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Original Paper

Quality and Readability of Web-Based Information for Patients With Pancreatic Cysts: DISCERN and Readability Test Analysis

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Abstract

Background: Pancreatic cysts are a complex medical problem with several treatment options. Patients use web-based health information to understand their conditions and to guide treatment choices.

Objective: The goal of this study was to describe the quality and readability of publicly available web-based information on pancreatic cysts and to compare this information across website affiliations.

Methods: A Google search for “pancreatic cysts” was performed and the first 30 websites were evaluated. Website affiliations were classified as academic, media, nonprofit, government, or not disclosed. Information describing cancer risk was recorded. The DISCERN instrument measured the quality of content regarding treatment choices. Four standardized tests were used to measure readability.

Results: Twenty-one websites were included. The majority of the websites (20/21, 95%) described the cancer risk associated with pancreatic cysts. Nearly half of the websites were written by an academic hospital or organization. The average DISCERN score for all websites was 40.4 (range 26-65.5, maximum 80). Websites received low scores due to lack of references, failure to describe the risks of treatment, or lack of details on how treatment choices affect quality of life. The average readability score was 14.74 (range 5.76-23.85, maximum 19+), indicating a college reading level. There were no significant differences across website affiliation groups.

Conclusions: Web-based information for patients with pancreatic cysts is of moderate quality and is written above the reading level of most Americans. Gastroenterological, cancer treatment organizations, and physicians should advocate for improving the available information by providing cancer risk stratification, treatment impact on quality of life, references, and better readability.

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KEYWORDS

internet; pancreatic cyst; health literacy; patient education; pancreas; information seeking

Introduction

The incidence of pancreatic cysts is increasing in developed countries owing to refined abdominal imaging and increasing use of imaging overall [1]. Although mostly benign, some types of pancreatic cysts have malignant potential and may transform into pancreatic cancer. Risk stratification is important to decide which patients should undergo surveillance with serial abdominal imaging (ie, magnetic resonance or endoscopic ultrasound) or which patients should be referred for surgical

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evaluation. A diagnosis of pancreatic cysts may, therefore, be a cause for concern in patients and may result in health information–seeking behavior. Approximately 70% of Americans use the internet to research health issues [2]. Although reviewing of web-based health information may empower patients to take a more active role in their treatment and improve their relationship, communication, and satisfaction during consultation with their treating physician, it may also introduce cyberchondria, and some websites have information that is of poor quality, is difficult to read, and inconsistent with medical practice guidelines [3-8]. Some of these problems exist because there is no regulation or oversight of web-based health information, which may result in information that is incomplete, unsupported, outdated, biased, or inappropriate for the average reader. Since web-based health information influences patients' perceived understanding of health issues and how they manage their health, this information must be accurate and readable [9]. Of all the available internet search engines, Google represents 80%-91% of the internet searches and web-based advertising worldwide, with more than 63,000 searches completed every second [10,11]. In this study, we aimed to describe the quality and readability of publicly available web-based information on pancreatic cysts by using the most popular search engine in the world. The secondary objective was to compare the quality and readability among different website affiliations.

Methods

A Google website search was performed from November 1, 2019 to December 31, 2019. Two reviewers (SO and HZ) independently rated the first 30 websites retrieved using the search term "pancreatic cysts." Inclusion criteria were websites intended for the general public with more than 100 words. Websites with associated fees to access content, duplicate websites, publicly modifiable websites, and those with most of the content in audio or video format were excluded. The affiliation of the website was verified using the WHOis.net database (Table 1). For comparison, the same search was performed using Bing and Yahoo search engines on January 8 and 9, 2021, respectively. The quality of the content was measured with the DISCERN instrument (Table 1) [12].

DISCERN was developed by an expert panel of researchers, clinicians, health journalists, and consumers and is funded by The British Library and the NHS Research and Development Program. The instrument is comprised of 16 questions designed for consumers and information providers to assess the quality of written information about available treatment options for any health issue. Each question uses a rating scale from 1 to 5 (1=definite no, 2-4=partially, 5=definite yes) to indicate whether the publication has met certain criteria. The use of DISCERN does not require specialist knowledge or expertise since it is used to judge the reliability of the sources of information and not the scientific quality or evidence. The DISCERN instrument consists of 3 sections. Section 1 addresses the reliability of the publication, specifically, whether the aims were clear, whether these aims were achieved, whether they were relevant, clear, and up-to-date sources of information, whether the information was balanced and unbiased, and whether it referred to any areas of uncertainty. Section 2 evaluates the specific information on the treatment choice(s) presented, specifically, whether they were fully described, whether the benefits and risks and consequences of withholding treatment were mentioned, how the treatment option(s) affect the quality of life, and whether shared decision making was supported. Section 3 rates the overall quality of the source of information (eg, low, moderate, or high). Raters are encouraged to use their independent judgment and their ratings from the proceeding questions, that is, if the majority of questions scored below 2, then the publication would receive low quality; scores in the mid-range would be rated as moderate; and scores mostly rating 4 or above would be rated as high.

Readability was analyzed using 4 standardized tests: Flesch-Kincaid Grade Level, Gunning Fog Index, Simple Measure of Gobbledygook (SMOG) Readability Formula, and Coleman-Liau Index (score range from 5=5th grade level of education to 19 or more=doctorate, Table 1). Scores from each test were averaged. These tests measure the approximate grade level of education needed to understand the written text. Higher scores correspond to a higher grade level of reading. The Flesch-Kincaid Grade Level evaluates word and sentence length; words with more syllables and sentences with more words are rated as more complex and receive a higher score. The Gunning Fog Index works similarly, using the number of words per sentence and the number of complex words (ie, words with 3 or more syllables) to calculate a score. SMOG produces a score based on the number of words with 3 or more syllables in 10 sentence samples. The Coleman-Liau Index assesses the number of characters in a word. The Readable ContentPro Software was used to calculate each of these scores [13].

The websites were grouped into 5 affiliation categories: nonprofit organization, academic, communication/media, government, and affiliation not disclosed. DISCERN scores from the 2 reviewers and the 4 readability tests were summarized as average and median values. Kruskal-Wallis tests compared the differences between the website groups. Interobserver agreement and κ statistic were calculated. Information regarding the cancer risk of pancreatic cysts was also recorded (Table 1).

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Table 1. Measuring instruments used for health information websites.

Parameters, question instruments	Description
Initial questions	
Affiliation	Nonprofit organization (.org), academic (.edu), communication/media, government (.gov), private/affiliation not disclosed (.com)
Cancer risk explanation	Mentions risk for pancreatic cancer
Quality of information	
DISCERN instrument	16 questions × 1-5 points each. Minimum score: 16 points; maximum score: 80 points
Readability	
Flesch-Kincaid Grade Level	Minimum score: 5 points, maximum score: 19 points 5 points: 5th grade 6 points: 6th grade 7 points: 7th grade 12 points: 12th grade 13 points: University 1st year 14 points: University 2nd year 15-16 points: University 3rd-4th year 17-18 points: Master's and professional degree 19+ points: Doctorate
Gunning Fog Index	Same scoring as mentioned for Flesch-Kincaid Grade Level
Simple Measure of Gobbledygook Readability Formula	Same scoring as mentioned for Flesch-Kincaid Grade Level
Coleman-Liau Index	Same scoring as mentioned for Flesch-Kincaid Grade Level

Results

Of the 30 websites examined, 21 met the inclusion criteria. Five of the 21 (23%) were written by nonprofit organizations, 10 (45%) by an academic hospital or organization, 5 (23%) by communication/media websites, and 1 (5%) by an organization without disclosed affiliation. No government websites (.gov) were identified in our sample. Three of the 5 websites published by nonprofit organizations were written by physicians. The Bing and Yahoo searches yielded similar search results as Google. For all 3 search engines, Mayo Clinic's website on pancreatic cysts was the first appearing search result. Healthline, Memorial Sloan Kettering Cancer Center, The National Pancreas Foundation, and MedicineNet were found in the top 10 websites for all 3 search engines. Hopkins Medicine, Columbia Surgery, and Harvard were common in the top 30 websites for all 3 search engines as well. Pancreatic cancer risk was explained in 20 of the 21 (95%) websites (Table 2).

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Table 2. Quality scores for the websites describing pancreatic cysts (DISCERN questionnaire, 1-5 points for each question).

Order[a]	Cancer risk[b]	Is the publication reliable? Questions #1-8 Average (1-5 points)[c]	Quality of information on treatment choices, Questions #9-15 Average (1-5 points)[d]	Overall quality, Q#16 (1-5 points)[e]	Total score (Q#1-16)[f]	Reference
1st	Yes	3.3	2.1	3.5	45.5	[14]
2nd	Yes	2.3	3.2	3.5	44.5	[15]
3rd	Yes	2.6	2.0	3	37.5	[16]
5th	Yes	2.9	1.8	2.5	38.0	[17]
6th	Yes	1.7	2.8	2	35.0	[18]
7th	Yes	2.1	1.9	2.5	32.5	[19]
8th	Yes	2.6	2.0	2.5	37.0	[20]
9th	Yes	2.4	2.5	3.5	40.0	[21]
10th	Yes	2.5	2.3	2.5	38.5	[22]
11th	Yes	3.6	1.1	1.5	38.0	[23]
12th	Yes	2.6	3.2	3	46.0	[24]
14th	Yes	2.1	3.2	3.5	42.5	[25]
15th	Yes	2.0	2.4	2.5	35.0	[26]
16th	Yes	4.1	4.0	4.5	65.5	[27]
17th	Yes	3.5	4.4	4.5	63.0	[28]
18th	Yes	2.2	2.0	2.5	34.0	[29]
20th	Yes	2.1	1.8	2	31.0	[30]
22nd	Yes	3.1	2.0	2.5	41.0	[31]
24th	Yes	3.3	2.4	2	45.0	[32]
29th	Yes	2.0	1.9	2.5	32.0	[33]
30th	No	1.6	1.6	2	26.0	[34]

[a]Order of appearance. Seven websites did not meet the inclusion criteria: 4th (requires payment); 13th, 23rd, and 27th (not intended for the general public); and 19th, 21st, and 25th (require payment and not intended for the general public).

[b]Did the website mention the risk of pancreatic cancer associated with pancreatic cysts?

[c]Average reliability of the publications=2.3.

[d]Average quality of the publications=2.4.

[e]Average overall quality=2.8.

[f]Average total score=40.4.

The approach and depth to describe cancer risk stratification were diverse. One media website presented a new test for cyst fluid aspirate (monoclonal antibody Das-1) that may predict cancer risk [32]. One nonprofit website provided a complete diagnostic algorithm for patients to discuss with their health care provider, including cancer risk stratification and surgery [27]. One academic website provided a comprehensive 36-page review that included common signs and symptoms of growing cysts, types of pancreatic cysts, treatment options, an agenda for future appointments, and additional references [28]. The average total DISCERN score for all the websites was 40.4 (range 26-65.5, Table 2). The questions that, on average, received the lowest ratings on DISCERN were question #4: “Is it clear what sources of information were used to compile the publication?” (average score 2.14, range 1-5); question #11: “Does it describe the risks of each treatment?” (average score 1.93, range 1-4.5); and question #13: “Does it describe how the treatment choices affect the overall quality of life?” (average score 1.62, range 1-4.5). The median DISCERN score for nonprofit organizations was 33.5 (range 25-74), that for academic hospital or organization was 41 (27-65), that for communication/media was 38 (24-58), and that for an organization without disclosed affiliation was 35 (31-39) (Figure 1). The average total readability score for all the websites was 14.74 (range 5.76-23.9, Table 3).

The median (IQR) readability score for nonprofit organizations was 13.01 (8.64-31.76), that for academic hospital or organization was 15.59 (1.54-20.55), that for communication/media was 15.40 (11.5-19.31), and that for an organization without disclosed affiliation was 14.70 (12.86-16.86) (Figure 1). Scores were similar among website affiliations (DISCERN P=.90 and readability P=.80; Figure 1). Interobserver agreement was adequate (76.2%) but κ was poor (κ= –0.08).

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Figure 1. Box plot comparing website quality (DISCERN score, range 16-80 points) and readability (average of 4 instruments, range 5-19 points) by publisher affiliation. Lines represent upper and lower quartiles and dots are outliers.

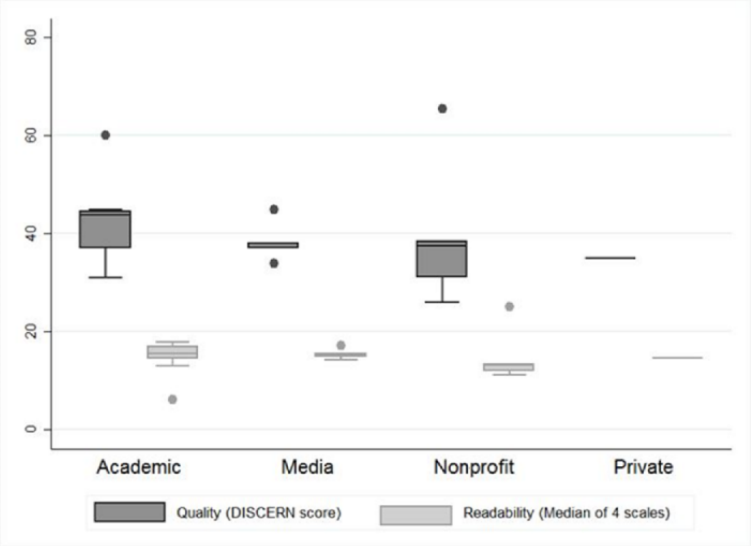

Table 3. Readability scores for websites describing pancreatic cysts.

Order[a]	Affiliation	Average readability[b]	Reference
1st	Academic	14.26	[14]
2nd	Academic	16.00	[15]
3rd	Nonprofit	23.85	[16]
5th	Media	14.83	[17]
6th	Private group	14.78	[18]
7th	Academic	12.43	[19]
8th	Media	15.30	[20]
9th	Academic	15.49	[21]
10th	Nonprofit	12.72	[22]
11st	Media	13.87	[23]
12nd	Academic	14.93	[24]
14th	Academic	17.40	[25]
15th	Academic	18.04	[26]
16th	Nonprofit	11.94	[27]
17th	Academic	5.76	[28]
18th	Media	17.30	[29]
20th	Nonprofit	10.70	[30]
22nd	Academic	17.50	[31]
24th	Media	15.04	[32]
29th	Academic	14.85	[33]
30th	Nonprofit	12.69	[34]

[a]Order of appearance. Seven websites did not meet the inclusion criteria: 4th (requires payment); 13th, 23rd, and 27th (not intended for the general public); and 19th, 21st, and 25th (require payment and not intended for the general public).

[b]Average readability of all websites=14.74.

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Discussion

This study is the first, to our knowledge, to evaluate the quality and readability of web-based information for pancreatic cysts. The findings of this study highlight a substantial gap in the quality and readability of web-based information for patients with pancreatic cysts. Quality was suboptimal due to incomplete descriptions of pancreatic cyst management, lack of clear sources of information, and incomplete descriptions of the risks associated with treatment or how treatment choices affect the overall quality of life. Few websites provided a complete description of the management options (ie, radiological surveillance vs surgical treatment). Similar limitations have been described for other health conditions such as pancreatic cancer and gynecological disorders [4,5,7,35,36]. Despite the overall lack of high-quality web-based health information, a few sources were excellent. The top 5 highest DISCERN-rated websites were The American Gastroenterological Association (DISCERN score 65.5), The University of Michigan Comprehensive Cancer Center, GI Oncology Program (DISCERN score 63), Columbia Surgery (DISCERN score 46), Mayo Clinic (DISCERN score 45.5), and MedicalXpress (DISCERN score 45). We found 2 websites, a publication by the American Gastroenterological Association and a publication by the University of Michigan, which had DISCERN scores greater than 60 [27,28]. Across different health conditions, these high-quality websites represent the minority of cases. Three studies comparing the educational materials for obstetric and pelvic diseases reported that only 5% (3/58) [5], 15% (8/54) [7], and 4% (1/24) [4] of the materials achieved DISCERN scores greater than 60. Encouragingly, in our review, high-quality websites appeared as earlier search hits (our 2 high scorers appeared as the 16th and 17th hits), suggesting that they are more recognizable sources of information for internet users.

We report median readability scores appropriate for a college reading level (range 13-16 points). This is problematic for most readers since only 35% of American citizens complete an undergraduate college education and most Americans read at an elementary school level (Table 4) [37].

Table 4. American population according to reading level (N=328 million).

Reading level	US population (millions), n (%)
6th grade	323 (98.5)
7th grade	317 (96.6)
12th grade	287 (87.5)
University 1st year	190 (57.9)
University 2nd year	127 (38.7)
University 3rd to 4th year	95 (28.9)
Master's and Professional degree	33 (10.1)
Doctorate	7 (2.1)

Studies have similarly found that the readability levels of web-based health information are above the reading levels of most Americans [4,5,7,35,36]. The American Medical Association, therefore, recommends a sixth-grade reading level for all patient-oriented educational materials [36]. However, text difficulty increases from medical jargon and an effort to maintain quality and accuracy of health information. The top 5 most readable websites were The University of Michigan Comprehensive Cancer Center, GI Oncology Program (average readability score 5.76), Pancreatic Cancer UK (average readability score 10.70), The American Gastroenterological Association (average readability score 11.94), Roswell Park Comprehensive Cancer Center (average readability score 12.43), and Virginia Mason (average readability score 12.69). We found only 1 academic website that was written at an adequate reading level [28]. Previous studies found that only 13% (3/24) [4], 5% (3/58) [5], and 0% (0/54) [7] of the websites evaluated were written at an appropriate reading level. Our findings support the paradox that increased quality and accuracy come with a tradeoff of challenging language, longer article length, and higher readability scores [36,38].

The second important finding of this study was similar quality and accuracy scores among different website affiliations. This homogeneity of low quality among different publishers is common in web-based materials describing other health care conditions [4,38,39]. Although no difference was discernible in this study, possibly due to smaller sample size and higher variability, some prior studies have shown important differences. Academic sites have previously been found to be of high accuracy but more difficult to read, while private sites tend to be easier to read with lower accuracy of information [40]. Media websites are both difficult to read and have the lowest accuracy scores [36]. Differences have also been linked to the internet domain used. Research shows that organization domains (ie, ".org") are an indicator of more accurate information [41] while sites that list references and those without financial interests are also associated with higher quality [42,43].

Our findings demonstrate the importance of balancing high-quality information (higher DISCERN scores) with lower reading levels (readability scores closer to 6) in patient handouts, websites, and reading materials [36,44]. For example, the material produced by the University of Michigan provides many pictorial representations of anatomy, pathology, procedures, and surgery. Houts et al [45] found that visual aids increase comprehension of complex medical information, which increases the understanding of health information, particularly among

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less literate patients [46]. Another avenue is patient testimonials. Although this study excluded websites that were mostly in the audiovisual format, video narrative presentations of breast cancer treatment wherein patients relate their experiences to other patients increase engagement with the material, with study participants spending more time viewing the information compared to text [47].

The Health of the Net was developed in 1995 to address issues with limited web-based health information quality and lack of supporting evidence. It is overseen by the Health of the Net Foundation in collaboration with the World Health Organization and consists of 8 principles that websites should follow to achieve the Code of Conduct (Health of the Net code) certification. The certification and display of the Health of the Net code seal are intended to help consumers identify reliable websites [48]. Another possible method to improve web-based information is for clinicians writing this information to consider why patients seek web-based information in the first place. For patients with cancer, seeking web-based information typically occurs right after receiving a diagnosis and before starting treatment. Patients may feel they received insufficient information from their providers and may turn to the internet to "fill in the gaps." Information-seeking behavior is also a coping mechanism by which patients convince themselves that all treatment options have been explored [49]. Treating physicians should be aware of these reasons and redirect patients to credible and appropriate sites for information.

There are some limitations in this study design that are important to consider. First, our results are subject to selection bias and confounding. An examination of the first 30 results from our Google search represents a very small fraction of the websites that contain information regarding pancreatic cysts (eg, a search of "pancreatic cysts" renders over 2 million results on Google). Further, internet search engines use complex algorithms based on geographical locations and previous searches performed. Despite this, most internet users read only the first few pages of the results and 2 separate search engines yielded common results; thus, our analysis is likely a valid representation of an initial search a patient may conduct [50]. Additionally, our search was limited to the English language and our results have limited external validity outside the United States. The small sample size precluded advanced statistical analysis comparing findings among different website affiliations. Other limitations include the DISCERN instrument, which requires an element of subjective analysis, and the fact that our raters were not blinded to website affiliation. Readability tests also do not measure understanding of the material nor do they account for reader motivation, prior knowledge and attitudes, and problems such as poor vision and illness as well as the role of active voice, personalization, and presentation of the information, including font, font size, and illustrations [51,52]. These limitations underline the importance of follow-up with health care providers to clear up any potential misunderstandings and secure additional imaging or treatment when needed. Our study also did not analyze "information completeness" as a variable. Critical information such as genetic implications, costs of surveillance, and treatment was not recorded in our study design.

In summary, our findings demonstrate a gap in the quality and readability of web-based health information regarding pancreatic cyst management. These websites require peer review to balance improved quality with writing closer to a sixth-grade reading level. Gastroenterology and leading cancer organizations should advocate for improving web-based information by calling for a complete description of cancer risk stratification and treatments, visible sources of information and references, and appropriate readability, regardless of the website affiliation. These improvements can help less literate patients understand the information, reduce stress and anxiety after a new diagnosis, and facilitate shared decision making with providers.

Authors' Contributions

SPO participated in the acquisition, analysis, and interpretation of data and in the drafting and editing of the manuscript. HZ participated in data acquisition and editing the manuscript. MRW participated in editing the manuscript. JEC participated in conceptualization, data analysis and interpretation, and editing the manuscript.

Conflicts of Interest

JEC received a travel grant from AbbVie Inc and received minor food and beverage from Boston Scientific Corporation and Cook Medical LLC.

