing symptoms (eg, fatigue, pain, and stress) with their doctor using the Calm app, 60% (49/82) reported that they would. Participants who reported that they would use this feature shared their ideas about how the feature would function (see Table 10).

Respondents shared that the feature would allow them to complete surveys about their cancer-related symptoms (eg, before or after a meditation session, n=7) and to use an in-app dashboard to create customizable reports about changes in their symptoms and app usage (n=4), which they could generate and then choose to share with their health care provider (n=12). Other individuals suggested that doctors could have more direct access to their symptom information, within the app (n=2), integrated into existing eHealth platforms within their health care systems (n=3), or through regular (eg, weekly and monthly), automatic emails that sent reports to providers (n=4).

Table 10. Participants' ideas for symptom-tracking and symptom-sharing features (N=33).

Mechanism or ability	Value, n
User-generated reports to share with health care providers	12
Surveys about symptoms within the app	7
Regular reports automatically sent or emailed to health care providers	4
Dashboard to create customizable symptom and app usage tracking reports	4
In-app feature that allows personal contact with users' health care provider	4
Integration with existing electronic health platforms within users' health care networks	3
Regular reports automatically sent or emailed to users	2
Feature allowing health care provider to directly access users' reports or data	2

Responses from participants who did not desire a feature allowing them to share their symptoms with their health care provider (33/82, 40%) indicated the primary reason was that it was easier or preferable to discuss symptoms or progress in person during visits (see Table 11). Others felt that this feature was unnecessary, as they already had a system in place for tracking their symptoms or had other means to easily contact their health care provider if they needed to discuss their symptoms.

Table 11. Reasons for not wanting to share symptoms with health care providers through Calm (N=23).

Reason	Value, n
Prefer to share symptoms with health care provider in person	10
Concerns about privacy or confidentiality	3
Already track symptoms with other methods or systems	3
Tracking and sharing symptoms is not relevant to current needs	3
Difficult or burdensome for self (eg, emotionally) or provider (eg, time)	3
Already satisfied with communication with health care provider	2
Not currently in treatment	1

Discussion

Principal Findings

The purpose of this study was to conduct formative research in a small convenience sample of cancer patients and survivors who use Calm to gather information (ie, perceptions and satisfaction) to advise the development of content and features that would better meet the needs of this population. This was the first study to assess perceptions of cancer patients and survivors who use a consumer-based mobile app for meditation. Data from this study may inform future design for consumer-based apps that target specific populations and provide a framework for evaluating their effects within those populations.

Interest in Cancer-Related Calm Content

Participants were highly satisfied with Calm and used the Daily Calm most frequently with high satisfaction. Calm's guided meditations related to anxiety, gratitude, and stress were considered to be the most helpful for cancer symptoms and survivorship. However, half of the participants did not think that the guided meditations were specifically helpful for their cancer-related symptoms or survivorship, and 73% (60/82) felt that there could be components of Calm modified to be more specific to the experiences of cancer patients and survivors. Suggestions for new content were mostly related to managing difficult emotions and fears and anxieties related to cancer, enduring fears of recurrence, and loving their bodies during and after cancer. Participants were interested in being connected with other Calm users who were cancer patients and survivors. Importantly, having a support community within the Calm app was overwhelmingly the most commonly suggested in-app tool for supporting app engagement. Most participants wanted to share their Calm use and the management of their symptoms with their care providers, but some preferred to do so in person.

Calm content was well received by cancer patients and survivors. Specifically, participants appreciated the stress-, anxiety-, and gratitude-related contents. This is likely because

cancer-related stress often persists well beyond the disease's diagnosis and treatment [39,40]. These stressors include fear of recurrence, limitations in physical function, and experiences and recovery from major treatments (eg, chemotherapy and radiation). Even transitioning out of treatment (eg, fewer medical visits) can cause stress because patients have more responsibility in monitoring and managing their symptoms. At present, Calm has 154 total pieces of content related to stress (98 pieces), anxiety (113 pieces), and a combination of stress and anxiety (57 pieces). Calm provides an easy way for cancer patients and survivors to access content that can help them cope with stress and anxiety. Other cancer-specific meditation mobile apps should consider content related to stress and anxiety.

Gratitude or the ability to notice and appreciate the present moment and the positive aspects of one's life plays an important role in cultivating and maintaining well-being [41]. Gratitude has also been shown to build resilience and to help individuals cope with stress and anxiety [42]. For example, studies in breast cancer patients using Web-based gratitude interventions or gratitude journaling have reported significant decreases in death-related fear, fear of reoccurrence, improvements in daily psychological functioning, greater use of adaptive coping strategies, and greater feelings of being supported by the people around them compared with control groups [43,44]. Calm currently has 57 pieces of content related to gratitude and may also be an effective way to manage cancer patient- and survivor-related stressors [40,45].