References

1. Moris M, Bridges MD, Pooley RA, Raimondo M, Woodward TA, Stauffer JA, et al. Association Between Advances in High-Resolution Cross-Section Imaging Technologies and Increase in Prevalence of Pancreatic Cysts From 2005 to 2014. Clin Gastroenterol Hepatol 2016 Apr;14(4):585-593.e3. [doi: 10.1016/j.cgh.2015.08.038] [Medline: 26370569]
2. Fox S. The social life of health information. Pew Research Center. 2014 Jan 15. URL: https://www.pewresearch.org/fact-tank/2014/01/15/the-social-life-of-health-information/ [accessed 2020-04-13]
3. McMullan RD, Berle D, Arnáez S, Starcevic V. The relationships between health anxiety, online health information seeking, and cyberchondria: Systematic review and meta-analysis. J Affect Disord 2019 Feb 15;245:270-278. [doi: 10.1016/j.jad.2018.11.037] [Medline: 30419526]
4. Fowler GE, Baker DM, Lee MJ, Brown SR. A systematic review of online resources to support patient decision-making for full-thickness rectal prolapse surgery. Tech Coloproctol 2017 Nov;21(11):853-862 [FREE Full text] [doi: 10.1007/s10151-017-1708-7] [Medline: 29101494]

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5. Ghai V, Pergialiotis V, Jan H, Duffy JMN, Doumouchtsis SK, CHORUS: an International Collaboration Harmonising Outcomes, Research,Standards in Urogynaecology Women's Health. Obstetric anal sphincter injury: a systematic review of information available on the internet. Int Urogynecol J 2019 May;30(5):713-723. [doi: 10.1007/s00192-018-3753-9] [Medline: 30159721]
6. Harris VC, Links AR, Hong P, Walsh J, Schoo DP, Tunkel DE, et al. Consulting Dr. Google: Quality of Online Resources About Tympanostomy Tube Placement. Laryngoscope 2018 Feb;128(2):496-501 [FREE Full text] [doi: 10.1002/lary.26824] [Medline: 28842989]
7. Hirsch M, Aggarwal S, Barker C, Davis CJ, Duffy JMN. Googling endometriosis: a systematic review of information available on the Internet. Am J Obstet Gynecol 2017 May;216(5):451-458.e1. [doi: 10.1016/j.ajog.2016.11.1007] [Medline: 27840143]
8. Tan SS, Goonawardene N. Internet Health Information Seeking and the Patient-Physician Relationship: A Systematic Review. J Med Internet Res 2017 Jan 19;19(1):e9 [FREE Full text] [doi: 10.2196/jmir.5729] [Medline: 28104579]
9. Baker L, Wagner TH, Singer S, Bundorf MK. Use of the Internet and e-mail for health care information: results from a national survey. JAMA 2003 May 14;289(18):2400-2406. [doi: 10.1001/jama.289.18.2400] [Medline: 12746364]
10. Company reports 2019. eMarketer. URL: https://www.emarketer.com/ [accessed 2020-04-23]
11. Search engine market share worldwide Mar 2019 - Mar 2020. Statscounter - Global. URL: https://gs.statcounter.com/search-engine-market-share [accessed 2020-04-23]
12. Charnock D, Shepperd S, Needham G, Gann R. DISCERN: an instrument for judging the quality of written consumer health information on treatment choices. J Epidemiol Community Health 1999 Feb;53(2):105-111 [FREE Full text] [doi: 10.1136/jech.53.2.105] [Medline: 10396471]
13. Readable. URL: https://readable.com [accessed 2019-12-15]
14. Pancreatic cysts. Mayo Clinic. URL: https://www.mayoclinic.org/diseases-conditions/pancreatic-cysts/symptoms-causes/syc-20375993 [accessed 2020-04-23]
15. Pancreatic cysts. Memorial Sloan Kettering Cancer Center. URL: https://www.mskcc.org/cancer-care/types/pancreatic-cysts [accessed 2020-04-23]
16. Pancreatic cysts. The National Pancreas Foundation. URL: https://pancreasfoundation.org/patient-information/ailments-pancreas/pancreatic-cysts/ [accessed 2020-04-23]
17. Identifying and treating cysts on the pancreas. Healthline. URL: https://www.healthline.com/health/cyst-on-pancreas [accessed 2020-04-23]
18. Pancreatic cysts. Digestive Specialists Inc. URL: https://www.digestivespecialists.com/conditions/pancreatic-cysts [accessed 2020-04-23]
19. Do pancreatic cysts become cancerous? Roswell Park Comprehensive Cancer Center. URL: https://www.roswellpark.org/cancertalk/201711/do-pancreatic-cysts-become-cancerous [accessed 2020-04-23]
20. Marks JW. Pancreatic cysts. MedicineNet. URL: https://www.medicinenet.com/pancreatic_cysts/article.htm#what_is_the_pancreas [accessed 2020-04-23]
21. Pancreatic cysts and pseudocysts. Cleveland Clinic. URL: https://my.clevelandclinic.org/health/diseases/14627-pancreatic-cysts-and-pseudocysts [accessed 2020-04-23]
22. What you should know about pancreatic cysts. Lets Win! Pancreatic Cancer. 2018 Jun 08. URL: https://letswinpc.org/managing-pancreatic-cancer/2018/06/08/what-you-should-know-pancreatic-cysts/ [accessed 2020-04-23]
23. Nassour I, Choti MA. Types of Pancreatic Cysts. JAMA 2016 Sep 20;316(11):1226 [FREE Full text] [doi: 10.1001/jama.2016.9035] [Medline: 27654619]
24. Pancreatic cysts. Columbia Surgery. URL: https://columbiasurgery.org/conditions-and-treatments/pancreatic-cysts [accessed 2020-04-23]
25. Pancreatic cysts. University of California San Francisco. URL: https://surgicaloncology.surgery.ucsf.edu/conditions--procedures/pancreatic-cysts.aspx [accessed 2020-04-23]
26. Symptoms of pancreatic cysts and masses. Stanford Health Care. URL: https://stanfordhealthcare.org/medical-conditions/digestion-and-metabolic-health/pancreatic-cysts/symptoms.html [accessed 2020-04-23]
27. American Gastroenterological Association. AGA Section. Managing Pancreatic Cysts: A Patient Guide. Gastroenterology 2015 Aug;149(2):498-499 [FREE Full text] [doi: 10.1053/j.gastro.2015.06.042] [Medline: 26134942]
28. A patient's guide to pancreatic cysts. University of Michigan Comprehensive Cancer Center, GI Oncology Program. 2012. URL: https://www.rogelcancercenter.org/files/pancreatic-cancer/pancreatic-cyst-handbook.pdf [accessed 2020-04-23]
29. Bennington-Castro J. What is a pancreatic cyst. EveryDay Health. 2018 Feb 01. URL: https://www.everydayhealth.com/pancreatitis/guide/pancreatic-cyst/ [accessed 2020-04-23]
30. Pancreatic cysts. Pancreatic Cancer UK. URL: https://www.pancreaticcancer.org.uk/information-and-support/facts-about-pancreatic-cancer/types-of-pancreatic-cancer/pancreatic-cysts/ [accessed 2020-04-23]
31. Earlier, more frequent removal of some pancreatic cysts may decrease cancer risk for some patients. Johns Hopkins Medicine. 2019 May 14. URL: https://www.hopkinsmedicine.org/news/newsroom/news-releases/earlier-more-frequent-removal-of-some-pancreatic-cysts-may-decrease-cancer-risk-for-some-patients [accessed 2020-04-23]

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32. Dryden J. Biomarker predicts which pancreatic cysts may become cancerous. MedicalXpress. 2019 Jun 05. URL: https://medicalxpress.com/news/2019-06-biomarker-pancreatic-cysts-cancerous.html [accessed 2020-04-23]
33. Pancreatic cysts. MedStar Georgetown University Hospital. URL: https://www.medstargeorgetown.org/our-services/gastroenterology/conditions/pancreatic-cysts/ [accessed 2020-04-23]
34. Pancreatic cysts FAQs. Virginia Mason. URL: https://www.virginiamason.org/pancreatic-cysts-faqs [accessed 2020-04-23]
35. Lovett J, Gordon C, Patton S, Chen CX. Online information on dysmenorrhoea: An evaluation of readability, credibility, quality and usability. J Clin Nurs 2019 Oct;28(19-20):3590-3598 [FREE Full text] [doi: 10.1111/jocn.14954] [Medline: 31162870]
36. Storino A, Castillo-Angeles M, Watkins AA, Vargas C, Mancias JD, Bullock A, et al. Assessing the Accuracy and Readability of Online Health Information for Patients With Pancreatic Cancer. JAMA Surg 2016 Sep 01;151(9):831-837. [doi: 10.1001/jamasurg.2016.0730] [Medline: 27144966]
37. Bustamante J. College Graduation Statistics. Educationdata.org. 2019 Jun 08. URL: https://educationdata.org/number-of-college-graduates/ [accessed 2020-04-30]
38. Bailey MA, Coughlin PA, Sohrabi S, Griffin KJ, Rashid ST, Troxler MA, et al. Quality and readability of online patient information for abdominal aortic aneurysms. J Vasc Surg 2012 Jul;56(1):21-26 [FREE Full text] [doi: 10.1016/j.jvs.2011.12.063] [Medline: 22521801]
39. Sullivan TB, Anderson JT, Ahn UM, Ahn NU. Can Internet information on vertebroplasty be a reliable means of patient self-education? Clin Orthop Relat Res 2014 May;472(5):1597-1604 [FREE Full text] [doi: 10.1007/s11999-013-3425-5] [Medline: 24338042]
40. Purdy AC, Idriss A, Ahern S, Lin E, Elfenbein DM. Dr Google: The readability and accuracy of patient education websites for Graves' disease treatment. Surgery 2017 Nov;162(5):1148-1154. [doi: 10.1016/j.surg.2017.07.011] [Medline: 28864099]
41. Fallis D, Frické M. Indicators of accuracy of consumer health information on the Internet: a study of indicators relating to information for managing fever in children in the home. J Am Med Inform Assoc 2002;9(1):73-79 [FREE Full text] [doi: 10.1136/jamia.2002.0090073] [Medline: 11751805]
42. Martin-Facklam M, Kostrzewa M, Schubert F, Gasse C, Haefeli WE. Quality markers of drug information on the Internet: an evaluation of sites about St. John's wort. Am J Med 2002 Dec 15;113(9):740-745. [doi: 10.1016/s0002-9343(02)01256-1] [Medline: 12517364]
43. Martin-Facklam M, Kostrzewa M, Martin P, Haefeli WE. Quality of drug information on the World Wide Web and strategies to improve pages with poor information quality. An intervention study on pages about sildenafil. Br J Clin Pharmacol 2004 Jan;57(1):80-85 [FREE Full text] [doi: 10.1046/j.1365-2125.2003.01954.x] [Medline: 14678344]
44. Walsh TM, Volsko TA. Readability assessment of internet-based consumer health information. Respir Care 2008 Oct;53(10):1310-1315. [Medline: 18811992]
45. Houts PS, Doak CC, Doak LG, Loscalzo MJ. The role of pictures in improving health communication: a review of research on attention, comprehension, recall, and adherence. Patient Educ Couns 2006 May;61(2):173-190. [doi: 10.1016/j.pec.2005.05.004] [Medline: 16122896]
46. Garcia-Retamero R, Cokely E. Communicating Health Risks With Visual Aids. Curr Dir Psychol Sci 2013 Sep 25;22(5):392-399. [doi: 10.1177/0963721413491570]
47. Shaffer VA, Owens J, Zikmund-Fisher BJ. The effect of patient narratives on information search in a web-based breast cancer decision aid: an eye-tracking study. J Med Internet Res 2013 Dec 17;15(12):e273 [FREE Full text] [doi: 10.2196/jmir.2784] [Medline: 24345424]
48. HONcode: How it started. Health On the Net. 2017 May 02. URL: https://www.hon.ch/HONcode/Patients/background.html [accessed 2020-04-13]
49. Eysenbach G. The impact of the Internet on cancer outcomes. CA Cancer J Clin 2003;53(6):356-371 [FREE Full text] [doi: 10.3322/canjclin.53.6.356] [Medline: 15224975]
50. Eysenbach G, Köhler C. How do consumers search for and appraise health information on the world wide web? Qualitative study using focus groups, usability tests, and in-depth interviews. BMJ 2002 Mar 09;324(7337):573-577 [FREE Full text] [doi: 10.1136/bmj.324.7337.573] [Medline: 11884321]
51. Davis TC, Arnold C, Berkel HJ, Nandy I, Jackson RH, Glass J. Knowledge and attitude on screening mammography among low-literate, low-income women. Cancer 1996 Nov 01;78(9):1912-1920. [doi: 10.1002/(sici)1097-0142(19961101)78:9<1912::aid-cncr11>3.0.co;2-0] [Medline: 8909311]
52. Mumford ME. A descriptive study of the readability of patient information leaflets designed by nurses. J Adv Nurs 1997 Nov;26(5):985-991. [doi: 10.1046/j.1365-2648.1997.00455.x] [Medline: 9372404]

Abbreviations

SMOG: Simple Measure of Gobbledygook

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Original Paper

Cardiovascular Assessment Tool for Breast Cancer Survivors and Oncology Providers: Usability Study

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Abstract

Background: Cardiovascular health is of increasing concern to breast cancer survivors and their health care providers, as many survivors are more likely to die from cardiovascular disease than cancer. Implementing clinical decision support tools to address cardiovascular risk factor awareness in the oncology setting may enhance survivors' attainment or maintenance of cardiovascular health.

Objective: We sought to evaluate survivors' awareness of cardiovascular risk factors and examine the usability of a novel electronic health record enabled cardiovascular health tool from the perspective of both breast cancer survivors and oncology providers.

Methods: Breast cancer survivors (n=49) recruited from a survivorship clinic interacted with the cardiovascular health tool and completed pre and posttool assessments about cardiovascular health knowledge and perceptions of the tool. Oncologists, physician assistants, and nurse practitioners (n=20) who provide care to survivors also viewed the cardiovascular health tool and completed assessments of perceived usability and acceptability.

Results: Enrolled breast cancer survivors (84% White race, 4% Hispanic ethnicity) had been diagnosed 10.8 years ago (SD 6.0) with American Joint Committee on Cancer stage 0, I, or II (45/49, 92%). Prior to viewing the tool, 65% of survivors (32/49) reported not knowing their level for one or more cardiovascular health factors (range 0-4). On average, only 45% (range 0%-86%) of survivors' known cardiovascular health factors were at an ideal level. More than 50% of survivors had ideal smoking status (45/48, 94%) or blood glucose level (29/45, 64%); meanwhile, less than 50% had ideal blood pressure (12/49, 24%), body mass index (12/49, 24%), cholesterol level (17/35, 49%), diet (7/49, 14%), and physical activity (10/49. 20%). More than 90% of survivors thought the tool was easy to understand (46/47, 98%), improved their understanding (43/47, 91%), and was helpful (45/47, 96%); overall, 94% (44/47 survivors) liked the tool. A majority of survivors (44/47, 94%) thought oncologists should discuss cardiovascular health during survivorship care. Most (12/20, 60%) oncology providers (female: 12/20, 60%; physicians:

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14/20, 70%) had been practicing for more than 5 years. Most providers agreed the tool provided useful information (18/20, 90%), would help their effectiveness (18/20, 90%), was easy to use (20/20, 100%), and presented information in a useful format (19/20, 95%); and 85% of providers (17/20) reported they would use the tool most or all of the time when providing survivorship care.

Conclusions: These usability data demonstrate acceptability of a cardiovascular health clinical decision support tool in oncology practices. Oncology providers and breast cancer survivors would likely value the integration of such apps in survivorship care. By increasing awareness and communication regarding cardiovascular health, electronic health record–enabled tools may improve survivorship care delivery for breast cancer and ultimately patient outcomes.

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KEYWORDS

electronic health records; clinical decision support; usability testing; cardiovascular diseases; cancer survivors; breast cancer

Introduction

Cardiovascular health is of increasing concern to breast cancer survivors and their health care providers [1,2], since older, postmenopausal survivors are more likely to die of cardiovascular disease rather than of cancer [3,4]. Breast cancer survivors are at greater risk of death due to cardiovascular disease, compared to age-matched women without a history of breast cancer [5]. Chemotherapy (eg, anthracyclines), monoclonal antibody treatment, hormonal treatments, and radiation all heighten cardiovascular disease risk among survivors [1,6], further increasing cardiovascular disease susceptibility among cancer survivors [5,7,8]. Addressing cardiovascular health is critical for all breast cancer survivors, especially those who receive cardiotoxic treatments [2,9,10].

According to 1582 long-term cancer survivors surveyed in California, 62% were overweight or obese, 55% were hypertensive, 21% were diabetic, 18% were physically inactive, and 5% were current smokers [11]. An analysis of these California cancer registry data highlighted the possible role of shared risk factors in the development of both cancer and cardiovascular disease, reporting that cancer survivors tend to have multiple cardiovascular disease risk factors and that survivorship care often does not address these risk factors [11,12]. Early recognition and treatment of cardiovascular risk factors may be important during survivorship, as this increased risk of cardiovascular death is evident approximately 7 years postdiagnosis [2,5].

Despite Institute of Medicine recommendations for adequate prevention efforts and care coordination for cancer survivors [13-15], cardiovascular risk continues to be undertreated in this population [16,17]. The majority of National Cancer Institute Community Oncology Research Program oncologists we interviewed (11 of 14) in a pilot study [18] reported cardiovascular health discussions to be “somewhat” or “very” important. Yet in general survivorship settings, few referrals for cardiovascular care are made by oncologists to primary care providers and cardiologists for guideline-driven follow-up care [11,16,19,20].

The American Heart Association’s (AHA) definition of cardiovascular health comprises modifiable risk factors, which are scored according to Table 1. Improvements in cardiovascular health can reduce cardiovascular disease and breast cancer recurrence risk [21-26], and increasing patient and provider awareness can enhance cardiovascular health [13]. Most cancer survivors do not meet AHA’s healthy standards in multiple cardiovascular health components such as body mass index (BMI), physical activity, diet, smoking, blood pressure, cholesterol level, and glucose level [2,11,21].

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Table 1. American Heart Association simple 7 measures of cardiovascular health, adapted from [27].

Measures	Poor health	Intermediate health	Ideal health
Health behaviors			
Smoking status	Current	Former ≤12 months	Never or quit >12 months
BMI	≥30 kg/m^2	25-29.9 kg/m^2	<25 kg/m^2
Physical activity	None	1-149 minutes/week moderate or 1-74 minutes/week vigorous or 1-149 minutes/week moderate and vigorous	≥150 minutes/week moderate or ≥75 minutes/week vigorous or ≥150 minutes/week moderate and vigorous
Healthy diet score	0-1 components	2-3 components	4-5 components
Health factors			
Total cholesterol level	≥240 mg/dL	200-239 mg/dL or treated to goal	<200 mg/dL
Blood pressure	Systolic ≥140 mm Hg or Diastolic ≥90 mm Hg	Systolic 120-139 mm Hg or Diastolic 80-89 mm Hg or treated to goal	Systolic <120 mm Hg Diastolic <80 mm Hg
Blood glucose level			
Fasting plasma glucose	≥126 mg/dL	100-125 mg/dL or treated to goal	<100 mg/dL
Hemoglobin A_{1c}	≥6.5%	5.7%-6.4% or treated to goal	≤5.6%

Clinical decision support can provide relevant data to the point-of-care to prompt appropriate disease management and referrals [28]. Our team has previously developed, implemented, and evaluated a cardiovascular health assessment tool, Stroke Prevention in Health care Delivery Environments (SPHERE), in the primary care setting [29,30]. Use of SPHERE resulted in improved BMI and diabetes status in the interventional primary care clinic but not the control clinic [31]. We refined this tool based upon feedback received from qualitative interviews with oncologists [18] and added information about receipt of potentially cardiotoxic cancer treatments. For this study, we evaluated the acceptability of the new Automated Heart-Health Assessment tool (AH-HA, Figure 1) among oncology providers and the Vigor-Us mobile app (Figure 1) among breast cancer survivors. We hypothesized that the majority of survivors and oncology providers would express positive views about the tools and their use in the cancer survivorship setting.

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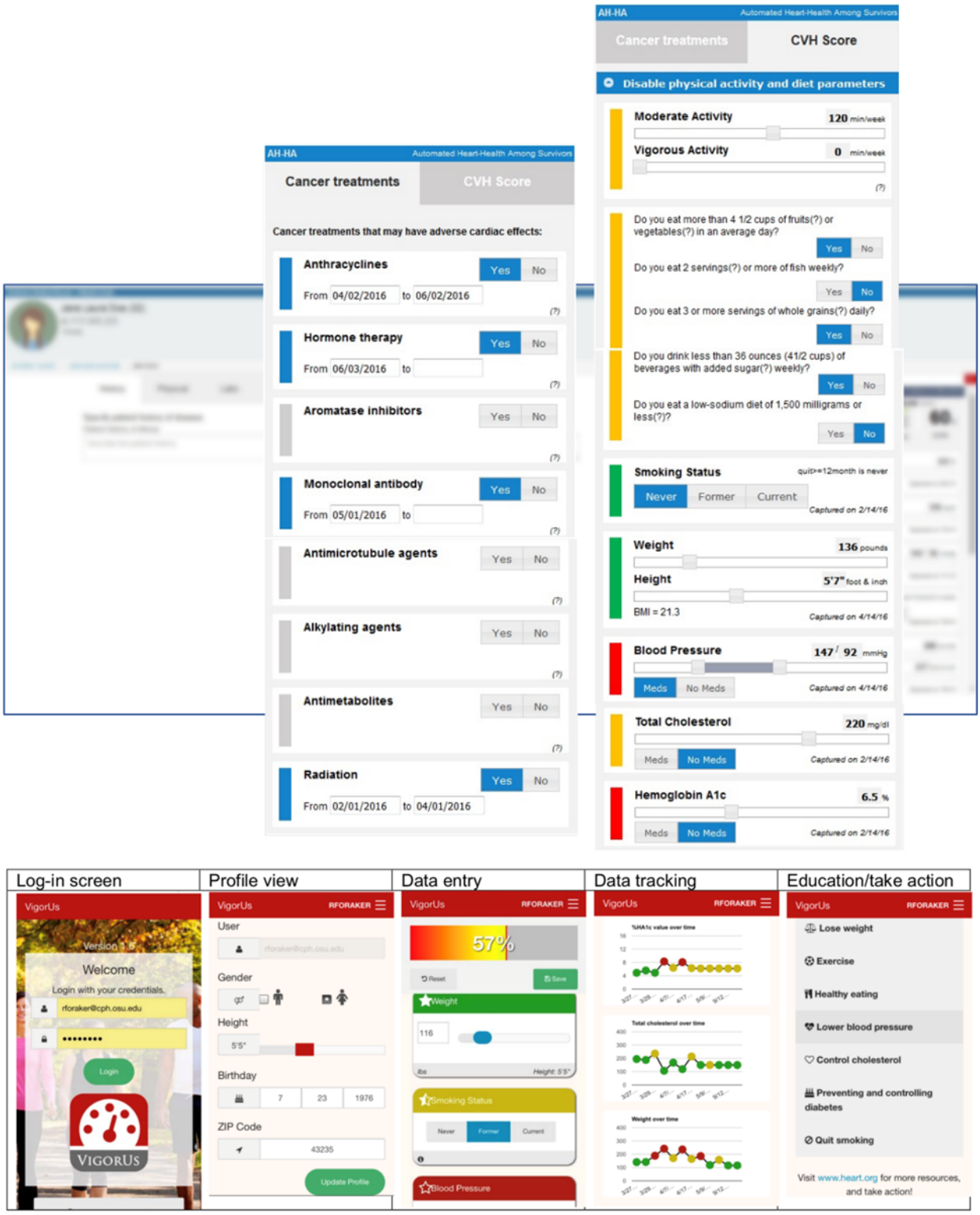
Figure 1. Adapted AH-HA tool (top) and the Vigor-Us tool (bottom).



The AH-HA tool was embedded within a simulated electronic health record environment and was intended to be used mainly with a cursor pointer (mouse). The Vigor-Us tool was a responsive web app suitable for both touch and click interactions, with larger interactivity components. AH-HA did not collect any data from the interface, whereas Vigor-Us collected all the information entered during the authenticated sessions (authenticated users, secure sockets layer–encrypted database).

Methods

Ethical Approval and Informed Consent

This study was approved by the Wake Forest Health Sciences Institutional Review Board. All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional research committee and with the 1964 Helsinki declaration and its later amendments or

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comparable ethical standards. The Wake Forest Health Sciences Institutional Review Board approved the study with a waiver of written informed consent.

Study Eligibility and Data Collection

Eligible survivors included those who were at least 21 years of age, diagnosed with nonmetastatic breast cancer, and at least 3 months after potentially curative cancer treatment (ie, surgery, chemotherapy, or radiation), excluding maintenance hormonal therapy. Additional inclusion criteria included no current evidence of disease or a history of cancer recurrence, a working email address, and ability to read medical information in English. Survivors were ineligible for the study if they had visual impairments that prohibited them from viewing material on a tablet device or if they were enrolled in hospice care or had a life expectancy less than 6 months. Survivors were identified through clinic appointment schedules and contacted by a research member prior to their appointment by telephone or immediately before their appointment in the waiting room.

Eligible providers included medical, radiation, gynecologic, and surgical oncologists; nurse practitioners, and physician assistants who provided survivorship care to posttreatment cancer survivors. A list of eligible oncologists, nurse practitioners, and physician assistants was procured from the oncology service line administrators, and providers were emailed an invitation to participate.

All participants provided informed consent prior to participation, and the study was approved by the Wake Forest Health Sciences Institutional Review Board (number 37786). Survivor participants completed a baseline survey, viewed the Vigor-Us tool (Figure 1) with their cardiovascular health information on a tablet computer with the study research coordinator, and then completed a brief postsurvey. The total research visit time was 15 to 20 minutes. Separate from the survivor assessment, provider participants were provided with a prototype of the enhanced AH-HA tool (Figure 1) on a tablet computer, introduced to the manipulation of slider bars and buttons, and asked to use the tool as they might with a cancer survivor. Providers also completed brief assessments before and after viewing the tool. Both survivor and provider participants received a US $10 gift card.

Cardiovascular Health Assessment Tools

The AH-HA tool (Figure 1) visualizes data regarding the AHA Simple 7 modifiable cardiovascular heath factors—BMI, smoking status, blood pressure, total cholesterol level, hemoglobin A_{1c} or fasting glucose level, healthy diet, and physical activity [27]—to promote discussions at the point of care between breast cancer survivors and oncology providers. AH-HA was adapted from the SPHERE [30] primary care tool to include information about receipt of potentially cardiotoxic chemotherapies (ie, anthracyclines, antimetabolites, hormone therapy, aromatase inhibitors, monoclonal antibodies, antimicrotubule agents, alkylating agents, and radiation) [32] and was designed to be integrated with electronic health records (EHR) using Fast Healthcare Interoperability Resources [33]. Breast cancer survivors viewed a patient-facing version of the SPHERE tool designed for personal computers and mobile devices, the Vigor-Us app (Figure 1). This app did not contain information about receipt of potentially cardiotoxic chemotherapies because our clinical advisory group felt that this information was best discussed with a medical provider.

Measures

Survivor cardiovascular risk information abstracted from the medical record include weight, height, smoking status, blood pressure, total cholesterol level, and hemoglobin A_{1c} level; self-reported factors included smoking, physical activity, and diet (Table 1). Survivor knowledge of cardiovascular health and perceived importance and appropriateness of heart health discussions during oncology care were evaluated with 6 questions assessing confidence in understanding risk of heart disease, understanding steps needed to improve heart health, perception that cancer (or heart disease) poses a risk to health, and desire to talk to a provider (oncologist or primary care provider) about heart health. Survivors were also asked about the numerical value of each heart health factor (with “I don’t know” as an option) and to rate each health factor as high (poor health), somewhat high (intermediate health), or low-risk (ideal health) according to Table 1. Following their use of the tool, survivors completed the same 6 preassessment questions along with 3 additional questions reflecting acceptability of heart health discussions with oncologists prior to, during, and after treatment completion. Survivor tool acceptability was assessed with 5 questions on a 5-point Likert scale (strongly agree to strongly disagree) regarding liking the tool, helpfulness, ease of understanding, picture/diagram improved understanding, and desire to use this tool with oncologist. Survivors also reported gender, race and ethnicity, years of education, internet and email usage, and health literacy [34].

Provider self-reported demographic and practice data included gender, race/ethnicity, years in practice, and percentage of time spent in patient care. Provider usability was assessed using 6 questions utilized in our previous study of general internal medicine physicians [29] assessing useful information, promotion of effectiveness, ease in accessing needed information, information meets needs, easy to use, and useful format. These questions were rated on a 7-point Likert scale from strongly agree to strongly disagree. Three questions reflecting potential use of tool prior to, during, and after treatment completion were rated on a 4-point Likert scale (never, almost, always, almost always).

Statistical Analyses

For this pilot study, the sample size for the oncology provider survey (n=20) is driven primarily by feasibility concerns. For the survivor survey, we estimated power to test the hypothesis that responses to each Likert scale question are generally positive, which we defined as testing the alternative hypothesis that the mean score for each question is greater than 3.5 (where a score of 3 denotes a neutral response to the question). Assuming a sample of 50 survivors and a standard deviation of 1.0, we will have >80% power provided the true mean score for a particular question is 3.9 or greater (roughly corresponds to an average response of agree).

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We conducted descriptive analyses and summarized oncology provider and survivor demographics and survey responses with counts and percentages. Providers' responses were assessed on a 7-point Likert scale from strongly disagree to strongly agree; we categorized responses of 5-7 as agreeing. Survivors' responses were assessed on a 5-point Likert scale from strongly agree to strongly disagree; responses of agree or strongly agree were categorized as agreeing. Wilcoxon signed rank tests were used to compare breast cancer survivors' knowledge regarding their cardiovascular risk factors and perceived importance of cancer and heart disease before and after viewing the tool. Comparisons were made individually for each of the 6 questions included on the questionnaire about cardiovascular risk factor knowledge and perceived importance and appropriateness of heart health discussions during oncology care. Sidak correction for multiple testing were utilized due to the 6 questions; P values <.0085 were considered significant for these outcomes. We calculated the percent of survivors who reported "I don't know" for each cardiovascular risk factor. Among those who did respond with a value for their risk factor, we calculated percent agreement between categorization of objective EHR data and the survivor's subjective assessment. Finally, we present survivor and provider data on usability of the tools. Specifically, we calculated the percent of survivors and providers who agreed or strongly agreed with the usability questions, and we presented data on the preferred timing of the intervention according to survivors and providers.

Results

Sociodemographic and Health Characteristics of Breast Cancer Survivors

We enrolled 49 breast cancer survivors (Table 2). An additional 13 survivors were screened and not enrolled (4 did not have an email address, 6 were not interested, and 3 could not stay after an appointment). The majority of enrolled survivors (92%) had an early-stage cancer and were on 11 years postdiagnosis (mean 10.8 years, SD 6); all received surgical treatment, 55% (27/49) received chemotherapy, and 69% (34/49) received radiation. With regards to receipt of potentially cardiotoxic cancer treatments, one-third (17/49, 35%) had received treatment with an anthracycline; almost half received hormone therapy (24/49, 49%); 45% (22/49) received aromatase inhibitors, 6% (3/49) received monoclonal antibodies, 29% (14/49) received antimicrotubule agents, 43% (21/49) received alkylating agents, and 8% (4/49) received antimetabolites. Almost half of survivors (23/49, 47%) reported graduating from college, and 96% (47/49) reported adequate health literacy. Most had a cell phone (47/49, 96%), used the internet (43/49, 88%), and used email almost every day (34/49, 69%). Almost all, survivors (47/49, 96%) completed the postvisit assessment and provided cardiovascular health tool usability data.

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Table 2. Characteristics of breast cancer survivor (n=49) and oncology provider (n=20) participants for usability testing of the AH-HA tool.

Characteristic	Breast cancer survivors (n=49)	Oncology providers (n=20)
Age (years), n (%)		
<65	28 (57)	N/A[a]
≥65	21 (43)	N/A
Sex, n (%)		
Female	49 (100)	12 (60)
Male	0 (0)	8 (40)
Race, n (%)		
White	41 (84)	14 (70)
Black or African American	4 (8)	2 (10)
Asian	1 (2.0)	1 (5)
Southeast Asian	0 (0)	3 (15)
American Indian	0 (0)	1 (5)
More than one race	2 (4)	0 (0)
Unknown	1 (2)	0 (0)
Hispanic ethnicity, n (%)	2 (4)	2 (10)
Time since cancer diagnosis (years), mean (SD)	10.8 (6.0)	N/A
Cancer treatment received, n (%)		
Surgery	49 (100)	N/A
Chemotherapy	27 (55)	N/A
Radiation	34 (69)	N/A
AJCC[b] stage, n (%)		
0	4 (8)	N/A
I	23 (47)	N/A
II	18 (37)	N/A
III	4 (8)	N/A
Education level, n (%)		
≤High school	7 (14)	N/A
Some college	19 (40)	N/A
College graduate	23 (47)	N/A
Email use every day or almost every day, n (%)		
Yes	34 (69)	N/A
No	15 (31)	N/A
Internet use past 30 days, n (%)		
Yes	43 (88)	N/A
No	6 (12)	N/A
Adequate health literacy, n (%)		
Yes	47 (96)	N/A
No	2 (4)	N/A
Provider type, n (%)		
Physician (MD or DO)	N/A	14 (70)
Physician assistant/nurse practitioner	N/A	6 (30)

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Characteristic	Breast cancer survivors (n=49)	Oncology providers (n=20)
Years in practice, n (%)		
≤5	N/A	8 (40)
6-10	N/A	4 (20)
≥11	N/A	8 (40)
Oncology specialty, n (%)		
Hematology	N/A	13 (65)
Radiation	N/A	1 (5)
Surgical	N/A	6 (30)
Time spent in direct patient care, n (%)		
≤50%	N/A	4 (20)
51-75%	N/A	7 (35)
>75%	N/A	9 (45)

[a]N/A: not applicable.

[b]AJCC: American Joint Committee on Cancer.

Cardiovascular Health and Awareness of Breast Cancer Survivors

Prior to viewing the tool, 90% of survivors (44/49) agreed that cancer posed a risk to their health, and 84% (41/49) agreed that cardiovascular disease posed a risk to their health. On average, only 45% (range 0%-86%) of survivors' known cardiovascular health factors were reported to be at an ideal level. More than 50% of survivors reported smoking status (45/49, 92%) and blood pressure (26/49, 53%) in the ideal category; less than one-third reported BMI, diet, and physical activity in the ideal range (Figure 2).

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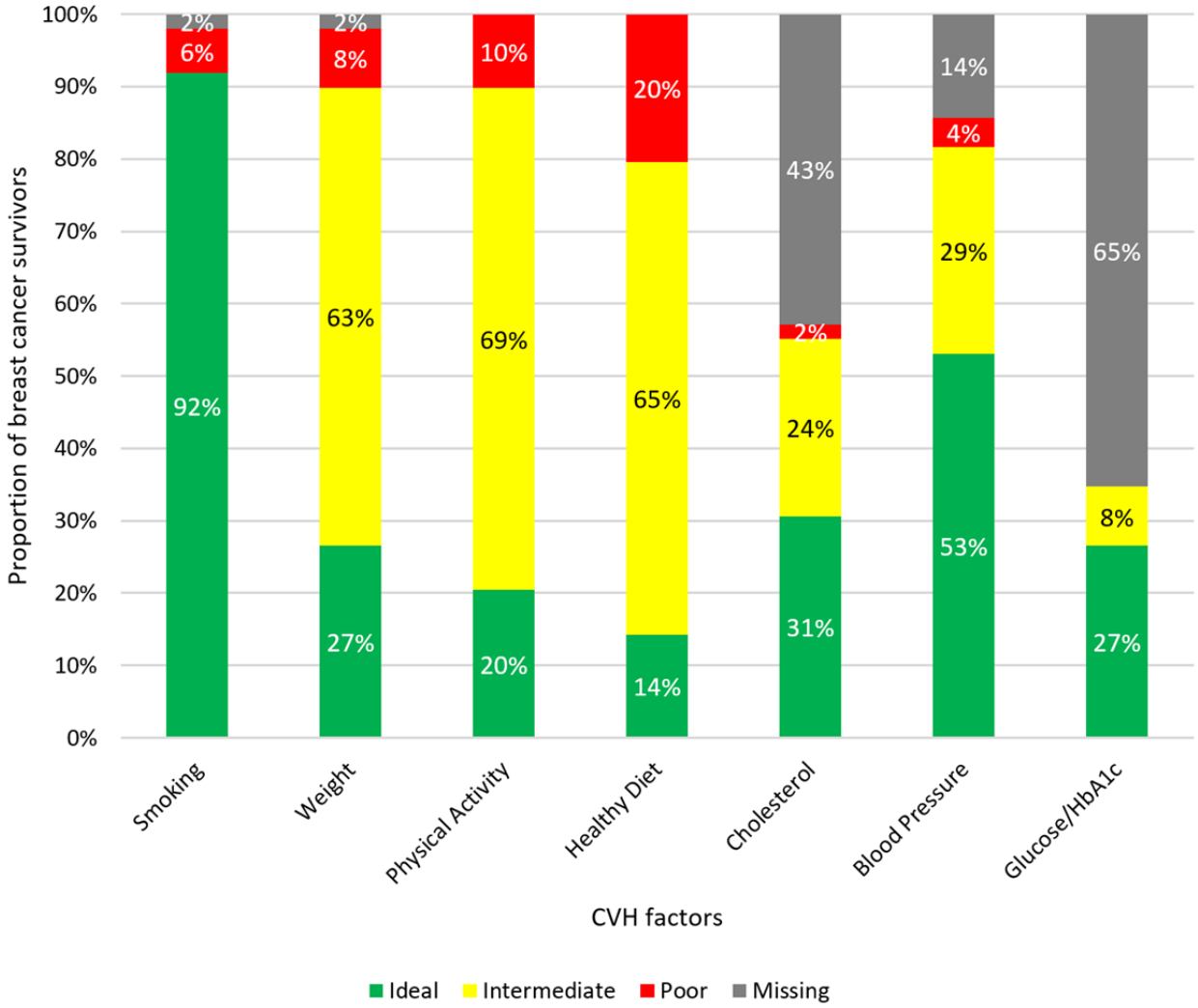
Figure 2. Proportion of breast cancer survivors (n=49) reporting poor (red), intermediate (yellow), ideal (green), and missing (gray) cardiovascular health factors. CVH: cardiovascular health.



Prior to viewing the tool, 24% of survivors (12/49) expressed strong agreement that they understood their risk of cardiovascular disease; 58% (28/49) agreed. Yet 65% (32/49) reported not knowing the level for one or more cardiovascular health factors (range 0-4). Cardiovascular risk factors most likely to be self-reported as "not known" (Figure 2) included hemoglobin A_{1c} (44/49, 90%), blood glucose level (32/49, 65%), cholesterol level (21/49, 43%), blood pressure (7/49, 14%), and BMI (1/49, 2%). When comparing concordance between the EHR and self-report for categorization of cardiovascular health factors as ideal vs nonideal among survivors who knew the categorization of their factor, 90% of survivors (44/49) were concordant for BMI, 47% (23/49) were concordant for blood pressure, 28% (14/49) were concordant for blood glucose level, and 34% (17/49) were concordant for cholesterol level (Figure 3).

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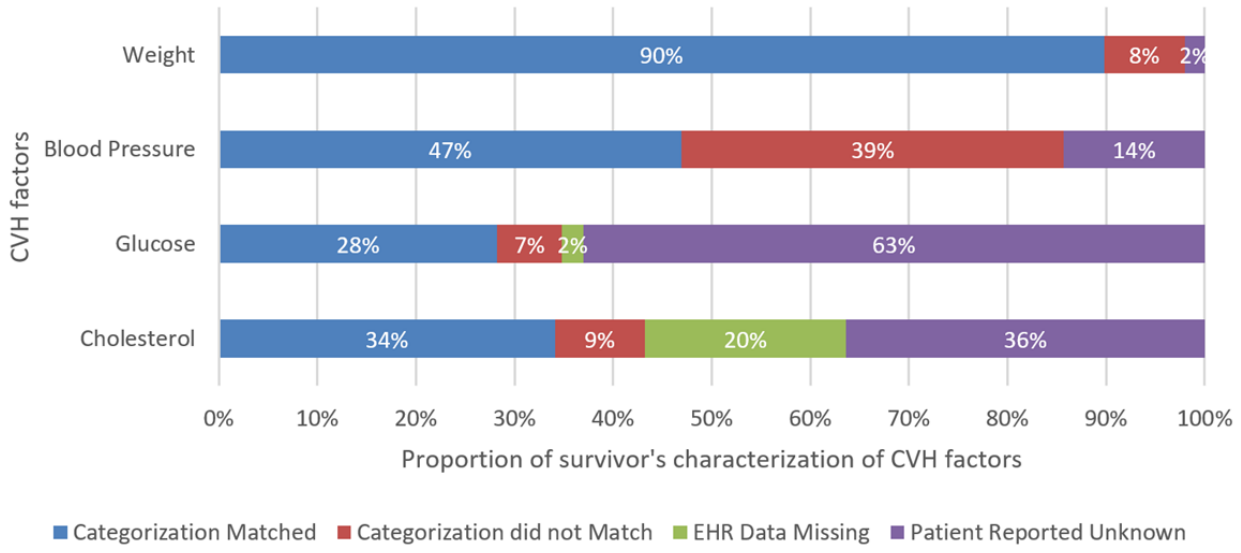
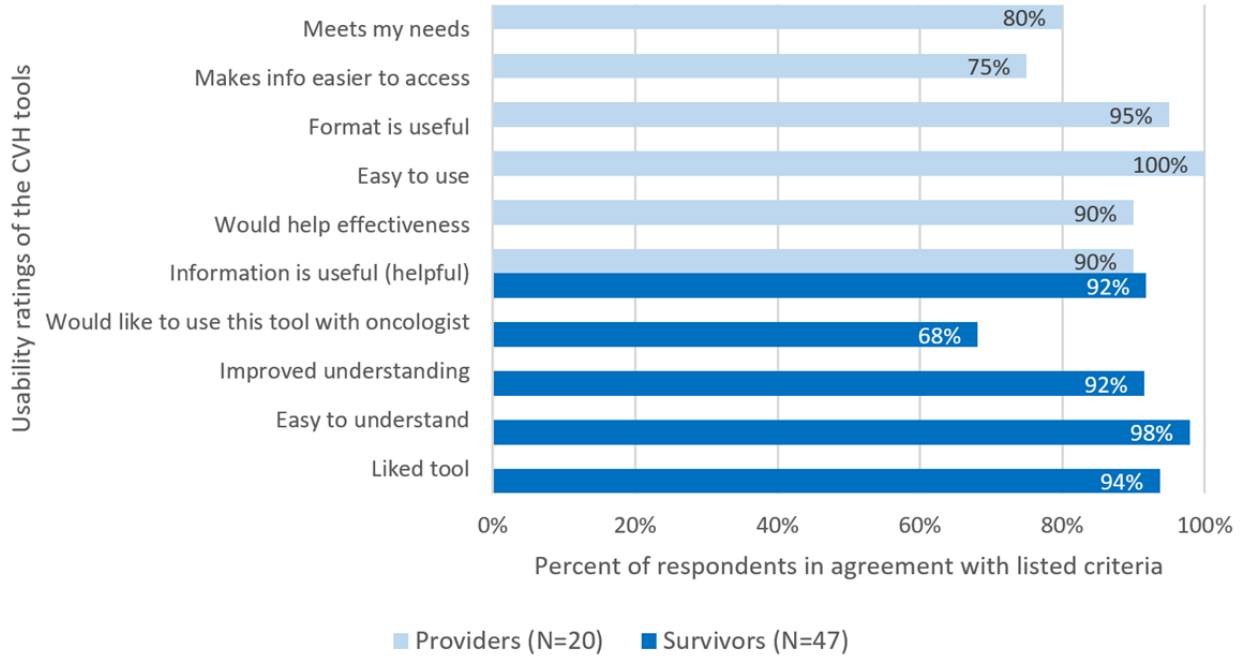
Figure 3. Survivor characterization of cardiovascular health factors. CVH: cardiovascular health; EHR: electronic health record.



Usability of the Tool Among Breast Cancer Survivors

Usability ratings of the tool by breast cancer survivors are shown in Figure 4. The majority of breast cancer survivors thought the tool was easy to understand (48/49, 98%), improved their understanding (45/49, 92%), and was helpful (45/49, 92%); 94% (46/49) liked the tool and agreed oncologists should discuss heart health during survivorship care. A majority (34/49, 69%) would like to use the tool with their oncologist at a future appointment. There were no differences in usability statistics by those 65 years and older versus those younger than 65 years.

Figure 4. Usability ratings of the tools among breast cancer survivors and oncology providers. CVH: cardiovascular health.



We also assessed survivors' perception of cardiovascular risk before and after viewing the tool (Figure 5). For all variables, survivors reported that they were in stronger agreement with the statements after viewing the tool (Figure 5). Significant changes were observed for understanding of cardiovascular risk (S=–65, P=.009), understanding steps to improve cardiovascular health (S=–70.5, P<.001, perception of health risk from cardiovascular disease (S=–45, P=.007), and desire to discuss cardiovascular risk with a primary care provider (S=–121, P<.001). There was no significant change in perception of health risk from cancer or desire to discuss cardiovascular risk with an oncologist.

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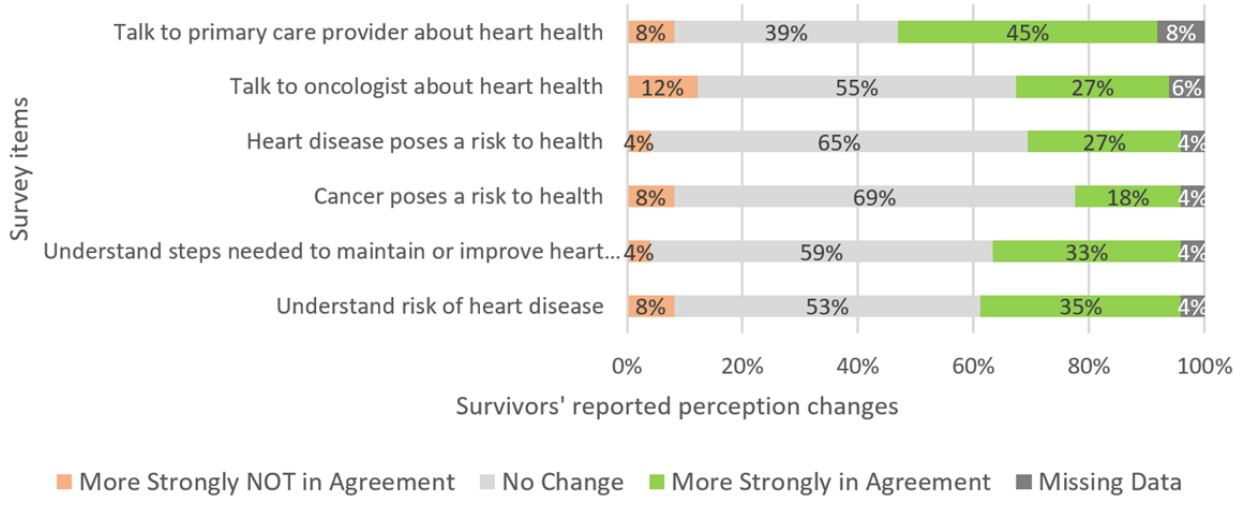
Figure 5. Proportion of breast cancer survivors (n=47) whose cardiovascular health perceptions changed before and after viewing the assessment tool.



Sociodemographic and Practice Characteristics of Providers

We enrolled 14 physicians, 2 physician assistants, and 4 nurse practitioners; 60% (12/20) were female, 70% (14/20) were White, 10% (2/20) were Black, and 10% (2/20) identified as Hispanic or Latino (Table 2). Hematology oncology was defined as the practice specialty for 65% of providers (13/20), 60% (12/20) had been practicing as an attending for more than 5 years, and 80% (16/20) spent more than 50% of their time in direct patient care. Only 50% (10/20) reported usually or always talking to their posttreatment patients about cardiovascular health, and 35% (7/20) usually or always initiated discussion about cardiovascular health with posttreatment patients. However, 95% (19/20) reported it was somewhat or very important to discuss cardiovascular health with posttreatment patients. About half of providers (9/20, 45%) reported a high level of comfort with cardiovascular health discussions.

Usability of the Tool Among Oncology Providers

Usability ratings of the tool by providers are shown in Figure 4. Most providers agreed the tool provided useful information (18/20, 90%), would help their effectiveness (18/20, 90%), was easy to use (20/20, 100%), and presented information in a useful format (19/20, 95%); and 85% of providers (17/20) reported they would use the tool most or all of the time when providing survivorship care, with 50% (10/20) reporting the same for initial treatment planning and 45% (9/20) during active treatment.

Discussion

Principal Results

Overall, our results suggest both the need for and suitability of a tailored cardiovascular health assessment tool to heighten awareness of cardiovascular health among oncology providers and breast cancer survivors. We present the first usability data from breast cancer survivors and oncology providers on the usability of EHR-integrated cardiovascular health assessment tools. On average, only 45% of breast cancer survivors' known cardiovascular health factors were at an ideal level, most survivors did not know the value or categorization of at least one of their cardiovascular health factors, and 94% of survivors (46/49) thought oncologists should discuss heart health during survivorship care. Nearly all providers indicated that it was either somewhat important or very important to discuss cardiovascular health with posttreatment patients. However, less than half of providers reported a high level of comfort with cardiovascular health discussions, and only half reported usually or always talking to their posttreatment patients about cardiovascular health. Usability data from providers and survivors demonstrate positive perceptions of the cardiovascular health apps; 85% of providers (17/20) reported they would use the tool most or all of the time when providing survivorship care. Thus, we conclude that clinical decision support tools such as AH-HA have potential to provide relevant data to providers at the point of care to initiate discussions and prompt appropriate referrals to primary care and cardiology—settings in which cardiovascular health can be managed effectively.