Those who felt Calm could offer more cancer-related content recommended guided meditations for coping with strong emotions that arise during cancer (eg, fear, shock, uncertainty, and isolation). In addition, respondents desired content addressing the unique challenges of life after cancer (eg, healing, trauma, and lifelong worry). There are few resources that have been specifically designed to support cancer patients as they transition out of cancer treatment or that specifically address ongoing needs of posttreatment survivors (eg, fear of recurrence, anxiety, impaired body image, fitting into their previous social roles, and fatigue) [46-48]. A recent systematic review identified 10 studies that used mHealth apps (only 1 used meditation) targeting breast cancer survivorship, concluding that there is some promise for these mHealth apps for weight loss, reducing stress, and improving the overall quality of life. More research is needed to confirm the benefits of mobile apps for cancer patients entering survivorship and the unique challenges associated with this. The Calm app currently provides an easily accessible platform from which both cancer patients and survivors could access some content related to fears, yet these are not cancer specific. Mobile apps for cancer patients and survivors may want to consider content related to fears and emotions associated with the transition from patient to survivor and the potential long-term burden of cancer survivorship.

Interest in Connecting With Other Cancer Patients and Survivors

It is not surprising that cancer patients and survivors using the Calm app want to connect with other users. It is important to note that the participants in this study were recruited on Facebook, biasing their response to social support. However, it is also well known and documented that cancer patients and survivors turn to social support to gather resources and to assist with the coping process, as they navigate their way through cancer treatment and survivorship [49,50]. Participants in the study cited that they wanted to have access to other cancer patients and survivors through the app. Cancer patients and survivors often turn to digital and social media–based support groups [51]. Digital media provide an attractive format through which to access support groups because of the greater potential for anonymity and the ability for the cancer patients and survivors to meet social and emotional needs that may not be met by friends and family who do not have cancer [49,50]. Preliminary work demonstrates the potential for the use of the Calm app to improve a range of symptoms among cancer patients and survivors (eg, sleep disturbance, fatigue, anxiety, and depression) [17,31]. Currently, Calm offers support through a Facebook page for users and allows users to share their meditations stats on social media (eg, minutes of meditation and days of meditation). Calm is a unique platform through which the delivery of potentially effective complementary care (ie, mindfulness meditation) *and* access to a support group for cancer patients and survivors via social media could be achieved. Mobile apps for cancer patients and survivors may want to consider ways to include a mechanism for social support among users.

Interest in Symptom-Tracking Features

More than 80% (67/82) of participants indicated that they used the meditation tracking components within the current Calm app, and most reported that they found these features to be useful. Approximately half of the participants felt that the ability to track cancer symptoms in concurrence with Calm usage would be helpful to them. In breast cancer patients, multiple studies support the feasibility and acceptability of using mobile apps to monitor symptoms related to sleep [52], daily functional activity [53], and mental health [54]. In addition, studies of cancer care providers' perceptions of mHealth apps and their potential clinical applications suggest that providers believe real-time outcome tracking is a promising utility, as it is often difficult for patients to accurately recount changing symptom trajectories over time [23,55]. Future development of cancer-specific mobile meditation apps should consider tracking not only minutes and days of meditation but also self-perceived symptoms over time (ie, stress, anxiety, and happiness) and potential illustrations of how these are related to time spent in meditation. This could be an effective strategy for helping cancer patients and survivors, in particular, adhere to participating in Calm long term.

Interestingly, there were divergent opinions about whether symptom information collected through Calm be shared with their health care providers, with approximately 60% (49/82) of participants indicating that they would share information with their health care providers and 40% (33/82) indicating that they would not. Apps that allow cancer patients and survivors a way to share information directly with health care providers are limited. A recent review of mobile apps for cancer found that 29 of the 151 available apps included features that allowed cancer patients and survivors to track symptoms (mainly fatigue, pain, mood, nausea, and sleep), 21 included the ability to

generate graphical summaries for personal use or to share with health care providers (eg, through email or at doctor's visits) [22]. Only 4 apps allowed users to log in and send messages to their health care team.