The use of the AH-HA and Vigor-Us tools are one strategy for improving risk assessment and personalized cardiovascular disease prevention in cancer survivorship programs, a research priority identified by the AHA [2]. A majority of breast cancer survivors did not know one or more of their cardiovascular health risk factors, despite a majority expressing agreement before viewing the tool that they understood their risk of heart disease. In particular, knowledge gaps exist among survivors with respect to their hemoglobin A_{1c} and cholesterol values, which are strong independent predictors of cardiovascular disease [35]. Self-reported understanding of cardiovascular risk increased among survivors with use of the tool, and survivors increased their interest in discussing their heart health with primary care providers following the use of the tool. This increased awareness and interest may facilitate linking survivors back into primary care so these risks can be addressed.

Comparison With Prior Work

Our results are consistent with our previous evaluation of general cardiovascular health clinical decision support in the primary care setting. In our previous study [29], providers indicated that the content and the accuracy of the tool met their needs always

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or most of the time. Primary care providers felt the tool was clear and presented data in a useful format, was easy to use and user-friendly, and provided up-to-date information in a timely manner [29].

Limitations

Limitations of this study include the smaller sample size, nonrandomized usability assessment, single-institution setting, and the absence of data regarding the impact of the tool on cardiovascular health and health care utilization. Although we focused on breast cancer survivors in this usability study, the tool may also be appropriate for other survivor populations who have significant competing risk from cardiovascular disease. Future testing of this tool should take place in more diverse multi-institutional settings.

Conclusions

The AH-HA point-of-care EHR-based visualization tool brings together personalized cardiovascular health and contextual cancer treatment data to address potential gaps in breast cancer survivorship care. Our previous SPHERE study [29] suggested that cardiovascular health clinical decision support tools are well-received in the primary care setting. Findings from the current study suggest that oncology providers and breast cancer survivors would benefit from and value the integration of cardiovascular health clinical decision support apps in survivorship care. A newly initiated study will test the effectiveness and implementation of the AH-HA app in a clinic-randomized trial in community oncology practices.

Acknowledgments

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Conflicts of Interest

None declared.

References

1. Shelburne N, Adhikari B, Brell J, Davis M, Desvigne-Nickens P, Freedman A, et al. Cancer treatment-related cardiotoxicity: current state of knowledge and future research priorities. J Natl Cancer Inst 2014 Sep;106(9) [FREE Full text] [doi: 10.1093/jnci/dju232] [Medline: 25210198]
2. Mehta LS, Watson KE, Barac A, Beckie TM, Bittner V, Cruz-Flores S, American Heart Association Cardiovascular Disease in WomenSpecial Populations Committee of the Council on Clinical Cardiology; Council on CardiovascularStroke Nursing;Council on Quality of CareOutcomes Research. Cardiovascular disease and breast cancer: where these entities intersect: a scientific statement from the American Heart Association. Circulation 2018 Feb 20;137(8):e30-e66 [FREE Full text] [doi: 10.1161/CIR.0000000000000556] [Medline: 29437116]
3. Hanrahan EO, Gonzalez-Angulo AM, Giordano SH, Rouzier R, Broglio KR, Hortobagyi GN, et al. Overall survival and cause-specific mortality of patients with stage T1a,bN0M0 breast carcinoma. JCO 2007 Nov 01;25(31):4952-4960. [doi: 10.1200/jco.2006.08.0499]
4. Chapman JW, Meng D, Shepherd L, Parulekar W, Ingle JN, Muss HB, et al. Competing causes of death from a randomized trial of extended adjuvant endocrine therapy for breast cancer. J Natl Cancer Inst 2008 Feb 20;100(4):252-260 [FREE Full text] [doi: 10.1093/jnci/djn014] [Medline: 18270335]
5. Bradshaw PT, Stevens J, Khankari N, Teitelbaum SL, Neugut AI, Gammon MD. Cardiovascular disease mortality among breast cancer survivors. Epidemiology 2016 Jan;27(1):6-13 [FREE Full text] [doi: 10.1097/EDE.0000000000000394] [Medline: 26414938]
6. Jones LW, Haykowsky MJ, Swartz JJ, Douglas PS, Mackey JR. Early breast cancer therapy and cardiovascular injury. J Am Coll Cardiol 2007 Oct 09;50(15):1435-1441 [FREE Full text] [doi: 10.1016/j.jacc.2007.06.037] [Medline: 17919562]
7. Armenian SH, Xu L, Ky B, Sun C, Farol LT, Pal SK, et al. Cardiovascular disease among survivors of adult-onset cancer: a community-based retrospective cohort study. J Clin Oncol 2016 Apr 01;34(10):1122-1130 [FREE Full text] [doi: 10.1200/JCO.2015.64.0409] [Medline: 26834065]
8. Dent SF, Kikuchi R, Kondapalli L, Ismail-Khan R, Brezden-Masley C, Barac A, et al. Optimizing cardiovascular health in patients with cancer: a practical review of risk assessment, monitoring, and prevention of cancer treatment-related cardiovascular toxicity. Am Soc Clin Oncol Educ Book 2020 Mar;40:1-15 [FREE Full text] [doi: 10.1200/EDBK_286019] [Medline: 32213102]
9. Lenihan DJ, Cardinale DM. Late cardiac effects of cancer treatment. J Clin Oncol 2012 Oct 20;30(30):3657-3664. [doi: 10.1200/JCO.2012.45.2938] [Medline: 23008297]

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10. Cardinale D, Bacchiani G, Beggiato M, Colombo A, Cipolla CM. Strategies to prevent and treat cardiovascular risk in cancer patients. Semin Oncol 2013 Apr;40(2):186-198. [doi: 10.1053/j.seminoncol.2013.01.008] [Medline: 23540744]
11. Weaver KE, Foraker RE, Alfano CM, Rowland JH, Arora NK, Bellizzi KM, et al. Cardiovascular risk factors among long-term survivors of breast, prostate, colorectal, and gynecologic cancers: a gap in survivorship care? J Cancer Surviv 2013 Jun;7(2):253-261 [FREE Full text] [doi: 10.1007/s11764-013-0267-9] [Medline: 23417882]
12. Vincent L, Leedy D, Masri SC, Cheng RK. Cardiovascular disease and cancer: is there increasing overlap? Curr Oncol Rep 2019 Apr 06;21(6):47. [doi: 10.1007/s11912-019-0796-0] [Medline: 30955114]
13. Institute of Medicine, National Research Council, Hewitt M, Greenfield S, Stovall E. From cancer patient to cancer survivor: lost in transition. In: The National Academies Press. Washington, DC: The National Academies Press; 2005.
14. Institute of Medicine. Cancer survivorship care planning 2005. American Psychosocial Oncology Society. Washington, DC: The National Academies Press; 2005 Nov. URL: https://apos-society.org/wp-content/uploads/2016/06/factsheetcareplanning.pdf [accessed 2020-03-16]
15. Institute of Medicine, Levit LA, Balogh EP, Nass SJ, Ganz PA. Delivering high-quality cancer care: charting a new course for a system in crisis. In: The National Academies Press. Washington, DC: The National Academies Press; 2013.
16. Ammon M, Arenja N, Leibundgut G, Buechel RR, Kuster GM, Kaufmann BA, et al. Cardiovascular management of cancer patients with chemotherapy-associated left ventricular systolic dysfunction in real-world clinical practice. J Card Fail 2013 Sep;19(9):629-634. [doi: 10.1016/j.cardfail.2013.07.007] [Medline: 24054339]
17. Stump TK, Robinson JK, Yanez B, Penedo F, Ezeofor A, Kircher S, et al. Physicians' perspectives on medication adherence and health promotion among cancer survivors. Cancer 2019 Dec 01;125(23):4319-4328 [FREE Full text] [doi: 10.1002/cncr.32410] [Medline: 31448414]
18. Kelley M, Foraker R, Lin ED, Kulkarni M, Lustberg M, Weaver KE. Oncologists' perceptions of a digital tool to improve cancer survivors' cardiovascular health. ACI Open 2019 Oct 03;03(02):e78-e87. [doi: 10.1055/s-0039-1696732]
19. Weaver KE, Aziz NM, Arora NK, Forsythe LP, Hamilton AS, Oakley-Girvan I, et al. Follow-up care experiences and perceived quality of care among long-term survivors of breast, prostate, colorectal, and gynecologic cancers. J Oncol Pract 2014 Jul;10(4):e231-e239 [FREE Full text] [doi: 10.1200/JOP.2013.001175] [Medline: 24695901]
20. Emery JD, Shaw K, Williams B, Mazza D, Fallon-Ferguson J, Varlow M, et al. The role of primary care in early detection and follow-up of cancer. Nat Rev Clin Oncol 2014 Jan;11(1):38-48. [doi: 10.1038/nrclinonc.2013.212] [Medline: 24247164]
21. Rasmussen-Torvik LJ, Shay CM, Abramson JG, Friedrich CA, Nettleton JA, Prizment AE, et al. Ideal cardiovascular health is inversely associated with incident cancer: the Atherosclerosis Risk In Communities study. Circulation 2013 Mar 26;127(12):1270-1275 [FREE Full text] [doi: 10.1161/CIRCULATIONAHA.112.001183] [Medline: 23509058]
22. Davies NJ, Batehup L, Thomas R. The role of diet and physical activity in breast, colorectal, and prostate cancer survivorship: a review of the literature. Br J Cancer 2011 Nov 8;105 Suppl 1:S52-S73 [FREE Full text] [doi: 10.1038/bjc.2011.423] [Medline: 22048034]
23. Cespedes Feliciano EM, Kwan ML, Kushi LH, Weltzien EK, Castillo AL, Caan BJ. Adiposity, post-diagnosis weight change, and risk of cardiovascular events among early-stage breast cancer survivors. Breast Cancer Res Treat 2017 Apr;162(3):549-557 [FREE Full text] [doi: 10.1007/s10549-017-4133-8] [Medline: 28176174]
24. Thomson CA, Rock CL, Thompson PA, Caan BJ, Cussler E, Flatt SW, et al. Vegetable intake is associated with reduced breast cancer recurrence in tamoxifen users: a secondary analysis from the Women's Healthy Eating and Living Study. Breast Cancer Res Treat 2011 Jan;125(2):519-527. [doi: 10.1007/s10549-010-1014-9] [Medline: 20607600]
25. Caan BJ, Kwan ML, Shu XO, Pierce JP, Patterson RE, Nechuta SJ, et al. Weight change and survival after breast cancer in the after breast cancer pooling project. Cancer Epidemiol Biomarkers Prev 2012 Aug;21(8):1260-1271 [FREE Full text] [doi: 10.1158/1055-9965.EPI-12-0306] [Medline: 22695738]
26. Lahart IM, Metsios GS, Nevill AM, Carmichael AR. Physical activity, risk of death and recurrence in breast cancer survivors: A systematic review and meta-analysis of epidemiological studies. Acta Oncol 2015 May;54(5):635-654. [doi: 10.3109/0284186X.2014.998275] [Medline: 25752971]
27. Lloyd-Jones DM, Hong Y, Labarthe D, Mozaffarian D, Appel LJ, Van HL, et al. Defining and setting national goals for cardiovascular health promotion and disease reduction: the American Heart Association's strategic Impact Goal through 2020 and beyond. Circulation 2010 Feb 2;121(4):586-613 [FREE Full text] [doi: 10.1161/CIRCULATIONAHA.109.192703] [Medline: 20089546]
28. Payne PRO, Lussier Y, Foraker RE, Embi PJ. Rethinking the role and impact of health information technology: informatics as an interventional discipline. BMC Med Inform Decis Mak 2016 Mar 29;16:40 [FREE Full text] [doi: 10.1186/s12911-016-0278-3] [Medline: 27025583]
29. Foraker RE, Kite B, Kelley MM, Lai AM, Roth C, Lopetegui MA, et al. EHR-based visualization tool: adoption rates, satisfaction, and patient outcomes. EGEMS (Wash DC) 2015;3(2):1159 [FREE Full text] [doi: 10.13063/2327-9214.1159] [Medline: 26290891]
30. Foraker RE, Shoben AB, Lopetegui MA, Lai AM, Payne PRO, Kelley M, et al. Assessment of Life's Simple 7 in the primary care setting: the Stroke Prevention in Healthcare Delivery EnviRonmEnts (SPHERE) study. Contemp Clin Trials 2014 Jul;38(2):182-189. [doi: 10.1016/j.cct.2014.03.007] [Medline: 24721482]

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31. Foraker RE, Shoben AB, Kelley MM, Lai AM, Lopetegui MA, Jackson RD, et al. Electronic health record-based assessment of cardiovascular health: The stroke prevention in healthcare delivery environments (SPHERE) study. Prev Med Rep 2016 Dec;4:303-308 [FREE Full text] [doi: 10.1016/j.pmedr.2016.07.006] [Medline: 27486559]
32. Valachis A, Nilsson C. Cardiac risk in the treatment of breast cancer: assessment and management. Breast Cancer (Dove Med Press) 2015;7:21-35 [FREE Full text] [doi: 10.2147/BCTT.S47227] [Medline: 25653554]
33. Mandel JC, Kreda DA, Mandl KD, Kohane IS, Ramoni RB. SMART on FHIR: a standards-based, interoperable apps platform for electronic health records. J Am Med Inform Assoc 2016 Feb 17;23(5):899-908 [FREE Full text] [doi: 10.1093/jamia/ocv189] [Medline: 26911829]
34. Chew LD, Griffin JM, Partin MR, Noorbaloochi S, Grill JP, Snyder A, et al. Validation of screening questions for limited health literacy in a large VA outpatient population. J Gen Intern Med 2008 May;23(5):561-566 [FREE Full text] [doi: 10.1007/s11606-008-0520-5] [Medline: 18335281]
35. Dawber TR, Kagan A, Revotskie N, Stokes J. Factors of risk in the development of coronary heart disease--six year follow-up experience. the Framingham study. Ann Intern Med 1961 Jul;55:33-50. [doi: 10.7326/0003-4819-55-1-33] [Medline: 13751193]

Abbreviations

AHA: American Heart Association
AH-HA: Automated Heart-Health Assessment
EHR: electronic health record
SPHERE: Stroke Prevention in Healthcare Delivery Environments

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Original Paper

Physical Activity, Mental Health, and Technology Preferences to Support Cancer Survivors During the COVID-19 Pandemic: Cross-sectional Study

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Abstract

Background: COVID-19 has had significant health-related and behavioral impacts worldwide. Cancer survivors (hereafter referred to as “survivors”) are particularly prone to behavioral changes and are encouraged to be more vigilant and observe stricter social distancing measures.

Objective: We explored (1) changes in physical activity and sedentary behaviors since the onset of COVID-19, along with changes in mental health status, and (2) alternative strategies to support survivors’ physical activity and social health during and after COVID-19, along with the role of digital health in such strategies.

Methods: A questionnaire was distributed among survivors participating (currently or previously) in the community-based physical activity program LIVESTRONG at the Young Men’s Christian Association (YMCA), from 3 sites outside an urban area in Massachusetts. Questions addressed pre–COVID-19 vs current changes in physical activity and sedentary behavior. Anxiety and depression were assessed using the 2-item Generalized Anxiety Disorder scale (GAD-2) and 2-item Patient Health Questionnaire (PHQ-2), and scores ≥3 indicated a clinical diagnosis of anxiety or depression, respectively. Digital health preferences were assessed through closed-ended questions. Open-ended responses addressing other preferences for physical activity programs and social support were analyzed, coded, and categorized into themes.

Results: Among 61 participants (mean age 62 [SD 10.4] years; females: 51/61 [83.6%]), 67.2% (n=41) reported decreased physical activity and 67.2% (n=41) reported prolonged sitting times since the onset of COVID-19. Further, 24.6% (n=15) and 26.2% (n=16) met the GAD-2 and PHQ-2 criteria for clinical anxiety and depression, respectively. All participants owned a cellphone; 90% (n=54) owned a smartphone. Preferences for physical activity programs (n=28) included three themes: (1) use of digital or remote platforms (Zoom, other online platforms, and video platforms), (2) specific activities and locations (eg, outdoor activities, walking, gardening, biking, and physical activities at the YMCA and at senior centers), and (3) importance of social support regardless of activity type (eg, time spent with family, friends, peers, or coaches). The survey revealed a mean score of 71.8 (SD 21.4; scale 0-100) for the importance of social support during physical activity programs. Social support

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preferences (n=15) revealed three themes: (1) support through remote platforms (eg, texting, Zoom, phone calls, emails, and Facebook), (2) tangible in-person support (YMCA and senior centers), and (3) social support with no specific platform (eg, small gatherings and family or friend visits).

Conclusions: Physical activity and mental health are critical factors for the quality of life of survivors, and interventions tailored to their activity preferences are necessary. Digital or remote physical activity programs with added social support may help address the ongoing needs of survivors during and after the pandemic.

(JMIR Cancer 2021;7(1):e25317) doi:10.2196/25317

KEYWORDS

cancer; COVID-19; digital; physical activity; support; technology

Introduction

COVID-19 first emerged in December 2019 [1]. COVID-19 and social distancing have had deleterious effects on physical activity and mental health in the general population, resulting in decreased activity levels and increased anxiety, depression, and stress levels [2,3]. Current cancer survivors (hereafter referred to as "survivors") and those previously undergoing treatment may have been affected in particular. Survivors have unique emotional needs owing to anxiety, depression, and familial and financial strains, along with many long-lasting preexisting health conditions [4-7]. However, few studies have addressed these concerns and explored means to provide additional support to survivors. Owing to their preexisting conditions and immunocompromised state, survivors are at an increased risk of disease and admission to the intensive care unit, increased ventilator use, and an increased risk of death due to COVID-19 [8,9]. Hence, survivors are encouraged to observe strict social distancing guidelines [10]. Further, many in-person survivorship resources, such as physical activity and mental health support, have been reduced [11].

We explored the effects of COVID-19 on a group of survivors who were current or previous participants in the community-based physical activity program, LIVESTRONG at the Young Men's Christian Association (YMCA) [12]. This 12-week program involves physical activity (ie, aerobic, muscle strengthening, and flexibility exercises) and social support (ie, group support sessions) delivered in person by trained staff, twice a week, free of cost to survivors at participating YMCA sites nationwide. The program has effectively improved survivors' physical activity, fitness, and quality of life [13]. In this study, we examined (1) changes in physical activity or sedentary behaviors since the onset of COVID-19, along with changes in their mental health status, and (2) alternative strategies to support survivors' physical activity and social health during and after COVID-19, including the role of digital health in these strategies. Although the role of digital health in promoting physical activity and mental health has been understudied among survivors [14], some trials [15] have reported the feasibility, adherence, and effectiveness of digital health [15]. Because the lasting effects of COVID-19 are unknown, this formative study may contribute to the development of digital community-based physical activity and social support programs.

Methods

Study Design

This cross-sectional study included individuals participating in the 12-week LIVESTRONG at the YMCA program, which delivers support for physical activities and social health free of cost for those who (1) have or have had a cancer diagnosis, (2) are over 18 years of age, and (3) were medically cleared by a physician to perform physical activity. We coordinated with the program director at one LIVESTRONG site, who contacted program directors at two additional local sites outside an urban area in Massachusetts, to describe the study and deliver an online questionnaire survey to current and past program participants. From among these three sites, we estimated that these listservs had >300 eligible participants, but we could not estimate the total number of emails sent. Participants were provided a US $10 gift card upon completion of the questionnaire. The Institutional Review Board at UMass Medical School approved this trial (IRB docket number H00020448).

Measures

Physical Activity and Sedentary Time

We assessed subjective changes in physical activity by asking the question, "Since COVID-19, has your physical activity (a) decreased, (b) increased, or (c) stayed the same?" We assessed changes in sedentary behaviors by asking the question, "Since COVID-19, has your time spent sitting (a) decreased, (b) increased, or (c) stayed the same?"

Mental Health

Anxiety and depression were assessed using the 2-item Generalized Anxiety Disorder scale (GAD-2) [16] and the 2-item Patient Health Questionnaire (PHQ-2) [17], respectively. Both these tools have acceptable sensitivity and specificity [18].

Physical Activity During or After COVID-19 and Digital Health Preferences

Participants were asked to report all their preferred physical activities during and after COVID-19 from among the following: (1) indoor or outdoor activities with family or friends, (2) indoor or outdoor activities by themselves, (3) physical activity delivered through online platforms, and (4) physical activity delivered through video calls with family, friends, or fitness professionals. They were then asked to respond to an optional open-ended question regarding other preferred means of receiving physical activity programs.

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Social Support and Digital Health Preferences

Participants ranked the importance of social support in a physical activity program (scale 0-100). They reported their most preferred means of receiving social support from among the following: (1) in person, (2) video calls, (3) social media, and (4) texting. They then responded to open-ended questions regarding their preferred means of receiving social support.

Statistical Analysis

We analyzed descriptive statistics for quantitative variables, using STATA (version 15, StataCorp). For the GAD-2 and PHQ-2, we summed the two questions and applied a cut-off ≥3 to generate a dichotomous variable. Scores ≥3 were classified as "clinically diagnosable" independently for anxiety and depression [16,17]. Responses to open-ended questions were open-coded verbatim to identify relevant themes and corroborated with two additional investigators.

Results

Participants (N=61) had a mean age of 62 (SD 10.4) years, were mainly female (n=51, 83.6%), and had pursued higher education (college diploma: n=18, 29.5%; bachelor's degree: n=15, 24.6%; advanced college degree: n=24, 39.3%). All of them owned a cell phone, and the vast majority (n=54, 90%) owned smartphones that can access the internet (Table 1).

Table 1. Demographic characteristics and technology usage among the study participants (N=61).

Variable	Value
Gender, n (%)	
Male	10 (16.4)
Female	51 (83.6)
Age (years), mean (SD)	62.0 (10.4)
Marital status, n (%)	
Married	38 (62.3)
Divorced/separated	10 (16.4)
Widowed	5 (8.2)
Single/unmarried	8 (13.1)
Education level, n (%)	
Finished high school or GED[a]	4 (6.6)
College diploma	18 (29.5)
Bachelor's degree	15 (24.6)
Advanced college degree	24 (39.3)
Uses the internet, n (%)	55 (90.2)
How do you use the internet?, n (%)	
Read information on websites	55 (90.2)
Send or receive emails	35 (57.4)
Watch videos/listen to audio clips	21 (34.4)
Use online social network sites	40 (65.6)
Owns a cell phone, n (%)	61 (100)
Owns a smartphone, n (%)	54 (90)
How do you use your cell phone?, n (%)	
Send or receive emails	39 (63.9)
Send or receive text messages	45 (73.8)
Access the internet	42 (68.9)
Look for health/medical information online	36 (61)
Take photographs	46 (78)

[a]GED: General Education Diploma.

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Physical Activity, Sedentary Time, and Mental Health

Most participants reported decreased physical activity (n=41, 67.2%) and a prolonged sitting time (n=41, 67.2%) since the onset of COVID-19 (Table 2). On mental health evaluation, 26.2% (n=16) and 24.6% (n=15) of participants had scores greater than the clinical cut-off for depression and anxiety, respectively.

Table 2. Changes in physical activity and sedentary time, mental health evaluation, and preferences for physical activity and social support among the study participants (N=61).

Variable	Value
Change in physical activity[a], n (%)	
More physically active	13 (21.3)
No change in physical activity	7 (11.5)
Less physically active	41 (67.2)
Change in sedentary time[a], n (%)	
Sitting more	41 (67.2)
No change in sitting time	16 (26.2)
Sitting less	4 (6.6)
PHQ-2[b] score, mean (SD)	1.35 (1.4)
<3, n (%)	45 (73.8)
≥3 (clinical cut-off), n (%)	16 (26.2)
GAD-2[c, mean (SD)]	1.84 (1.53)
<3, n (%)	46 (75.4)
≥3 (clinical cut-off), n (%)	15 (24.6)
Physical activity preference during COVID-19[d], n (%)	
Online programs	17 (27.9)
Indoor or outdoor activities with family or friends	26 (42.6)
Indoor or outdoor activities by themselves	40 (65.6)
Video calls (with family, friends, or fitness professionals)	25 (42.6)
Physical activity preference after COVID-19[d], n (%)	
Online programs	31 (50.8)
Indoor or outdoor activities with family or friends	24 (39.3)
Indoor or outdoor activities by self	24 (39.3)
Video calls (with family, friends, or fitness professionals)	14 (23)
Importance of social support for physical activity programs (scale 0-100), mean (SD)	71.8 (21.4)
Social support preference, n (%)	
In-person	42 (68.9)
Video calls	13 (21.3)
Social media groups	3 (4.9)
Texting	3 (4.9)

[a]Questions addressing variables for comparison with pre–COVID-19 values.

[b]PHQ-2: 2-item Patient Health Questionnaire.

[c]GAD-2: 2-item Generalized Anxiety Disorder.

[d]Participants were asked to check all applicable responses.

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Physical Activity During or After COVID-19 and Digital Health Preferences

Table 2 highlights the preferred physical activities during and after COVID-19. During COVID-19, survivors most preferred indoor activities by themselves (n=40, 65.6%) in person; after COVID-19, online programs (n=31, 50.8%). Three main themes were identified from the open-ended responses (n=28) regarding the survivors' preferences for other physical activity programs. The present themes and sample responses are provided below.

Digital and Remote Programs

One participant who was in enrolled in the LIVESTRONG program stated the following when the program was moved to an online platform: "I like the Zoom program better than anything I have ever done." Three others (10.7%) reported the following regarding remote activities and the use of technology: "Challenges on Fitbit," "online," and "videos or DVDs."

Specific Activities or Specific Locations for Activities

In total, 4 (14.3%) survivors preferred "walking, light hiking," "walking trails," and "swimming" at no specified location, 6 (25%) others preferred additional outdoor activities including "outdoor activities - walking, biking," "bike riding, fishing, gardening," "yard work," and "anything outdoors," and 4 (16.7%) participants preferred indoors "gym," "senior center," "LIVESTRONG," and "market walking."

Importance of Social Support Regardless of Activity Type

In total, 6 (25%) participants preferred social support in addition to their preferred physical activity, such as "phone call with a friend while walking 'together'" and "walking with friends, family, or other people," "gym with cancer patients," and "I need a partner to hold me accountable."

Preferences for Alternative Means of Social Support

Table 2 highlights the participant preferences for social support and digital health. Three main themes were identified from the questions on open-ended preferences (n=15) for other forms of social support.

Using Digital Platforms for Support

In total, 5 (33.3%) participants preferred social support to be delivered through a remote or digital platform, such as "phone calls, emails, Zoom, texting, Google, Nest, WhatsApp, and Facebook." Others (n=2, 13.3%) indicated the involvement of specific individuals, such as "text messages with peers or coaches," and "video conferencing or phone calls with friends or family."

Tangible In-Person Support

In total, 3 (20%) participants preferred in-person support ("I would like to have support in person, but [the Y] is just too far away from my house…" and "to attend senior center," "Gym or fitness center").

Social Support With no Specified Platform

In total, 5 (33.3%) participants preferred social support but did not specify whether they preferred in-person or remote support ("an advocate to help with the things I struggle with," "visits with friends or family," and "small groups").

Discussion

Principal Findings

Survivors self-reported decreased physical activity levels and greater anxiety and depression levels, similar to those of the general population [2]. In both our quantitative and qualitive analyses, survivors reported their preferences for digital health. Other reported preferences highlighted the importance of social support.

Reductions in the survivors' physical activity and increases in sedentary behaviors are concerning, as physical activity is critical for their physical and mental health [19-21]. The proportions of our participants who met the diagnostic criteria for depression and anxiety (n=16 [26.2%] and n=15 [24.6%], respectively) were higher than those previously reported for prostate cancer survivors (9.4% and 7.9%, respectively) but lower than those of breast cancer survivors (32.2% and 38.2%, respectively) [22,23]. Overall proportions of survivors are much higher than those of the general US population (3.1% of the general US population adults >18 years have been diagnosed with generalized anxiety disorder and 7.1% with major depressive disorder) [24]. It is critical to develop methods to support the mental health needs of survivors, and our study suggests that the pandemic and social isolation may increase the need for such support.

Survivors expressed their interest in support from digital health platforms for physical activities after COVID-19. While more survivors (n=40, 65.6%) reported their preferences for indoor or outdoor activities by themselves during COVID-19, they may possibly not have had the opportunity to receive support from digital health programs thus far. During and after COVID-19, digital health platforms may serve as a substitute for in-person support for survivors, and they can be tailored to augment the benefits of in-person support, potentially providing long-term support to survivors. COVID-19 has forced practitioners and survivors to embrace digital technology to promote and maintain health care provision and deliver physical activity programs [25]. Some oncological trials assessing physical activity have shifted to digital platforms [26]; however, community-based programs may provide less support and resources to convert in-person programs to virtual ones. A worldwide survey of fitness trends in 2021 reported that online programs ranked 1st in 2021 as opposed to 26th in 2020 [27], indicating that COVID-19 has brought about a paradigm shift in the fitness industry, and practitioners will need to adjust to this trend.

Furthermore, survivors acknowledged the importance of social support, and some expressed preferences for peer support. Telephonically delivered support by trained peer coaches coupled with remote activity monitoring has led to an increase in physical activity in a randomized trial with breast cancer survivors [28]. Although, in this study, 69% (n=42) of survivors preferred in-person social support, peer support for survivors delivered digitally is ideal for those who are unable to attend in-person programs and need additional support [29]. A digital health intervention that includes social support (ie, from family or friends, peer coaches, or other survivors) may address the preferences of survivors for remote programs and their

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accountability, while potentially improving their physical activity and mental health [30]. However, larger trials are required to examine the causal effects of different types of social support among survivors [31].

Limitations

This exploratory study had a small cohort size; therefore, the statistical power was not high enough to enable hypothesis testing to assess relationships among variables. Survivors having already participated in the LIVESTRONG at the YMCA program might have been more motivated than those not enrolled in this program; thus, reductions in physical activity reported here may underestimate the prevalence of this issue in the general survivor population. Although this study lacks data on cancer types, previous studies have reported data from a higher proportion of breast cancer survivors [13]. These studies and our study show the homogeneity of the characteristics of participants in the LIVESTRONG to the YMCA program [13], and future trials will need to examine more diverse populations. Program directors had access to email listservs through the YMCA but did not have access to the number of participants registered on them; hence, we could not determine neither the final number of emails sent to eligible participants nor the valid response rate. All responses are self-reported and were obtained in a cross-sectional manner, warranting future assessments of baseline measures to assess longitudinal changes objectively, for example, using activity monitors.

Conclusions

In conclusion, during and after COVID-19, survivors may benefit from support to sustain their physical activity levels and mental health. The survivors in our study voiced various preferences for physical activity and social support, some preferring indoor physical activity by themselves during COVID-19 and others preferring online or remote programs along with social support, including support from family or friends and peer coaches, after COVID-19. Community-based physical activity programs can successfully engage survivors if they provide programs tailored to individual preferences during and after the COVID-19 pandemic.

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Conflicts of Interest

None declared.

References

1. Coronavirus (COVID-19) 2020 updated April 17, 2020. World Health Organization. 2020 Oct 12. URL: https://www.who.int/emergencies/diseases/novel-coronavirus-2019/question-and-answers-hub/q-a-detail/q-a-coronaviruses [accessed 2020-10-20]
2. Tison GH, Avram R, Kuhar P, Abreau S, Marcus GM, Pletcher MJ, et al. Worldwide Effect of COVID-19 on Physical Activity: A Descriptive Study. Ann Intern Med 2020 Nov 03;173(9):767-770 [FREE Full text] [doi: 10.7326/M20-2665] [Medline: 32598162]
3. Marroquín B, Vine V, Morgan R. Mental health during the COVID-19 pandemic: Effects of stay-at-home policies, social distancing behavior, and social resources. Psychiatry Res 2020 Nov;293:113419 [FREE Full text] [doi: 10.1016/j.psychres.2020.113419] [Medline: 32861098]
4. Reed SC, Bell JF, Miglioretti DL, Nekhlyudov L, Fairman N, Joseph JG. Fear of cancer recurrence and associations with mental health status and individual characteristics among cancer survivors: Findings from a nationally representative sample. J Psychosoc Oncol 2020;38(2):125-142. [doi: 10.1080/07347332.2019.1649338] [Medline: 31510882]
5. Aaronson NK, Mattioli V, Minton O, Weis J, Johansen C, Dalton SO, et al. Beyond treatment - Psychosocial and behavioural issues in cancer survivorship research and practice. EJC Suppl 2014 Jun;12(1):54-64 [FREE Full text] [doi: 10.1016/j.ejcsup.2014.03.005] [Medline: 26217166]
6. Carrera PM, Kantarjian HM, Blinder VS. The financial burden and distress of patients with cancer: Understanding and stepping-up action on the financial toxicity of cancer treatment. CA Cancer J Clin 2018 Mar;68(2):153-165 [FREE Full text] [doi: 10.3322/caac.21443] [Medline: 29338071]
7. Aziz NM. Cancer survivorship research: state of knowledge, challenges and opportunities. Acta Oncol 2007;46(4):417-432. [doi: 10.1080/02841860701367878] [Medline: 17497308]
8. Eckert A, Higgins D. Common Questions About the COVID-19 Outbreak. American Cancer Society. 2020 Mar 03. URL: https://www.cancer.org/latest-news/common-questions-about-the-new-coronavirus-outbreak.html [accessed 2020-10-20]
9. Liang W, Guan W, Chen R, Wang W, Li J, Xu K, et al. Cancer patients in SARS-CoV-2 infection: a nationwide analysis in China. Lancet Oncol 2020 Mar;21(3):335-337 [FREE Full text] [doi: 10.1016/S1470-2045(20)30096-6] [Medline: 32066541]

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10. Staying Well While Staying at Home: A Guide for Cancer Patients and Their Caregivers and Family Members 2020 updated March 26th, 2020. Centers for Disease Control and Prevention. 2020 Mar 26. URL: https://www.cdc.gov/cancer/survivors/staying-well-at-home.htm [accessed 2020-11-03]
11. National Cancer Survivorship Resource Center. American Cancer Society. 2021. URL: https://www.cancer.org/health-care-professionals/national-cancer-survivorship-resource-center.html [accessed 2020-11-03]
12. Heston A, Schwartz A, Justice-Gardiner H, Hohman K. Addressing physical activity needs of survivors by developing a community-based exercise program: LIVESTRONG® at the YMCA. Clin J Oncol Nurs 2015 Apr;19(2):213-217. [doi: 10.1188/15.CJON.213-217] [Medline: 25840387]
13. Irwin ML, Cartmel B, Harrigan M, Li F, Sanft T, Shockro L, et al. Effect of the LIVESTRONG at the YMCA exercise program on physical activity, fitness, quality of life, and fatigue in cancer survivors. Cancer 2017 Apr 01;123(7):1249-1258 [FREE Full text] [doi: 10.1002/cncr.30456] [Medline: 27893938]
14. Børøsund E, Ehlers SL, Varsi C, Clark MM, Andrykowski MA, Cvancarova M, et al. Results from a randomized controlled trial testing StressProffen; an application-based stress-management intervention for cancer survivors. Cancer Med 2020 Jun;9(11):3775-3785 [FREE Full text] [doi: 10.1002/cam4.3000] [Medline: 32243717]
15. Roberts AL, Fisher A, Smith L, Heinrich M, Potts HWW. Digital health behaviour change interventions targeting physical activity and diet in cancer survivors: a systematic review and meta-analysis. J Cancer Surviv 2017 Dec;11(6):704-719 [FREE Full text] [doi: 10.1007/s11764-017-0632-1] [Medline: 28779220]
16. Kroenke K, Spitzer RL, Williams JBW. The Patient Health Questionnaire-2: validity of a two-item depression screener. Med Care 2003 Nov;41(11):1284-1292. [doi: 10.1097/01.MLR.0000093487.78664.3C] [Medline: 14583691]
17. Löwe B, Kroenke K, Gräfe K. Detecting and monitoring depression with a two-item questionnaire (PHQ-2). J Psychosom Res 2005 Feb;58(2):163-171. [doi: 10.1016/j.jpsychores.2004.09.006] [Medline: 15820844]
18. Staples LG, Dear BF, Gandy M, Fogliati V, Fogliati R, Karin E, et al. Psychometric properties and clinical utility of brief measures of depression, anxiety, and general distress: The PHQ-2, GAD-2, and K-6. Gen Hosp Psychiatry 2019;56:13-18 [FREE Full text] [doi: 10.1016/j.genhosppsych.2018.11.003] [Medline: 30508772]
19. Campbell KL, Winters-Stone KM, Wiskemann J, May AM, Schwartz AL, Courneya KS, et al. Exercise Guidelines for Cancer Survivors: Consensus Statement from International Multidisciplinary Roundtable. Med Sci Sports Exerc 2019 Nov;51(11):2375-2390. [doi: 10.1249/MSS.0000000000002116] [Medline: 31626055]
20. Ibrahim EM, Al-Homaidh A. Physical activity and survival after breast cancer diagnosis: meta-analysis of published studies. Med Oncol 2011 Sep;28(3):753-765. [doi: 10.1007/s12032-010-9536-x] [Medline: 20411366]
21. Garcia DO, Thomson CA. Physical activity and cancer survivorship. Nutr Clin Pract 2014 Dec;29(6):768-779 [FREE Full text] [doi: 10.1177/0884533614551969] [Medline: 25335787]
22. Meissner VH, Herkommer K, Marten-Mittag B, Gschwend JE, Dinkel A. Prostate cancer-related anxiety in long-term survivors after radical prostatectomy. J Cancer Surviv 2017 Dec;11(6):800-807. [doi: 10.1007/s11764-017-0619-y] [Medline: 28528448]
23. Tsaras K, Papathanasiou I, Mitsi D, Veneti A, Kelesi M, Zyga S, et al. Assessment of Depression and Anxiety in Breast Cancer Patients: Prevalence and Associated Factors. Asian Pac J Cancer Prev 2018 Jun 25;19(6):1661-1669 [FREE Full text] [doi: 10.22034/APJCP.2018.19.6.1661] [Medline: 29938451]
24. 2017 National Survey on Drug Use and Health: Methodological summary and definitions. Center for Behavioral Health Statistics and Quality. 2018 Sep. URL: https://www.samhsa.gov/data/report/2017-methodological-summary-and-definitions [accessed 2020-11-24]
25. Bland K, Bigaran A, Campbell K, Trevaskis M, Zopf E. Exercising in Isolation? The Role of Telehealth in Exercise Oncology During the COVID-19 Pandemic and Beyond. Phys Ther 2020 Sep 28;100(10):1713-1716 [FREE Full text] [doi: 10.1093/ptj/pzaa141] [Medline: 32737965]
26. Newton RU, Hart NH, Clay T. Keeping Patients With Cancer Exercising in the Age of COVID-19. JCO Oncol Pract 2020 Oct;16(10):656-664 [FREE Full text] [doi: 10.1200/OP.20.00210] [Medline: 32603253]
27. Thompson WR. Worldwide Survey of Fitness Trends for 2021. ACSM's Health and Fitness Journal 2021;25(1):10-19 [FREE Full text] [doi: 10.1249/fit.0000000000000631]
28. Pinto BM, Stein K, Dunsiger S. Peers promoting physical activity among breast cancer survivors: A randomized controlled trial. Health Psychol 2015 May;34(5):463-472 [FREE Full text] [doi: 10.1037/hea0000120] [Medline: 25110844]
29. Houlihan MC, Tariman JD. Comparison of Outcome Measures for Traditional and Online Support Groups for Breast Cancer Patients: An Integrative Literature Review. J Adv Pract Oncol 2017;8(4):348-359 [FREE Full text] [Medline: 30018841]
30. Mishra SI, Scherer RW, Snyder C, Geigle P, Gotay C. Are exercise programs effective for improving health-related quality of life among cancer survivors? A systematic review and meta-analysis. Oncol Nurs Forum 2014 Nov 01;41(6):E326-E342 [FREE Full text] [doi: 10.1188/14.ONF.E326-E342] [Medline: 25355029]
31. McDonough MH, Beselt LJ, Daun JT, Shank J, Culos-Reed SN, Kronlund LJ, et al. The role of social support in physical activity for cancer survivors: A systematic review. Psychooncology 2019 Oct;28(10):1945-1958. [doi: 10.1002/pon.5171] [Medline: 31278800]

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Abbreviations

GAD-2: 2-item Generalized Anxiety Disorder
PHQ-2: Patient Health Questionnaire
YMCA: Young Men's Christian Association

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Original Paper

Use of mHealth to Increase Physical Activity Among Breast Cancer Survivors With Fatigue: Qualitative Exploration

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Abstract

Background: Physical activity has shown beneficial effects in the treatment of breast cancer fatigue; nevertheless, a significant portion of patients remain insufficiently physically active after breast cancer. Currently most patients have a smartphone, and therefore mobile health (mHealth) holds the promise of promoting health behavior uptake for many of them.

Objective: In this study, we explored representations, levers, and barriers to physical activity and mHealth interventions among inactive breast cancer patients with fatigue.

Methods: This was an exploratory, qualitative study including breast cancer patients from a French cancer center. A total of 4 focus groups were conducted with 9 patients; 2 independent groups of patients (groups A and B) were interviewed at 2 consecutive times (sessions 1 to 4), before and after their participation in a 2-week mHealth group experience consisting of (1) a competitive virtual exercise group activity (a fictitious world tour), (2) participation in a daily chat network, and (3) access to physical activity information and world tour classification feedback. We used a thematic content analysis.

Results: Several physical activity levers emerged including (1) physical factors such as perception of physical benefit and previous practice, (2) psychological factors such as motivation increased by provider recommendations, (3) social factors such as group practice, and (4) organizational factors including preplanning physical activity sessions. The main barriers to physical activity identified included late effects of cancer treatment, lack of motivation, and lack of time. The lack of familiarity with connected devices was perceived as the main barrier to the use of mHealth as a means to promote physical activity. The tested mHealth group challenge was associated with several positive representations including well-being and good habit promotion and being a motivational catalyzer. Following feedback, modifications were implemented into the mHealth challenge.

Conclusions: mHealth-based, easily accessed group challenges were perceived as levers for the practice of physical activity in this population. mHealth-based group challenges should be explored as options to promote physical activity in a population with fatigue after breast cancer.

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KEYWORDS

mHealth; physical activity; breast cancer; cancer-related fatigue; qualitative study; survivorship

Introduction

There are over 2 million new cases of breast cancer diagnosed worldwide each year, and 80% to 90% of the patients will be alive and free of disease 5 years after diagnosis [1]. In this setting, a focus on management of late and long-term physical, cognitive, psychological, and social effects of cancer and cancer treatment has emerged in the last decade [1-5]. Cancer-related fatigue is reported in up to 50% of breast cancer patients after

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treatment [1-4,6] and negatively impacts overall quality of life (QoL) of breast cancer patients [6,7].

Several interventions have proven to be effective in reducing cancer-related fatigue among breast cancer survivors and are recommended by cancer societies including the National Comprehensive Cancer Network, Oncology Nursing Society, and American Society of Clinical Oncology [8-10]. Among strategies to decrease cancer-related fatigue, physical activity has been supported by several studies [11-18]. A meta-analysis of 27 exercise intervention studies showed that exercise led to a reduction of cancer-related fatigue with a mean effect size of 0.32 (95% CI 0.21-0.43) during cancer treatment and 0.38 (95% CI 0.21-0.54) following treatment completion. Therefore, it is now recommended that patients, including those experiencing cancer-related fatigue, get at least 150 minutes of moderate intensity aerobic physical activity or 75 minutes of vigorous intensity aerobic physical activity per week or an equivalent combination [19,20]. It is also well documented that fatigue can be a barrier to physical activity engagement [21]. Nevertheless, research suggests that cancer-related fatigue is largely underreported and undertreated [11], and a substantial proportion of breast cancer survivors are inactive during and after treatment [22,23].

Currently a vast proportion of breast cancer patients have smartphones and can easily access the internet [24]. Mobile health (mHealth) uses mobile technology to deliver and share personalized health information and holds the promise of becoming a way to deliver behavioral interventions that are embedded into individuals' daily routines, with the great potential to reach diverse populations and of being generalizable [25-28]. Some feasibility studies using mHealth to empower breast cancer patients and survivors have been conducted, and some presented promising results [29-35]. Uhm et al [36] conducted a prospective multicenter trial examining the effect of an mHealth-based exercise intervention among breast cancer patients that suggested this strategy could be effective in increasing physical activity in this population. Several companies are designing mHealth options to monitor patient-reported outcomes and promote engagement in health behaviors such as physical activity. Recently, Kiplin, a company in France, developed an mHealth group challenge that provides patients the opportunity of engaging in virtual exercise group challenges [37].

We conducted a qualitative study to explore representations, levers, and barriers to physical activity and mHealth interventions among patients with breast cancer and cancer-related fatigue. Our overarching goal was to explore mHealth as a facilitator to increase physical activity in patients with fatigue after breast cancer. In addition, we tested satisfaction with the Kiplin mHealth group challenge among this population.

Methods

This qualitative study was conducted following the Consolidated Criteria for Reporting Qualitative Studies (COREQ) [38].

Participants

Eligible participants had a diagnosis of stage I to III breast cancer according to the American Joint Committee on Cancer version 8 and were followed at a French comprehensive cancer center. Patients were invited to participate by the treating physician if they reported (1) cancer-related fatigue rated as equal or higher than 4/10 on a visual analog scale, (2) declared they did not meet the World Health Organization recommendations for physical activity (ie, 150 or 75 minutes per week of moderate or vigorous activity or equivalent combinations) [19], (3) had a smartphone with internet access, (4) spoke French fluently, and (5) had no physical or medical contraindications to the proposed activity. All patients should have completed breast cancer primary treatment between 3 and 18 months before the first group meeting. We used purposive sampling. Health care professionals asked patients if they were willing to participate in the study when they were at the outpatient clinic. Patients interested in participating were contacted by a trained PhD sociologist (EM) by email or phone call, who would introduce herself and explain the study. In addition, all patients received written information explaining the objectives and the process of the focus group.

Procedures and Data Collection

A total of 4 focus groups were conducted by EM (sociologist, PhD, experienced in qualitative study) assisted by ADM (medical oncologist, MD, experienced in survivorship and cancer care) between June and November 2018 at the cancer center and lasted on average 90 minutes. Two independent groups of patients were interviewed 2 consecutive times (group A session 1 and 2 and group B, session 3 and 4).

A focus group guide was developed for each interview with diverse stakeholder input, including medical oncologists, psychologists, researchers, and breast cancer survivors who reviewed the content and topic areas and provided feedback (Multimedia Appendices 1 and 2).

Levers and Barriers to Physical Activity and mHealth Use

The first focus sessions of each group (sessions 1 and 3) were designed to explore physical activity and mHealth use representations, levers, and barriers. In the end of the focus group, instructions for an mHealth group challenge were given, followed by 2 weeks of participation in the actual challenge.

Kiplin mHealth Group Challenge

The second focus groups (sessions 2 and 4) were performed within 2 weeks of the end of the mHealth-based physical activity challenge and designed to evaluate satisfaction with the mHealth group challenge. As prespecified in the study protocol, the first patient group (group A) feedback led to changes to the challenge for the second one (group B). All participants completed a brief survey that assessed sociodemographic and clinical information on the day of the first focus group. Details of this survey are provided in Multimedia Appendix 3.

Intervention

The intervention consisted of 2 weeks of the mHealth group challenge. This is a playful challenge developed by Kiplin

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consisting of (1) a competitive virtual exercise group activity, namely a fictious world tour, (2) participation in a daily chat network with other patients, and (3) access to physical activity information and world tour classification feedback. Patients had a daily goal of doing 6000 steps, recorded by a pedometer. For this challenge, 2 teams were assembled in each group. Details of our adaptation of the mHealth challenge used in a previous study and Kiplin visuals are provided in Multimedia Appendix 4 and Figures 1 and 2.

Informed consent forms were sent by email beforehand to the participants and signed by all participants and the researcher on the day of the first focus group. Participants' names were not directly linked in any way with the audio recordings. The study received the approval of the national ethics committee (RCB No. 2017-A02062-51).

Figure 1. Map (Kiplin's world tour).

Figure 2. Activity tab (Kiplin's activity tab example).