To our knowledge, there is little research on the effects of patients or survivors tracking symptoms and sharing this information with their providers (either in person or using an app). A small study of cancer patients (N=9) reported that using an mHealth app with the ability to access, monitor, and share their health-related information (eg, access care-related information and sharing information during visits) with providers during visits was empowering [56]. However, studies assessing the feasibility of tracking cancer symptoms via mobile apps have not included information about sharing this information with cancer care providers. Despite the potential benefits of tracking and sharing cancer-related symptoms through an app, health care providers have noted concerns about the privacy, communication, and storage of sensitive patient data [23,55]. Although mHealth technology may benefit users by encouraging them to assume an active role in managing their health and allowing them to engage in a more collaborative relationship with their providers [57], this adds complexity to determining and understanding the ownership of patient records, a role that has historically been held by the health care institution. Changes in these roles give rise to questions about which data should be shared and who should be responsible for safeguarding these data [58]. In order for meditation apps to incorporate features that connect cancer patients and survivors to their health care team, both parties should feel confident in the security and confidentiality of personal health information [59] and understand the extent to which the privacy of these data are and are not protected (eg, under Health Insurance Portability and Accountability Act [HIPAA] rules) [60].

Limitations

The findings of this study should be interpreted in light of its limitations. First, survey participants were recruited via the Calm Facebook page. Owing to the fact that respondents were already Calm users, satisfaction with Calm was likely higher than would be observed in nonusers or users who were less engaged. However, it is notable that a substantial number of participants who were already satisfied with Calm agreed that the app could include components that better address the needs of cancer patients and survivors; this may highlight the broader appeal of a cancer-specific meditation app (eg, if individuals who do not currently use Calm but may consider using it and if it were specific to cancer). Future studies should also collect additional data about the proposed features or components of the current app that respondents were dissatisfied with and their reasons for dissatisfaction, as this information will inform future apps and potentially contribute to their long-term adherence. In addition, survey respondents were already engaged with the Calm community on social media such that the desire to connect with other Calm users may be higher than would be expected in the overall user population. The generalizability of these results may also be affected by the small sample size. To increase the potential benefits of a cancer-specific meditation app, questions about the desired features (eg, means of connecting with other users) should be further explored in larger, more diverse samples of cancer patients and survivors. Future research should also extend to others affected by cancer, such as caregivers and health care providers, who may have unique needs that could be addressed through a meditation app for cancer.

Conclusions

This was the first study to survey cancer patients and survivors who use Calm and participate in Calm's Facebook group to explore the desirability of a cancer-specific meditation app and to collect information about the types of content and features that would be most helpful for these users. Respondents felt that the components, content, and tools in the current Calm app could be better tailored to meet the needs of cancer patients and survivors. There was a desire for content that addressed cancer-specific anxieties (eg, scan anxiety and fear of recurrence) and content that focused on coping with strong emotions. Many patients and survivors indicated that they would benefit from features that tracked cancer-related symptoms in concurrence with app usage, but respondents were divided as to whether this information could be shared with health care providers through the app. This highlights the need for future apps for cancer patients and survivors to be customizable such that the users have the ability to turn different features on and off. Although future research should address these topics in larger, more diverse samples, these data may serve as a starting point for the development of meditation apps for specific patient groups and provide a framework for evaluating their effects within the target populations.

Acknowledgments

The authors would like to acknowledge Shannon Clark-Sienkiewicz for her help with drafting survey questions.

Conflicts of Interest

JH is currently the Director of Science at Calm. JH has been conducting research with Calm as a partner for almost 5 years before becoming the Director of Science and serving on the Scientific Advisory Board. Her role is to ensure the quality of Calm's science. There are no financial incentives from the growth of Calm for any author. The remaining authors declare no conflicts of interest.

Multimedia Appendix 1
Calm for Cancer survey questions.
[PDF File (Adobe PDF File), 68 KB - cancer_v6i1e16926_app1.pdf]

Multimedia Appendix 2
Clinical cancer characteristics in sample.
[DOCX File , 71 KB - cancer_v6i1e16926_app2.docx]

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Abbreviations

eHealth: electronic health
HIPAA: Health Insurance Portability and Accountability Act
mHealth: mobile health
REDCap: Research Electronic Data Capture

Edited by G Eysenbach; submitted 05.11.19; peer-reviewed by T Ewais, S Fazel, YM Schoenberger; comments to author 26.11.19; revised version received 09.12.19; accepted 16.12.19; published 10.02.20.

Please cite as:
Huberty J, Puzia M, Eckert R, Larkey L
Cancer Patients' and Survivors' Perceptions of the Calm App: Cross-Sectional Descriptive Study
JMIR Cancer 2020;6(1):e16926
URL: http://cancer.jmir.org/2020/1/e16926/
doi:10.2196/16926
PMID:

Publisher:
JMIR Publications
130 Queens Quay East.
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