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Analysis

All focus group sessions were audiorecorded and professionally transcribed verbatim with identifiers removed. In addition, field notes were assembled. We used a grounded theory approach to comprehensively explore and explain the subject, acknowledging that due to our small number of focus groups, back and forth between field work and analyses was limited [39]. Analysis of the focus group data was made using a 3-step process involving (1) reading the transcripts several time to ensure familiarization of the data, reviewing field notes, and creating a codebook based on themes identified and (2) conducting manual thematic content analysis [38] (EM). This was a pilot study with 4 focus groups with 233 minutes total. In this setting, we opted to manually perform thematic content analyses [40]. The research team is highly experienced in manual thematic content analyses. Coding continued until dominant themes that emerged from within the data were clearly identified and the codes from steps 1 and 2 were generalized into broader themes. Data were coded and codes/themes were discussed within the team (EM, IVL [medical oncologist, MD PhD, experienced in survivorship and cancer care], ADM). Our interpretation was submitted to the critical scrutiny of an independent team including psychologists, oncologists, and patient advocates involved in clinical research during a prespecified seminar aimed at presenting the work in progress. After the completion of each focus group, a preliminary analysis was performed to determine the extent to which the information collected was considered sufficiently rich. Descriptive statistics including means, medians, and frequency distributions were used to characterize study participants.

Results

Study Participants

Of the 20 patients approached to be enrolled in the study, 9 agreed to participate. Reasons for refusal included unavailability on the predefined date and time for first focus group (n=5), not comfortable using a smartphone (n=3), not a smartphone owner (n=1), distance from research facility (n=1), and pain that prevented exercise practice (n=1). Of the 9 women who participated in the focus groups, 5 were enrolled in the first group of patients (group A) and 4 in the second group of patients (group B). Participant median age at diagnosis was 47 (range 29-60) years, most were married (6/9) and with children (8/9), most lived in towns with more than 20,000 inhabitants (8/9), and all participants were professionally active: 4 clerks, 4 managerial or professional occupations, and 1 with a technician or associate professional position (Table 1).

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Table 1. Characteristics of the participants.

Characteristics	Focus group session 1 (n=5)	Focus group session 2 (n=4)	Total (n=9)
Age in years, mean (SD)	49.6 (7.28)	42.5 (8.07)	46.4 (8.42)
<40, n	1	1	2
40-49, n	2	2	4
50-59, n	1	1	2
≥60, n	1	0	1
Type of town, n			
Village (<2000 inhabitants)	0	0	0
Town (<20,000 inhabitants)	1	1	2
Town (>20,000 inhabitants)	4	3	7
Family situation, n			
Single	0	1	1
Married	3	3	6
Divorced	2	0	2
Occupational categories, n			
Higher professional or manager	2	2	4
Manual worker	0	0	0
Technician or associate professional	1	0	1
Clerk	2	2	4
Self-employed	0	0	0
Inactive	0	0	0
Breast surgery, n			
Mastectomy	3	1	4
Breast-conserving surgery	2	3	5
Lymph node surgery, n			
Lymphadenectomy	3	2	5
Sentinel node biopsy	2	2	4
Radiotherapy, n	4	4	8
Chemotherapy, n	5	4	9
Hormotherapy, n	4	4	8
Trastuzumab, n	1	0	1

Levers and Barriers to Physical Activity and mHealth Use

All patients expressed positive representations of physical activity associating it with physical benefit; nevertheless, some stated feeling that using exercise to reduce fatigue seemed counterintuitive.

> *The doctor said to me: "Exercise help feeling less fatigued." So, I told myself: Ok. Well, it's weird, but I need to walk. Well, I need to do adapted physical activity ... Often, when I woke up in the morning, my knees hurt badly and when we exercise, we can already feel the benefit of it. It hurts less! And this is a little bit counterintuitive because usually, when you feel pain, you decrease your activity.* [Rose, 47 years, working part-time]

No negative representations of physical activity were conveyed.

A total of 7 overarching themes were identified regarding levers and barriers of physical activity. The 4 main levers identified for physical activity were (1) physical levers including the perception of physical benefit (5/9) and previous practice experience (4/9), (2) psychological levers including the incentive driven by the recommendation of a health care provider (4/9), (3) social levers including the group activity (4/9), and (4) organizational levers with the inclusion of exercise on a regular daily basis (2/9).

The main barriers included were of physical, psychological, and organizational nature. Physical barriers were the late effects

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of cancer treatment (fatigue; joint and muscle pain; menopausal symptoms; lymphedema; shortness of breath; hand, foot, and mouth syndrome; neuropathy; and weight gain).

> *It's hard, and well, I don't have the right to use my arm since my lymph nodes were removed.* [Corinne, 48 years, sick leave]

Psychological barriers included lack of motivation, lack of habit, counterintuitive approach, having stopped working out during treatment, fear of being pushed too much, or practicing alone.

> *Me? Nothing at all. I don't do sports. I walk but I don't do physical activity. No incentive to do it.* [Sandrine, 44 years, working part-time]

Organizational barriers included lack of time, resuming work and/or working full time, and family commitments (Table 2).

> *I've started working again right after treatments, full time. In addition, I have one hour of transportation time.* [Marie, 46 years, full-time]

Regarding the use of mHealth to be more active, only user-related levers and barriers were identified (eg, psychological levers and barriers). The main lever to the use of mHealth by breast cancer patients was motivation driven by the ability to track activity (3/9), and the main barriers were lack of familiarity, lack of information/explanations, and lack of interest about mHealth (6/9). Table 2 describes themes, messages and quotes from patients regarding levers and barriers of using physical activity and mHealth.

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Table 2. Levers and barriers to physical activity and mHealth use.

Theme	Message emerging from the analyses	Number of patients citing it	Quotes
PA[a] after breast cancer			
Levers			
Physical	Physical benefits and previous practice are important levers	Physical benefits 5/9; Previous practice 4/9	• And there is another thing that is beneficial too; it's that I have a lot of joint pain. And indeed, when I move, it hurts less. [Sylvie, 50 years, working part-time] • So, it helps the fact that was doing a little bit of physical activity before getting sick. [Rose, 47 years, working part-time]
Psychological	Oncologist's recommendation is an incentive	4/9	• So, indeed, it's the oncologist who told me and this made me want to move: "Well, you are tired, there aren't a hundred options: it's physical activity!" [Anne, 60 years, sick leave]
Social	Doing it in a group, with friends, or with relatives are seen as levers	4/9	• Because me too, I like doing it in a group. Otherwise it's hard for me to do physical activity. [Christine, 39 years, working part-time]
Organizational	Planning PA sessions to fit PA in the daily regular schedule is helpful	Planning PA 2/9	• When I come home from work at night ... I feel really exhausted ... So I'm lucky to be able to do physical activity at work at lunch time. [Rose, 47 years, working part-time]
Barriers			
Physical	Late effects of cancer treatment can negatively impact the practice	Late effects 9/9	• And regarding fatigue level, after the end of primary treatments, I was at 10/10. Today, I don't know, I may be at... it decreased though: I'm at 6/10. But still always with this permanent exhaustion feeling, it is hard to exercise. [Rose, 47 years, working part-time]
Psychological	Lack of motivation is a main psychological barrier cited	3/9	• I'm really not motivated at all. [Sandrine, 44 years, working part-time] • So me, I try to do it. But motivation is not always there. [Sylvie, 50 years, working part-time]
Organizational	Lack of time is a main organizational barrier cited	2/9	• But I don't always have time... It's also a lack of time. [Rose, 47 years, working part-time]
Use of mHealth			
Lever			
Psychological	To be able to know how many steps a day and track the activity they do is associated with motivation and facilitates the use of these strategies	3/9	• It's a tool that allows us to see what we are doing, either when we don't do a lot, or when we do a lot. [Sylvie, 50 years, working part-time]
Barriers			
Psychological	Some patients are not familiar or interested in mHealth, which can be a barrier to their use	6/9	• I think I have a friend who has one. But I have never asked for more details. [Marie, 46 years, full-time] • I'm not really interested about that. [Marlène, 29 years, sick leave] • Oh, me, I'm not a "connected device" person. I'm not a geek at all. [Anne, 60 years, sick leave]

[a]PA: physical activity.

Kiplin mHealth Group Challenge

All patients felt positively about the Kiplin mHealth group challenge and would recommend such an intervention to other patients and considered it an acceptable proposal. Several positive and negative aspects were identified with the challenge tested. Positive aspects included motivation (7/9), sense of physical and psychological well-being (6/9), promoting good habits (5/9), allowing a group experience (4/9), allowing tracking activity (3/9), and being fun (2/9) (Table 3). Particularly, some patients reported subjective feelings of fatigue improvement.

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Personally I think it was a good fatigue ... and I found again, that feeling of sweat pouring from all of my body and that kind of well-being like when I was doing physical activity before [cancer]. [Corinne, 48 years, sick leave]

It's not a fatigue that makes you complain, it's a comforting fatigue. [Marie, 46 years, working full-time]

The 4 main negative aspects included lack of information (4/9), challenge is optimized only for walking (4/9), challenge is time-consuming (4/9), and some experienced technical problems (3/9). Challenge modifications implemented by the second group of patients (group B) based on feedback from the first group (group A) included technical simplifications (eg, design changes, improvement of functionalities) and improvement of information tools (eg, FAQ). These modifications resulted in the resolution of some of the negative aspects mentioned by the first group of patients (group A).

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Table 3. Opinion about Kiplin mHealth group challenge.

Theme and message emerging from the analyses	Number citing it	Quotes
Preference/advantages		
It motivates and push to surpass oneself	7/9	• I have to say, it's really motivating, this thing! It pushes! It pushes you! [Marie, 46 years, working full-time] • That suits me perfectly; because it will make me... it will push me! And I am a competitor at heart. [Corinne, 48 years, sick leave] • Yes, I think I will take on the challenge. Just by nature! [Sandrine, 44 years, working part-time]
It makes them feel good (physically and morally)	6/9	• I think it was a good fatigue.... And I found again when I was doing physical activity (at the end of practice, when I sweat from every pore), this kind of well-being! [Corinne, 48 years, sick leave] • I found benefit regarding the leg pain that I had. And it's one of the reasons I think that I kept doing it afterward. I'm not saying it's all gone, but I saw a benefit quite quickly actually. [Sylvie, 50 years, working part-time]
It generates good habits	5/9	• What's good is that I kept going afterward. So I kept my 6000 steps objective every day. [Sylvie, 50 years, working part-time] • I kept the habits afterwards too. And so I keep doing my 6000 steps a day. Well... on average. [Rose, 47 years, working part-time]
It is a group challenge	4/9	• I find it nice, the double objective: in teams and the fact that we move forward together. Because even if we progress in different teams, it's our cumulative steps that made everyone go forward. [Christine, 39 years, working part-time] • Undeniably, I would really recommend working in groups to be physically active again. [Sylvie, 50 years, working part-time]
It helps quantify their activity	3/9	• Me, I found one positive thing, it's that it objectifies, at least regarding the number of steps we do when we walk. [Anne, 60 years, sick leave]
It's fun	2/9	• So, everything that's fun, board games and shared moments, it's something that drives me. [Corinne, 48 years, sick leave] • Me, I like to play, so, I like this! [Sandrine, 44 years, working part-time]
Obstacles/inconveniences		
It's time consuming	4/9	• The main obstacle, it's the time we can allow to it. [Sylvie, 50 years, working part-time] • But me, it still required significant changes on my way of life! Whereas in vacations, it was easy! But at work, personally, I only had on average 800 steps. [Sylvie, 50 years, working part-time] • It took a lot of my time! ... The only problem is that I had less time with my children! [Marie, 46 years, working full time] • In my opinion, it takes too much time in my life you know. I got back at work not a long time ago. It's already hard for me since I got back at work to be able to do everything that I need. Because works, it takes a lot of time! And for one and a half years I was on sick-leave. So I feel like I do not have time! [Pascale, 55 years, working part-time]
Lack of information	4/9	• Maybe it would have been useful to explain more. It's true that we discovered some things when we started talking to each other in the chat box. [Sylvie, 50 years, working part-time] • I think that for people like me, who are not used to this kind of thing, it should be explained again, from the beginning, every stage! [Pascale, 55 years, working part-time]
Only optimized for walking	4/9	• So it works inside my bag. It works if I have it in my hand. It works! Except when I go cycling, then it doesn't work. [Sylvie, 50 years, working part-time] • Personally, I was really disappointed that it was not taking my scooter time into account! [Rose, 47 years, working part-time]

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Theme and message emerging from the analyses	Number citing it	Quotes
Technical problems	3/9	• I was not able to access the app to fill the first mini-game! I had to copy-paste from the internet to open the page. I don't even remember what I did, but it was complicated. [Marlène, 29 years, sick leave]

Discussion

Principal Findings

Physical activity is a well-recognized strategy to improve fatigue after breast cancer, and mHealth can be a good platform to facilitate physical activity. In this study, we focused on a population of inactive breast cancer survivors with documented cancer-related fatigue to, through focus groups, gain in-depth and nuanced insight into participants' perceptions, opinions, and motivations regarding physical activity and mHealth interventions. After engaging in our mHealth intervention for inactive breast cancer patients with fatigue, several physical activity levers emerged including physical factors (eg, perception of physical benefit and previous practice), psychological factors (eg, motivation increased by provider recommendations), social factors (eg, group practice), and organizational factors (eg, preplanning physical activity sessions). The main barriers to physical activity identified in this study included late effects of cancer treatment, lack of motivation, and lack of time. The lack of familiarity with connected devices was perceived as the main barrier to the use of mHealth as a mean to promote physical activity. The tested mHealth group challenge was associated with several positive representations including well-being, good habit promotion, and motivational catalyzer.

First, the barriers to physical activity practice that were identified mostly aligned to what has been previous presented in the literature. The main barriers for breast cancer survivors to engage in physical activity reported in the literature include organizational barriers, with a substantial proportion of patients reporting lack of time or lack of access to facilities, physical factors including late and long-term effects of cancer treatment, and social/psychosocial factors such as lack of motivation or lack of social support [20,41-43].

Second, as previously shown in literature, peer support in a group was seen as an important incentive to physical activity practice, having a positive impact on both initiation and persistence of these kinds of behavioral changes [42,44]. In our population, one of the main levers of engagement in and pursuit of physical activity was perceiving physical benefit (eg, reduction of joint pain was considered an incentive to maintain physical activity). In addition, perceived benefits in weight and health management, improvement of body image, personal fulfillment, regaining normality, positive beliefs about efficacy and outcomes, and positive emotions (eg, enjoyment) also seemed to play roles as levers [20,42,45].

Third, although several mHealth interventions for breast cancer patients targeting physical activity or cancer-related fatigue have been conducted [29-31,36,46-51], to our knowledge, none of them has examined levers and barriers to physical activity among cancer patients with cancer-related fatigue as a primary outcome within the context of an mHealth intervention. In previous studies in the overall population, there were 3 main barriers for patients to engage with mHealth: user-related barriers (eg, lack of digital literacy, lack of motivation), health-related barriers (eg, late effect of treatments, lack of physical ability), and technology-related barriers (eg, technical problems, intrusiveness) [52,53]. In our population, we found similar obstacles. In addition, the literature also presents several levers/facilitators to engage with mHealth among cancer patients that were also identified in our population: user-related levers (eg, planning physical activity, motivation, self-efficacy, social support), health-related levers (eg, feeling good), and technology-related levers (eg, convenience, tailoring of the intervention, ease of use) [52,53]. Some solutions to reduce barriers to physical activity and to the use of mHealth are presented in Table 4.

These findings suggest that mHealth can be an acceptable option to promote physical activity in this population of breast cancer survivors. mHealth is emerging as way to monitor patient-reported outcomes and promote health behavior improvement for a large proportion of patients. Wearable devices (eg, phone or pedometer) are an effective strategy to increase physical activity [54]. With phones having a growing importance in our lives, app-based mHealth interventions can be a good way to help patients. mHealth offers a new way to propose cost-effective health care interventions; indeed, app-based or web-based interventions allow care to be accessible to an increasing number of people outside of the hospital [49]. Several mHealth apps for cancer patients have been developed these past few years, and some are being tested in clinical trials [52-55]. Acceptability of mobile phone apps has been shown to be high among users [53]. Participant engagement with the challenge was substantial; nevertheless, our challenge was short and prior literature suggests a decrease in adherence to these solutions over time [56-58]. Therefore, when using these strategies to help exercise engagement among breast cancer patients with fatigue, it will be important to include elements such as the usability of the technology, motivating factors, data monitoring, personal contact with the study personnel/support, and personalized feedback that has shown before to contribute to better adherence [59].

Even if mHealth solutions are used by a large number of people and are a good tool to use for some populations, we acknowledge that not all types of patients are interested in or able to use them. Thus, alternative nonvirtual offerings may also be required. Regarding physical activity and fatigue after breast cancer, joining an association offering adapted physical activity for cancer patients, engaging with a personal trainer, practicing in a group or with a family member, participating in group counseling, or using self-monitoring and goal setting may be effective solutions.

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Table 4. Solutions to reduce barriers.

Barrier	Solution
Barriers to physical activity	
Joint pain and fatigue	Explain that being physically active can help reduce joint pain and fatigue
Reduced motivation	Offering rewards inside the challenge for regularity and improvements
Lack of time (eg, working again, family commitment)	Show different ways to gain steps each day without needing a lot of time (eg, leaving the bus/metro one stop early, parking the car farther away from the workplace/stores, taking the stairs, using the bathroom on another floor at work). Help participants to find ways of freeing some time
Counterintuitiveness of being active when fatigued or feeling pain	Explain that being physically active can help reduce joint pain and fatigue; tell them they will likely feel it after a few days
Barriers to the use of mHealth and challenge improvements	
Complexity of the device's use	A simpler way to record steps
Device only adapted to walking	An only device recording all kind of physical activity (cycling, swimming, etc)
Visibility of new messages in the chat	Build a pop-up alert when a new message is posted in the chat
Visibility of the itinerary (world tour) of the challenge on a mobile device	Seeing the map of the challenge more clearly on the phone (world tour) or finding another way to present it
Information about step counts	A day-by-day recap of the step count
Reduced motivation	Add more mini-games, more interactions between participants
Playing with strangers	Use the challenge in groups that already know each other

The first version of the Kiplin mHealth group challenge was web-based and used a pedometer to record step count; they then developed an app-based challenge with a built-in step-counter. Kiplin adapted the mHealth challenge to this population of breast cancer patients with fatigue by decreasing the number of steps to reach per day. The tailoring of the intervention to several kinds of populations may ensure feasibility and adherence. Indeed, patients were satisfied after participation in the challenge and gave positive feedback. The group challenge that we exposed our patients to was seen as motivational, fun, and a good way to track steps; in addition, it generated good habits and made women feel good both physically and emotionally. Our study suggests that this kind of challenge might be a good way to engage patients to be physically active after the end of treatment, with the group-based objectives and games acting as ways to make physical activity less difficult, more attractive, and motivational for patients. Kiplin's mHealth group challenge may be a way to overcome some of the barriers to engaging in physical activity commonly encountered such as access, motivation, and social support. It can also help overcome some of the barriers to engaging in mHealth technology; some troubleshooting and technical support was provided along the course of the challenge to patients who were experiencing difficulties with app settings or overall functioning.

Limitations

We acknowledge our study has limitations. First, this was an exploratory study with limited sample size, so even if we discovered a range of barriers and levers represented in our focus groups and found some redundancy, the generalizability of study findings might be limited, and these preliminary data should be further investigated in a randomized controlled trial. Second, participants were predominantly college-educated, and this may constitute another limit to the generalizability of our results. Third, we acknowledge selection bias performed both by providers (they may have been inclined to pick well-disposed patients) but also regarding patient acceptability (those not being comfortable using a smartphone or not owning a smartphone are likely to have refused participation in the study). Fourth, the duration of the challenge was limited to a 2-week period, and conducting a study for a longer period may lead to collecting different perceptions from patients. Thus, making assumptions of efficacy of the intervention in question is not possible. Finally, we tested a specific intervention, and perceptions can be different if a different mHealth intervention is used.

Conclusion

Kiplin's mHealth group challenges were perceived as levers for the practice of physical activity in this population. This qualitative exploration aided the improvement of the challenge. mHealth group challenges should be explored as options to promote physical activity in a population with fatigue after breast cancer.

Acknowledgments

This study was the result of a collaboration with Kiplin, who provided the equipment free of charge. The funding source did not play a part in the conduct of the study. We have full control of all primary data, and we agree to allow the journal to review our data if requested.

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Authors' Contributions

MS, IVL, EM, and ADM worked on the study conception and design. EM and ADM were responsible for acquisition of data. EM, ADM, CC, JA, and IVL were responsible for the analysis and interpretation of the data. EM, IVL, and ADM drafted the manuscript. ADM, CC, ARF, AG, MB, BF, JA, BP, MS and IVL contributed to the critical revision of the paper.

Conflicts of Interest

ADM reports honoraria from Thermo Fisher. ARF reports personal and other fees from Roche and Novartis outside the submitted work. MB and BF are employees of Kiplin, who provided the challenge. BP reports grants and nonfinancial support from Puma Biotechnology; grants, personal fees, and nonfinancial support from Novartis; nonfinancial support from Merus; grants from Myriad Genetics; grants from Pierre Fabre; nonfinancial support from Pfizer; personal fees and nonfinancial support from Astra Zeneca; and personal fees from MSD Oncology outside the submitted work. IVL reports personal fees from Novartis, personal fees from Amgen, personal fees from AstraZeneca, and personal fees from Kephren outside the submitted work. EM, CC, AG, JA, and MS declare no conflicts of interest.

Multimedia Appendix 1
Focus group session 1 script.
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Multimedia Appendix 2
Focus group session 2 script.
[DOCX File , 15 KB - cancer_v7i1e23927_app2.docx]

Multimedia Appendix 3
Sociodemographic questionnaire.
[DOCX File , 53 KB - cancer_v7i1e23927_app3.docx]

Multimedia Appendix 4
Kiplin solution development, adapted.
[DOCX File , 22 KB - cancer_v7i1e23927_app4.docx]

References

1. Abrahams HJG, Gielissen MFM, Schmits IC, Verhagen CAHHVM, Rovers MM, Knoop H. Risk factors, prevalence, and course of severe fatigue after breast cancer treatment: a meta-analysis involving 12 327 breast cancer survivors. Ann Oncol 2016 Jun;27(6):965-974. [doi: 10.1093/annonc/mdw099] [Medline: 26940687]
2. Dow KH, Ferrell BR, Leigh S, Ly J, Gulasekaram P. An evaluation of the quality of life among long-term survivors of breast cancer. Breast Cancer Res Treat 1996;39(3):261-273. [doi: 10.1007/BF01806154] [Medline: 8877006]
3. Curt GA. The impact of fatigue on patients with cancer: overview of FATIGUE 1 and 2. Oncologist 2000;5 Suppl 2:9-12 [FREE Full text] [doi: 10.1634/theoncologist.5-suppl_2-9] [Medline: 10896323]
4. Broeckel JA, Jacobsen PB, Horton J, Balducci L, Lyman GH. Characteristics and correlates of fatigue after adjuvant chemotherapy for breast cancer. J Clin Oncol 1998 May;16(5):1689-1696. [doi: 10.1200/JCO.1998.16.5.1689] [Medline: 9586880]
5. Ferreira AR, Di Meglio A, Pistilli B, Gbenou AS, El-Mouhebb M, Dauchy S, et al. Differential impact of endocrine therapy and chemotherapy on quality of life of breast cancer survivors: a prospective patient-reported outcomes analysis. Ann Oncol 2019 Nov 01;30(11):1784-1795 [FREE Full text] [doi: 10.1093/annonc/mdz298] [Medline: 31591636]
6. Bower JE, Ganz PA, Desmond KA, Rowland JH, Meyerowitz BE, Belin TR. Fatigue in breast cancer survivors: occurrence, correlates, and impact on quality of life. J Clin Oncol 2000 Feb;18(4):743-753. [doi: 10.1200/JCO.2000.18.4.743] [Medline: 10673515]
7. Servaes P, Gielissen MFM, Verhagen S, Bleijenberg G. The course of severe fatigue in disease-free breast cancer patients: a longitudinal study. Psychooncology 2007 Sep;16(9):787-795. [doi: 10.1002/pon.1120] [Medline: 17086555]
8. Berger A, Mooney K, Alvarez-Perez A, Breitbart WS, Carpenter KM, Cella D, National comprehensive cancer network. Cancer-Related Fatigue, Version 2.2015. J Natl Compr Canc Netw 2015 Aug;13(8):1012-1039 [FREE Full text] [doi: 10.6004/jnccn.2015.0122] [Medline: 26285247]
9. Fatigue. Oncology Nursing Society. URL: https://www.ons.org/pep/fatigue [accessed 2021-02-27]
10. Bower JE, Bak K, Berger A, Breitbart W, Escalante CP, Ganz PA, American Society of Clinical Oncology. Screening, assessment, and management of fatigue in adult survivors of cancer: an American Society of Clinical oncology clinical practice guideline adaptation. J Clin Oncol 2014 Jun 10;32(17):1840-1850 [FREE Full text] [doi: 10.1200/JCO.2013.53.4495] [Medline: 24733803]

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11. Zeng Y, Huang M, Cheng ASK, Zhou Y, So WKW. Meta-analysis of the effects of exercise intervention on quality of life in breast cancer survivors. Breast Cancer 2014 May;21(3):262-274. [doi: 10.1007/s12282-014-0521-7] [Medline: 24569944]
12. Duijts SFA, Faber MM, Oldenburg HSA, Aaronson NK. Effectiveness of behavioral techniques and physical exercise on psychosocial functioning and health-related quality of life in breast cancer patients and survivors: a meta-analysis. Psychooncology 2011 Feb;20(2):115-126. [doi: 10.1002/pon.1728] [Medline: 20336645]
13. Tian L, Lu HJ, Lin L, Hu Y. Effects of aerobic exercise on cancer-related fatigue: a meta-analysis of randomized controlled trials. Support Care Cancer 2016 Feb;24(2):969-983. [doi: 10.1007/s00520-015-2953-9] [Medline: 26482381]
14. Hayes SC, Rye S, Disipio T, Yates P, Bashford J, Pyke C, et al. Exercise for health: a randomized, controlled trial evaluating the impact of a pragmatic, translational exercise intervention on the quality of life, function and treatment-related side effects following breast cancer. Breast Cancer Res Treat 2013 Jan;137(1):175-186. [doi: 10.1007/s10549-012-2331-y] [Medline: 23139058]
15. Sprod LK, Hsieh CC, Hayward R, Schneider CM. Three versus six months of exercise training in breast cancer survivors. Breast Cancer Res Treat 2010 Jun;121(2):413-419 [FREE Full text] [doi: 10.1007/s10549-010-0913-0] [Medline: 20443054]
16. Marcus BH, Williams DM, Dubbert PM, Sallis JF, King AC, Yancey AK, American Heart Association Council on Nutrition, Physical Activity,Metabolism (Subcommittee on Physical Activity), American Heart Association Council on Cardiovascular Disease in the Young, Interdisciplinary Working Group on Quality of Care and Outcomes Research. Physical activity intervention studies: what we know and what we need to know: a scientific statement from the American Heart Association Council on Nutrition, Physical Activity, and Metabolism (Subcommittee on Physical Activity); Council on Cardiovascular Disease in the Young; and the Interdisciplinary Working Group on Quality of Care and Outcomes Research. Circulation 2006 Dec 12;114(24):2739-2752. [doi: 10.1161/CIRCULATIONAHA.106.179683] [Medline: 17145995]
17. Warburton DER, Bredin SSD. Health benefits of physical activity: a systematic review of current systematic reviews. Curr Opin Cardiol 2017 Sep;32(5):541-556. [doi: 10.1097/HCO.0000000000000437] [Medline: 28708630]
18. Kim J, Choi WJ, Jeong SH. The effects of physical activity on breast cancer survivors after diagnosis. J Cancer Prev 2013 Sep;18(3):193-200 [FREE Full text] [doi: 10.15430/jcp.2013.18.3.193] [Medline: 25337546]
19. Global recommendations on physical activity for health, 2010. World Health Organization. URL: http://www.who.int/dietphysicalactivity/global-PA-recs-2010.pdf [accessed 2021-02-27]
20. Brunet J, Taran S, Burke S, Sabiston CM. A qualitative exploration of barriers and motivators to physical activity participation in women treated for breast cancer. Disabil Rehabil 2013;35(24):2038-2045. [doi: 10.3109/09638288.2013.802378] [Medline: 23772995]
21. Fisher A, Wardle J, Beeken RJ, Croker H, Williams K, Grimmett C. Perceived barriers and benefits to physical activity in colorectal cancer patients. Support Care Cancer 2016 Feb;24(2):903-910 [FREE Full text] [doi: 10.1007/s00520-015-2860-0] [Medline: 26268781]
22. Mason C, Alfano CM, Smith AW, Wang C, Neuhouser ML, Duggan C, et al. Long-term physical activity trends in breast cancer survivors. Cancer Epidemiol Biomarkers Prev 2013 Jun;22(6):1153-1161 [FREE Full text] [doi: 10.1158/1055-9965.EPI-13-0141] [Medline: 23576689]
23. Irwin ML, Crumley D, McTiernan A, Bernstein L, Baumgartner R, Gilliland FD, et al. Physical activity levels before and after a diagnosis of breast carcinoma: the Health, Eating, Activity, and Lifestyle (HEAL) study. Cancer 2003 Apr 01;97(7):1746-1757 [FREE Full text] [doi: 10.1002/cncr.11227] [Medline: 12655532]
24. Measuring digital development: facts and figures 2020. Geneva, Switzerland: International Telecommunication Union; 2020. URL: https://www.itu.int/en/ITU-D/Statistics/Documents/facts/FactsFigures2020.pdf [accessed 2021-03-03]
25. Mobasheri MH, Johnston M, King D, Leff D, Thiruchelvam P, Darzi A. Smartphone breast applications: what's the evidence? Breast 2014 Oct;23(5):683-689. [doi: 10.1016/j.breast.2014.07.006] [Medline: 25153432]
26. Panayi ND, Mars MM, Burd R. The promise of digital (mobile) health in cancer prevention and treatment. Future Oncol 2013 May;9(5):613-617. [doi: 10.2217/fon.13.42] [Medline: 23647287]
27. Hou I, Lan M, Shen S, Tsai PY, Chang KJ, Tai H, et al. The development of a mobile health app for breast cancer self-management support in Taiwan: design thinking approach. JMIR Mhealth Uhealth 2020 Apr 30;8(4):e15780 [FREE Full text] [doi: 10.2196/15780] [Medline: 32352390]
28. Jongerius C, Russo S, Mazzocco K, Pravettoni G. Research-tested mobile apps for breast cancer care: systematic review. JMIR Mhealth Uhealth 2019 Feb 11;7(2):e10930 [FREE Full text] [doi: 10.2196/10930] [Medline: 30741644]
29. Quintiliani LM, Mann DM, Puputti M, Quinn E, Bowen DJ. Pilot and feasibility test of a mobile health-supported behavioral counseling intervention for weight management among breast cancer survivors. JMIR Cancer 2016;2(1) [FREE Full text] [doi: 10.2196/cancer.5305] [Medline: 27761518]
30. McCarroll ML, Armbruster S, Pohle-Krauza RJ, Lyzen AM, Min S, Nash DW, et al. Feasibility of a lifestyle intervention for overweight/obese endometrial and breast cancer survivors using an interactive mobile application. Gynecol Oncol 2015 Jun;137(3):508-515. [doi: 10.1016/j.ygyno.2014.12.025] [Medline: 25681782]
31. Geng Y, Myneni S. Patient engagement in cancer survivorship care through mhealth: a consumer-centered review of existing mobile applications. AMIA Annu Symp Proc 2015;2015:580-588 [FREE Full text] [Medline: 26958192]

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32. Lozano-Lozano M, Galiano-Castillo N, Martín-Martín L, Pace-Bedetti N, Fernández-Lao C, Arroyo-Morales M, et al. Monitoring energy balance in breast cancer survivors using a mobile app: reliability study. JMIR Mhealth Uhealth 2018 Mar 27;6(3):e67 [FREE Full text] [doi: 10.2196/mhealth.9669] [Medline: 29588273]
33. Chow PI, Showalter SL, Gerber M, Kennedy EM, Brenin D, Mohr DC, et al. Use of mental health apps by patients with breast cancer in the united states: pilot pre-post study. JMIR Cancer 2020 Apr 15;6(1):e16476 [FREE Full text] [doi: 10.2196/16476] [Medline: 32293570]
34. Pope Z, Lee JE, Zeng N, Lee HY, Gao Z. Feasibility of smartphone application and social media intervention on breast cancer survivors' health outcomes. Transl Behav Med 2018 Feb 17;9(1):11-22. [doi: 10.1093/tbm/iby002] [Medline: 29471477]
35. Nápoles AM, Santoyo-Olsson J, Chacón L, Stewart AL, Dixit N, Ortiz C. Feasibility of a mobile phone app and telephone coaching survivorship care planning program among spanish-speaking breast cancer survivors. JMIR Cancer 2019 Jul 09;5(2):e13543 [FREE Full text] [doi: 10.2196/13543] [Medline: 31290395]
36. Uhm KE, Yoo JS, Chung SH, Lee JD, Lee I, Kim JI, et al. Effects of exercise intervention in breast cancer patients: is mobile health (mHealth) with pedometer more effective than conventional program using brochure? Breast Cancer Res Treat 2017 Feb;161(3):443-452. [doi: 10.1007/s10549-016-4065-8] [Medline: 27933450]
37. Kiplin. URL: https://www.kiplin.com/ [accessed 2021-02-27]
38. Braun V. Thematic analysis. In: Liamputtong P, editor. Handbook of Research Methods in Health Social Sciences. Hoboken: Springer; 2019:843-860.
39. Charmaz K. Constructing Grounded Theory: A Practical Guide through Qualitative Analysis. London: Sage Publications; 2006.
40. Jennings BM. Qualitative analysis: a case of software or "peopleware"? Res Nurs Health 2007 Oct;30(5):483-484. [doi: 10.1002/nur.20238] [Medline: 17893929]
41. Eng L, Pringle D, Su J, Shen X, Mahler M, Niu C, et al. Patterns, perceptions, and perceived barriers to physical activity in adult cancer survivors. Support Care Cancer 2018 Nov;26(11):3755-3763. [doi: 10.1007/s00520-018-4239-5] [Medline: 29808379]
42. Wurz A, St-Aubin A, Brunet J. Breast cancer survivors' barriers and motives for participating in a group-based physical activity program offered in the community. Support Care Cancer 2015 Aug;23(8):2407-2416 [FREE Full text] [doi: 10.1007/s00520-014-2596-2] [Medline: 25605568]
43. Hefferon K, Murphy H, McLeod J, Mutrie N, Campbell A. Understanding barriers to exercise implementation 5-year post-breast cancer diagnosis: a large-scale qualitative study. Health Educ Res 2013 Oct;28(5):843-856 [FREE Full text] [doi: 10.1093/her/cyt083] [Medline: 23969632]
44. Sandlund C, Kane K, Ekstedt M, Westman J. Patients' experiences of motivation, change, and challenges in group treatment for insomnia in primary care: a focus group study. BMC Fam Pract 2018 Jul 09;19(1):111 [FREE Full text] [doi: 10.1186/s12875-018-0798-2] [Medline: 29986651]
45. Husebø AML, Karlsen B, Allan H, Søreide JA, Bru E. Factors perceived to influence exercise adherence in women with breast cancer participating in an exercise programme during adjuvant chemotherapy: a focus group study. J Clin Nurs 2015 Feb;24(3-4):500-510. [doi: 10.1111/jocn.12633] [Medline: 24890796]
46. Hatchett A, Hallam JS, Ford MA. Evaluation of a social cognitive theory-based email intervention designed to influence the physical activity of survivors of breast cancer. Psychooncology 2013 Apr;22(4):829-836. [doi: 10.1002/pon.3082] [Medline: 22573338]
47. Bruggeman-Everts FZ, Wolvers MDJ, van de Schoot R, Vollenbroek-Hutten MMR, Van der Lee ML. Effectiveness of two web-based interventions for chronic cancer-related fatigue compared to an active control condition: results of the. J Med Internet Res 2017 Oct 19;19(10):e336 [FREE Full text] [doi: 10.2196/jmir.7180] [Medline: 29051138]
48. Abrahams HJG, Gielissen MFM, Donders RRT, Goedendorp MM, van der Wouw AJ, Verhagen CAHHVM, et al. The efficacy of Internet-based cognitive behavioral therapy for severely fatigued survivors of breast cancer compared with care as usual: a randomized controlled trial. Cancer 2017 Oct 01;123(19):3825-3834 [FREE Full text] [doi: 10.1002/cncr.30815] [Medline: 28621820]
49. Kuiper AJ, Wolvers MDJ, Vonk D, Hagenbeek A. Untire: an all-embracing self-management eHealth program to cope with cancer-related fatigue. Ecancermedicalscience 2018;12:ed81 [FREE Full text] [doi: 10.3332/ecancer.2018.ed81] [Medline: 29662537]
50. Foster C, Grimmett C, May CM, Ewings S, Myall M, Hulme C, et al. A web-based intervention (RESTORE) to support self-management of cancer-related fatigue following primary cancer treatment: a multi-centre proof of concept randomised controlled trial. Support Care Cancer 2016 Jun;24(6):2445-2453 [FREE Full text] [doi: 10.1007/s00520-015-3044-7] [Medline: 26643072]
51. Yun YH, Lee KS, Kim Y, Park SY, Lee ES, Noh D, et al. Web-based tailored education program for disease-free cancer survivors with cancer-related fatigue: a randomized controlled trial. J Clin Oncol 2012 Apr 20;30(12):1296-1303 [FREE Full text] [doi: 10.1200/JCO.2011.37.2979] [Medline: 22412149]

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52. Brown-Johnson CG, Berrean B, Cataldo JK. Development and usability evaluation of the mHealth Tool for Lung Cancer (mHealth TLC): a virtual world health game for lung cancer patients. Patient Educ Couns 2015 Apr;98(4):506-511 [FREE Full text] [doi: 10.1016/j.pec.2014.12.006] [Medline: 25620075]
53. Payne HE, Lister C, West JH, Bernhardt JM. Behavioral functionality of mobile apps in health interventions: a systematic review of the literature. JMIR Mhealth Uhealth 2015;3(1):e20 [FREE Full text] [doi: 10.2196/mhealth.3335] [Medline: 25803705]
54. Bravata DM, Smith-Spangler C, Sundaram V, Gienger AL, Lin N, Lewis R, et al. Using pedometers to increase physical activity and improve health: a systematic review. JAMA 2007 Nov 21;298(19):2296-2304. [doi: 10.1001/jama.298.19.2296] [Medline: 18029834]
55. Fu MR, Axelrod D, Guth A, Scagliola J, Rampertaap K, El-Shammaa N, et al. A web- and mobile-based intervention for women treated for breast cancer to manage chronic pain and symptoms related to lymphedema: randomized clinical trial rationale and protocol. JMIR Res Protoc 2016 Jan 21;5(1):e7 [FREE Full text] [doi: 10.2196/resprot.5104] [Medline: 26795447]
56. Meyerowitz-Katz G, Ravi S, Arnolda L, Feng X, Maberly G, Astell-Burt T. Rates of attrition and dropout in app-based interventions for chronic disease: systematic review and meta-analysis. J Med Internet Res 2020 Sep 29;22(9):e20283 [FREE Full text] [doi: 10.2196/20283] [Medline: 32990635]
57. Pfammatter AF, Mitsos A, Wang S, Hood SH, Spring B. Evaluating and improving recruitment and retention in an mHealth clinical trial: an example of iterating methods during a trial. Mhealth 2017;3:49 [FREE Full text] [doi: 10.21037/mhealth.2017.09.02] [Medline: 29184901]
58. Fleming T, Bavin L, Lucassen M, Stasiak K, Hopkins S, Merry S. Beyond the trial: systematic review of real-world uptake and engagement with digital self-help interventions for depression, low mood, or anxiety. J Med Internet Res 2018 Jun 06;20(6):e199 [FREE Full text] [doi: 10.2196/jmir.9275] [Medline: 29875089]
59. Druce KL, Dixon WG, McBeth J. Maximizing engagement in mobile health studies: lessons learned and future directions. Rheum Dis Clin North Am 2019 May;45(2):159-172 [FREE Full text] [doi: 10.1016/j.rdc.2019.01.004] [Medline: 30952390]

Abbreviations

COREQ: Consolidated Criteria for Reporting Qualitative Studies
mHealth: mobile health
QoL: quality of life

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Original Paper

Effects and Implementation of a Mindfulness and Relaxation App for Patients With Cancer: Mixed Methods Feasibility Study

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Abstract

Background: Cancer diagnosis and cancer treatment can cause high levels of distress, which is often not sufficiently addressed in standard medical care. Therefore, a variety of supportive nonpharmacological treatments have been suggested to reduce distress in patients with cancer. However, not all patients use these interventions because of limited access or lack of awareness. To overcome these barriers, mobile health may be a promising way to deliver the respective supportive treatments.

Objective: The aim of this study is to evaluate the effects and implementation of a mindfulness and relaxation app intervention for patients with cancer as well as patients' adherence to such an intervention.

Methods: In this observational feasibility study with a mixed methods approach, patients with cancer were recruited through the web and through hospitals in Switzerland. All enrolled patients received access to a mindfulness and relaxation app. Patients completed self-reported outcomes (general health, health-related quality of life, anxiety, depression, distress, mindfulness, and fear of progression) at baseline and at weeks 4, 10, and 20. The frequency of app exercise usage was gathered directly through the app to assess the adherence of patients. In addition, we conducted interviews with 5 health professionals for their thoughts on the implementation of the app intervention in standard medical care. We analyzed patients' self-reported outcomes using linear mixed models (LMMs) and qualitative data with content analysis.

Results: A total of 100 patients with cancer (74 female) with a mean age of 53.2 years (SD 11.6) participated in the study, of which 25 patients used the app regularly until week 20. LMM analyses revealed improvements in anxiety (P=.04), distress (P<.001), fatigue (P=.01), sleep disturbance (P=.02), quality of life (P=.03), and mindfulness (P<.001) over the course of 20 weeks. Further LMM analyses revealed a larger improvement in distress (P<.001), a moderate improvement in anxiety (P=.001), and a larger improvement in depression (P=.03) in patients with high levels of symptoms at baseline in the respective domains. The interviews revealed that the health professionals perceived the app as a helpful addition to standard care. They also made suggestions for improvements, which could facilitate the implementation of and adherence to such an app.

Conclusions: This study indicates that a mindfulness and relaxation app for patients with cancer can be a feasible and effective way to deliver a self-care intervention, especially for highly distressed patients. Future studies should investigate if the appeal of the app can be increased with more content, and the effectiveness of such an intervention needs to be tested in a randomized controlled trial.

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KEYWORDS

mobile app; mobile phone; mindfulness; relaxation; cancer; qualitative research; implementation science; mHealth; evaluation study; patient compliance; patient participation; patient preference

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Introduction

Background

Cancer diagnosis and subsequent medical treatments can cause high levels of distress [1-4]. However, adequate psychological support for patients with cancer is often lacking in standard medical care [5,6]. Therefore, a variety of supportive treatments have been suggested to reduce distress in patients with cancer, such as mind-body medicine (MBM) [7]. MBM combines various effective treatments such as mindfulness meditation, relaxation, yoga, and tai chi [7,8]. Such MBM treatments can have beneficial effects on cancer-related symptoms, such as pain, fatigue, and sleep disturbance [9-11]. Furthermore, MBM treatments can have beneficial effects on the quality of life of patients with cancer [12-14]. These treatments can be provided through guided MBM programs for patients with cancer, where the patients learn various exercises (eg, physical exercises, relaxation, and stress reduction) and are encouraged to practice these newly learned exercises at home [15,16].

However, the uptake of supportive treatments in distressed patients with cancer is moderate [17]. Barriers for the uptake of such treatments include stigmatization, unawareness of such interventions, or limited access [18,19]. This is problematic because untreated, elevated levels of distress can lead to additional negative effects, such as reduced quality of life, daily functioning, and lower adherence to medical treatment [20,21]. Access can be restricted, for instance, because of geographical distance, lack of treatment providers or knowledge thereof, and financial constraints [22-24]. To overcome these limitations in access, eHealth and mobile health (mHealth) interventions have been proposed. eHealth is defined more broadly as the delivery of health services or information through the internet and related technologies [25], whereas mHealth uses mobile technologies such as smartphones for the delivery of health services [26]. So far, research indicates that eHealth interventions with mindfulness or relaxation components can have beneficial effects on health outcomes in various patient populations [27-29]. However, eHealth studies focusing on patients with cancer have shown inconsistent results [30,31]. Nonetheless, eHealth interventions seem promising because they can have positive effects on the well-being of patients with cancer [31].

Although mHealth interventions have some advantages over web-based eHealth interventions (eg, more flexible access because of mobility, the possibility of reaching a large number of patients because of the large popularity of smartphones), little is known about the best practices for the implementation of mHealth interventions [32,33]. In addition, mHealth research so far indicates that the adoption of mHealth interventions by health professionals and patients can be inhibited by various factors, such as perceived usefulness and ease of use [34,35]. Furthermore, there is a lack of mHealth studies with mindfulness or relaxation-based interventions [27]. Therefore, we developed a research app to conduct a feasibility study of a mindfulness- and relaxation-based mHealth intervention for patients with cancer [36]. The app included 3 exercises, namely, mindfulness meditation, guided imagery, and progressive muscle relaxation.

Objectives

The aim of this study is to assess the feasibility of this mHealth intervention using the Reach, Effectiveness, Adoption, Implementation, and Maintenance (RE-AIM) evaluation framework, which was developed for the evaluation of public health interventions [37]. Although the results for the reach of the dimensions, adoption over the course of 10 weeks, and maintenance were published elsewhere [36], the present analyses focus on the 3 dimensions of effectiveness, adoption, and implementation over the course of 20 weeks to assess the pre-post effects of the app on a variety of health outcomes and adherence to the app intervention. In doing so, we investigate whether such an app may be a beneficial, supportive care tool for patients with cancer.

Methods

Study Design

For this feasibility study, we used a mixed methods approach. For quantitative data, we assessed 4 paper-and-pencil questionnaires that were sent to patients with cancer at baseline and at weeks 4, 10, and 20. Demographics and patient characteristics were assessed at baseline, and health outcomes (physical, mental, and social health, health-related quality of life, anxiety, depression, distress, mindfulness, and fear of progression) were assessed over the 4 time points. Qualitative data consisted of semistructured interviews with 5 health professionals. In those interviews, we inquired about health professionals' perspectives on a mindfulness- and relaxation-based mHealth intervention for patients with cancer and its implementation in standard medical care. To receive feedback from different health professionals, we conducted 2 face-to-face group interviews (1 interview with 2 nursing experts and the second interview with 2 psychologists providing MBM treatment for patients with cancer) and 1 individual interview with an oncologist. All interviewees received access to the app before the interview and could test the app. The interviewer also demonstrated the app and its content to the interviewees before the interview started.

To assess the feasibility of our mHealth intervention, we used the RE-AIM implementation science framework [37]. Ethical approval for the study was granted in April 2016 by the cantonal ethics committee Zurich (BASEC-Nr. 2016-00258), and we registered the study in the German Clinical Trials Register (DRKS00010481).

Participants

Patients were eligible if they (1) had any cancer diagnosis at any stage of cancer, (2) were aged 18 years or older, and (3) owned either an iPhone (Apple Inc). or an Android-based smartphone with at least a weekly connection to the internet. Patients were excluded if they had suicidal ideation or insufficient German language skills, if they intended to move to another country, or if they had insufficient knowledge on how to use a smartphone. The patient recruitment process is described in detail elsewhere [36]. For the interviews with health professionals, we invited experts (an oncologist, nursing experts,

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and psychologists) from the University Hospital Zurich, who provide health care for patients with cancer.

App Intervention

All enrolled patients received the mindfulness and relaxation app, which was specifically developed for this study and only available for patients participating in the study. The app could be downloaded in the Apple iTunes store and Google Play Store for Android devices and accessed with a code, which was provided to the patients after study inclusion. The app offered 3 exercises: mindfulness meditation, guided imagery, and progressive muscle relaxation. The exercises were included in the app as audio files with a duration of approximately 15 minutes each, and the patients could choose between a female or male narrator. Patients were free to choose which exercises they wanted to use and how often they wanted to practice. However, we recommended to the patients to use an exercise of their choice on a daily basis, ideally 5 times per week. To help patients practice regularly, the app included an optional notification feature that patients could set up to receive a daily push notification on the mobile device, reminding them to practice at an individually set time. Information about the use of exercises (exercise type, date, and start and end times) was saved in the backend and was only accessible to the researchers as an XML log file. More information about the app is presented in a previously published paper [36].

Outcomes

Effects

As we conducted a single-arm study without a control group, we were not able to assess the effectiveness of the app intervention. Therefore, for the RE-AIM dimension effectiveness, we looked into pre-post effects in a variety of health outcomes relevant to patients with cancer. We assessed physical, mental, and social health using the Patient-Reported Outcomes Measurement Information System (PROMIS 29) [38]. PROMIS 29 is a 29-item scale assessing 7 health domains: physical function (Cronbach α=.81), fatigue (Cronbach α=.94), pain interference (Cronbach α=.96), depressive symptoms (Cronbach α=.85), anxiety (Cronbach α=.81), ability to participate in social roles and activities (Cronbach α=.88), and sleep disturbance (Cronbach α=.86) with 4 items, each on a 5-point scale, and pain intensity with a single item on a 10-point numeric rating scale.

For the assessment of health-related quality of life for patients with cancer, we administered the Functional Assessment of Cancer Therapy—General (FACT-G) [39,40]. The FACT-G consists of 4 subscales: physical well-being (Cronbach α=.85), social well-being (Cronbach α=.76), emotional well-being (Cronbach α=.70), and functional well-being (Cronbach α=.79), measured with 27 items on a 5-point scale. A higher score indicates a better quality of life.

For the assessment of distress, we administered the Distress Thermometer [41]. The Distress Thermometer is a numeric rating scale, ranging from 0 to 10. A score of 5 or higher is considered to indicate clinically relevant distress [42].

For the assessment of mindfulness, we administered the short version of the Freiburg Mindfulness Inventory (FMI) [43]. The FMI (Cronbach α=.87) assesses mindfulness with 14 items on a 4-point scale, with a higher score indicating higher mindfulness.

We measured anxiety and depression using the Hospital Anxiety and Depression Scale (HADS). The HADS assesses 7 items for the subscales anxiety (Cronbach α=.79) and depression (Cronbach α=.67) on a 4-point scale, with a maximum score of 21 for each subscale. A score of up to 7 is considered normal, a score between 8 and 11 is considered borderline, and a score above 11 is considered caseness [44].

For the assessment of fear of progression, we administered the Fear of Progression Questionnaire-Short Form (FoP-Q-SF) [45]. The FoP-Q-SF (Cronbach α=.81) consists of 12 items with a 5-point scale. A higher score indicates a greater fear of progression.

We assessed PROMIS 29, FACT-G, and FMI at baseline and at weeks 4, 10, and 20 and HADS, FoP-Q-SF, and Distress Thermometer at baseline and at weeks 10 and 20. We defined a continuous app user as a patient who regularly used the app exercises (at least one exercise per week). We counted an exercise as completed if the patient played the exercise audio file for at least 10 minutes of the total time of 15 minutes. We defined an intervention dropout as a patient who stopped using the exercises for 4 consecutive weeks because regular practice might be a prerequisite for a beneficial intervention. We defined the first week when the patient stopped using the exercises as a dropout week. A patient who never used an app exercise was counted as a week 1 intervention dropout.

Adoption

For the RE-AIM dimension adoption, we looked at the number of completed app exercises over 20 weeks and app exercise preferences. We reported the median of completed app exercises by all enrolled patients per week as well as the median of completed app exercises by continuous app users. For exercise preferences, we reported frequencies of used exercises for all enrolled patients, stratified by gender of the patient and the narrator.

Implementation

For the RE-AIM dimension implementation, we reported results from interviews with health professionals regarding their opinion on the implementation of the app intervention in addition to standard medical care. In the interviews, we inquired about the general impression regarding the app, implementation of the app as an addition to standard medical care, and suggestions for improvements.

Sample Size

One aspect evaluated in our feasibility study was the characteristics and number of patients with cancer who participated in the study (evaluation dimension reach), which was reported previously [36]. Therefore, we did not perform an a priori analysis to determine the required sample size for adequate power. However, we aimed to recruit at least 100 patients, which is sufficient to achieve 80% power for a

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two-tailed *t* test with an α level set at .05 and a small effect size of Cohen *d* of 0.28.

Data Analysis

Quantitative Data

All printed case report forms were entered by trained researchers into the electronic database REDCap (Research Electronic Data Capture), which was hosted at the University Hospital Zurich. All analyses were carried out in SPSS version 25.0 (IBM Corp).

For baseline characteristics of patients, we used descriptive statistics (frequencies and percentages for categorical variables and mean and SD for continuous variables). For the analyses of pre-post effects, we used linear mixed models (LMMs) to analyze changes over time (baseline, week 4, week 10, and week 20) in health outcomes as well as differences between continuous app users and intervention dropouts in health outcomes. All patients who provided baseline data were included in the analyses, and because we used LMMs, patients with missing data in weeks, 4, 10, and 20 questionnaires were included. The dependent variables were the 7 PROMIS 29 domains, FACT-G, HADS subscales anxiety and depression, Distress Thermometer, FMI, and FoP-Q-SF. Furthermore, we looked at the changes in the respective health outcomes for subsamples with high distress (Distress Thermometer score ≥5), high anxiety (HADS anxiety score of ≥8), and high depression (HADS depression score of ≥8). As a covariance type, we used an autoregressive covariance structure (AR1). Time was included as a fixed effect. For group analyses, (continuous app users vs intervention dropouts), we added group and time-by-group as fixed effects. Hedge *g* effect sizes were calculated as mean differences (baseline and week 20) divided by pooled SDs for each health outcome of interest.

Qualitative Data

For the dimension implementation, we recorded the interviews and transcribed the interviews verbatim. We used thematic coding for structuring the interviews using MAXQDA 11 (VERBI Software), and we used content analysis according to Mayring [46].

Results

Patient Characteristics

Between June 2016 and December 2018, we were able to recruit 100 patients with cancer, all of whom provided baseline information. At week 20, 72 (72%) patients completed questionnaire 4 (Figure 1). Baseline characteristics of all enrolled patients (N=100) as well as subsamples of patients with high distress (62/100, 62%), high anxiety (35/100, 26%), and high depression (20/100, 20%) are summarized in Table 1. Most patients (74/100, 74%) were female. The mean age of all patients was 53.24 (SD 11.55) years, ranging from 23 to 84 years. Patients predominantly owned an iPhone smartphone (67/100, 67%), whereas 30 patients (30/100, 30%) owned an Android smartphone, and a few (3/100, 3%) owned both.

Figure 1. Flowchart.

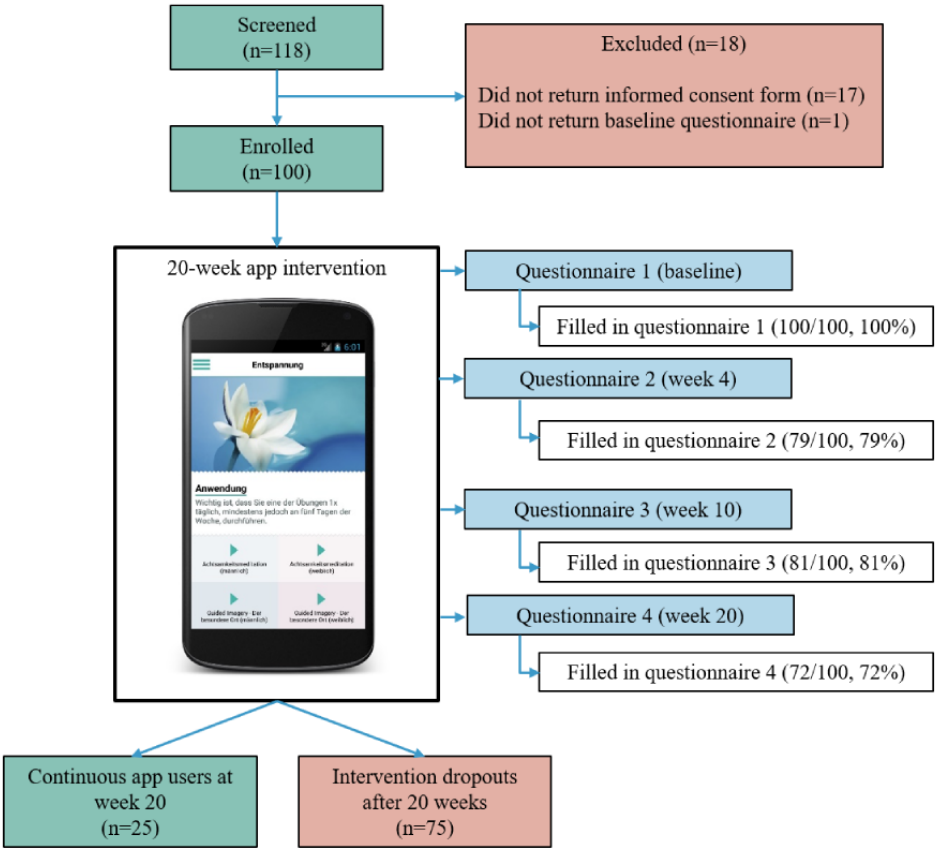

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Table 1. Demographics for the total sample and high distress, high depression, and high anxiety subsamples.

Patient demographics	Total sample (N=100)	High distress[a] subsample (n=62)	High anxiety[b] subsample (n=35)	High depression[c] subsample (n=20)
Gender, n (%)				
Female	74 (74)	48 (77)	26 (74)	15 (75)
Male	26 (26)	14 (23)	9 (26)	5 (25)
Age (years), mean (SD)	53.24 (11.55)	52.74 (10.67)	51.22 (10.67)	51.74 (11.63)
Type of cancer, n (%)				
Breast cancer	39 (39)	27 (44)	18 (51)	8 (40)
Colon cancer	9 (9)	7 (11)	2 (6)	3 (15)
Ovarian or cervical cancer	6 (6)	3 (5)	2 (6)	0 (0)
Lung cancer	6 (6)	3 (5)	0 (0)	1 (5)
Others	40 (40)	22 (35)	13 (37)	8 (40)
Status of cancer treatment, n (%)				
Total removal	46 (46)	33 (53)	24 (69)	11 (55)
Recurrence or incomplete removal	25 (25)	15 (24)	6 (17)	5 (25)
Uncertain	3 (3)	1 (2)	1 (3)	2 (10)
Other	26 (26)	13 (21)	4 (11)	4 (20)
Highest education, n (%)				
Primary school	3 (3)	2 (3)	2 (6)	0 (0)
Apprenticeship	22 (22)	16 (26)	5 (14)	5 (25)
Secondary education	41 (41)	21 (34)	14 (40)	7 (35)
University degree	33 (33)	22 (35)	14 (40)	7 (35)
Unknown	1 (1)	1 (2)	0 (0)	1 (5)

[a]Distress Thermometer score ≥5.

[b]Hospital Anxiety and Depression Scale anxiety score ≥8.

[c]Hospital Anxiety and Depression Scale depression score ≥8.

Effects

The health outcome values at baseline and at week 20 as well as effect sizes for the total sample and the high distress, high anxiety, and high depression subsamples are presented in Table 2. Baseline distress was 5.29 (SD 2.31); therefore, patients were on average above an assumed clinically relevant threshold of 5, with 62% of patients (62/100) reporting a distress level of 5 or higher. At week 20, distress decreased to an average of 4.1 (SD 2.12; Hedge g=0.53). The mean HADS anxiety score at baseline was 6.88 (SD 3.50) and dropped to 6.31 (SD 3.78; Hedge g=0.16) at week 20. Overall, 35% (35/100) of patients reported an elevated HADS anxiety score (≥8) at baseline (mean 10.71, SD 1.95), which dropped to 8.85 (SD 3.50; Hedge g=0.68) at week 20. For HADS depression, the mean score at baseline was 4.96 (SD 2.78) and dropped to 4.55 (SD 3.31; Hedge g=0.14) at week 20. Overall, 20% (20/100) of patients reported an elevated HADS depression score (≥8) at baseline (mean 9.00, SD 1.12), which dropped to 8.85 (SD 3.50; Hedge g=0.61) at week 20. For the remaining measures without a proposed threshold (PROMIS, FACT-G, FMI, and FoP-Q-SF), changes from baseline to week 20 were small, with Hedges g effect sizes ranging from 0.04 to 0.33.

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Table 2. Mean values of health outcomes at baseline and week 20, response rate (n), and effect sizes (N=100).

Sample and outcome	Baseline		Week 20		Hedges *g* (95% CI)
	Mean (SD)	n	Mean (SD)	n	
Total sample					
HADS[a] anxiety	6.88 (3.50)	99	6.31 (3.78)	71	−0.16 (−0.46 to 0.15)
HADS depression	4.96 (2.78)	100	4.55 (3.31)	71	−0.14 (−0.44 to 0.17)
Distress	5.29 (2.31)	99	4.10 (2.12)	71	−0.53 (−0.84 to 0.22)
PROMIS physfunct[b]	46.55 (6.54)	99	46.30 (7.32)	71	−0.04 (−0.34 to 0.27)
PROMIS anxiety[c]	55.97 (6.46)	99	55.01 (6.83)	70	−0.15 (−0.45 to −0.16)
PROMIS depression[d]	55.20 (6.81)	100	53.88 (7.81)	71	−0.18 (−0.49 to 0.12)
PROMIS fatigue[e]	56.11 (9.23)	99	52.40 (10.31)	70	−0.38 (−0.69 to −0.07)
PROMIS sleep[f]	51.44 (8.85)	100	49.52 (8.02)	70	−0.23 (−0.53 to 0.08)
PROMIS social[g]	48.42 (7.64)	99	49.84 (7.87)	71	0.18 (−0.12 to 0.49)
PROMIS pain[h]	52.88 (9.10)	97	51.96 (9.38)	70	0.10 (−0.41 to 0.21)
FACT-G[i]	75.54 (13.85)	99	79.62 (14.81)	70	0.29 (−0.02 to 0.59)
FMI[j]	38.46 (6.62)	96	41.80 (6.42)	69	0.51 (−0.20 to 0.83)
FoP[k]	31.33 (7.83)	93	30.28 (7.99)	64	−0.13 (−0.45 to 0.19)
High distress[l]					
Distress	6.79 (1.36)	62	4.39 (2.19)	46	−1.36 (−1.79 to −0.94)
High anxiety[m]					
HADS anxiety	10.71 (1.95)	35	8.85 (3.50)	26	−0.69 (−1.20 to −0.16)
High depression[n]					
HADS depression	9.00 (1.12)	20	7.47 (3.52)	17	−0.61 (−1.27 to 0.05)

[a]HADS: Hospital Anxiety Depression Scale; negative effect=improvement.

[b]PROMIS physfunct: Patient-Reported Outcomes Measurement Information System Physical Function; positive effect=improvement.

[c]PROMIS anxiety: Patient-Reported Outcomes Measurement Information System Anxiety; negative effect=improvement.

[d]PROMIS depression: Patient-Reported Outcomes Measurement Information System Depression; negative effect=improvement.

[e]PROMIS fatigue: Patient-Reported Outcomes Measurement Information System Fatigue; negative effect=improvement.

[f]PROMIS sleep: Patient-Reported Outcomes Measurement Information System Sleep Disturbance; negative effect=improvement.

[g]PROMIS social: Patient-Reported Outcomes Measurement Information System Ability to Participate in Social Roles and Activities; positive effect=improvement.

[h]PROMIS pain: Patient-Reported Outcomes Measurement Information System Pain Interference; negative effect=improvement.

[i]FACT-G: Functional Assessment of Cancer Therapy—General; positive effect=improvement.

[j]FMI: Freiburg Mindfulness Inventory; positive effect=improvement.

[k]FoP: Fear of Progression; negative effect=improvement.

[l]Distress Thermometer score ≥5; negative effect=improvement; n=62.

[m]HADS anxiety score ≥8; negative effect=improvement; n=35.

[n]HADS depression score ≥8; negative effect=improvement; n=20.

The results for effects over time are presented in Table 3. LMM analyses revealed that there was a significant decrease over time in distress (P<.001), fatigue (P=.01), sleep disturbance (P=.02), and anxiety (P=.04) measured with the HADS. Furthermore, there was a significant increase in quality of life (P=.03) and mindfulness (P<.001). No significant effects were found for physical functioning, anxiety measured with PROMIS, depression, ability to participate in social roles and activities, and fear of progression. LMM analyses for the subsamples revealed that distress decreased significantly in the high distress subsample (P<.001), anxiety decreased significantly in the high anxiety subsample (P=.001), and depression decreased significantly in the high depression subsample (P=.03). Dose-response analyses using LMMs with group-by-time revealed no significant results.

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Table 3. Linear mixed models: estimates of fixed effect of time on health outcomes from baseline to week 20.

Sample and dependent variable	Estimates of fixed effects (time)		
	Estimate (95% CI)	*t* test (*df*)	*P* value
Total sample (N=100)			
HADS[a] anxiety	−0.40 (−0.79 to −0.01)	−2.04 (201.95)	.04
HADS depression	−0.29 (−0.62 to 0.04)	−1.71 (206.42)	.09
Distress	−0.41 (−0.62 to −0.21)	−3.96 (325.86)	<.001
PROMIS physfunct[b]	−0.13 (−0.68 to 0.43)	−.45 (318.35)	.66
PROMIS anxiety[c]	−0.46 (−1.09 to 0.18)	−1.42 (325.74)	.16
PROMIS depression[d]	−0.52 (−1.11 to 0.07)	−1.72 (324.81)	.09
PROMIS fatigue[e]	−1.15 (−2.02 to −0.28)	−2.61 (324.73)	.01
PROMIS sleep[f]	−0.85 (−1.55 to −0.15)	−2.39 (322.65)	.02
PROMIS social[g]	0.43 (−0.15 to 1.01)	1.45 (314.63)	.15
PROMIS pain[h]	−0.14 (−0.94 to 0.66)	−.34 (322.51)	.74
FACT-G[i]	1.13 (0.10 to 2.15)	2.16 (307.58)	.03
FMI[j]	1.11 (0.62 to 1.59)	4.46 (300.46)	<.001
FoP[k]	−0.68 (−1.56 to .20)	−1.52 (180.05)	.13
High distress[l] (n=62)			
Distress	−0.81 (−1.05 to −0.57)	−6.64 (200.45)	<.001
High anxiety[m] (n=35)			
HADS anxiety	−1.13 (−1.77 to −0.48)	−3.47 (81.69)	.001
High depression[n] (n=20)			
HADS depression	−0.87 (−1.65 to −0.09)	−2.23 (47.99)	.03

[a]HADS: Hospital Anxiety Depression Scale.
[b]PROMIS physfunct: Patient-Reported Outcomes Measurement Information System Physical Function.
[c]PROMIS anxiety: Patient-Reported Outcomes Measurement Information System Anxiety.
[d]PROMIS depression: Patient-Reported Outcomes Measurement Information System Depression.
[e]PROMIS fatigue: Patient-Reported Outcomes Measurement Information System Fatigue.
[f]PROMIS sleep: Patient-Reported Outcomes Measurement Information System Sleep Disturbance.
[g]PROMIS social: Patient-Reported Outcomes Measurement Information System Ability to Participate in Social Roles and Activities.
[h]PROMIS pain: Patient-Reported Outcomes Measurement Information System Pain Interference.
[i]FACT-G: Functional Assessment of Cancer Therapy—General.
[j]FMI: Freiburg Mindfulness Inventory.
[k]FoP: Fear of Progression.
[l]Distress Thermometer score ≥5.
[m]HADS anxiety score ≥8.
[n]HADS depression score ≥8.

Adoption

According to our definition, 25% (25/100) of all enrolled patients used the app continuously (ie, at least one completed exercise per week) at week 20 of the intervention. The average number (median) of completed exercises during the 20-week intervention for all patients as well as continuous app users is presented in Figure 2. Across all patients, the median of completed exercises was 2 during the first week and dropped to 0 at week 9. For continuous app users, who completed an app exercise at least once per week until week 20, the median of completed exercises at week 1 was 6. For the subsequent weeks up to week 20, the median of completed exercises varied between a median of 3 and 5 for the continuous app users.

The percentage of completed exercises is presented in Figure 3. All patients together completed 3526 exercises. Mindfulness meditation was used most often, with a total of 1633 completed

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exercises (46.31%), followed by guided imagery with 1077 completed exercises (30.55%). Progressive muscle relaxation was used least frequently, with 816 completed exercises (23.14%). In both mindfulness meditation and guided imagery, the female narrator voice was preferred.

Furthermore, female patients showed a preference for exercises with a female narrator (1935 completed exercises with a female narrator vs 1031 completed exercises with a male narrator). However, male patients preferred exercises with a male narrator (389 completed exercises with a male narrator vs 171 completed exercises with a female narrator). The probability of choosing the same sex in audio files is therefore increased for women by 87% and for men by 127%, which corresponds to a 2-fold higher preference for the same sex as the narrator.

Figure 2. Completed app exercises by all enrolled patients (N=100) and by continuous app users (n=25) per week (median).

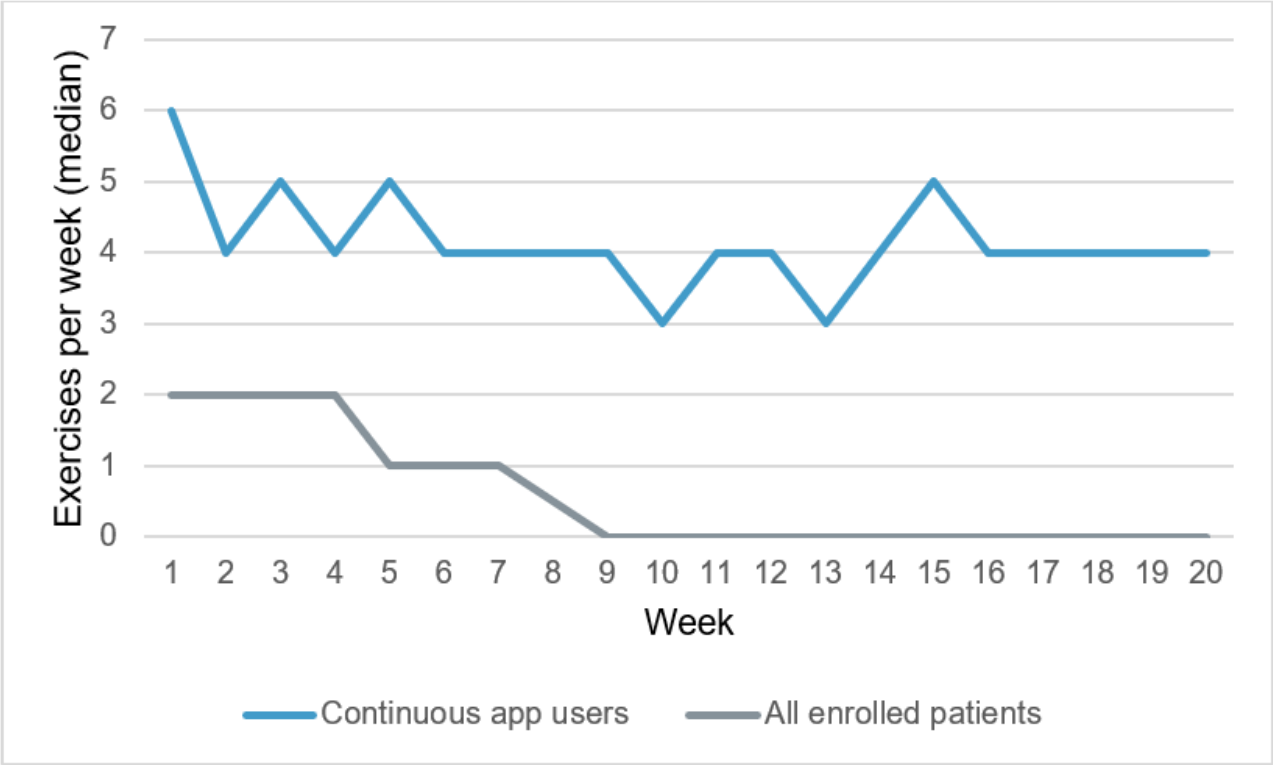
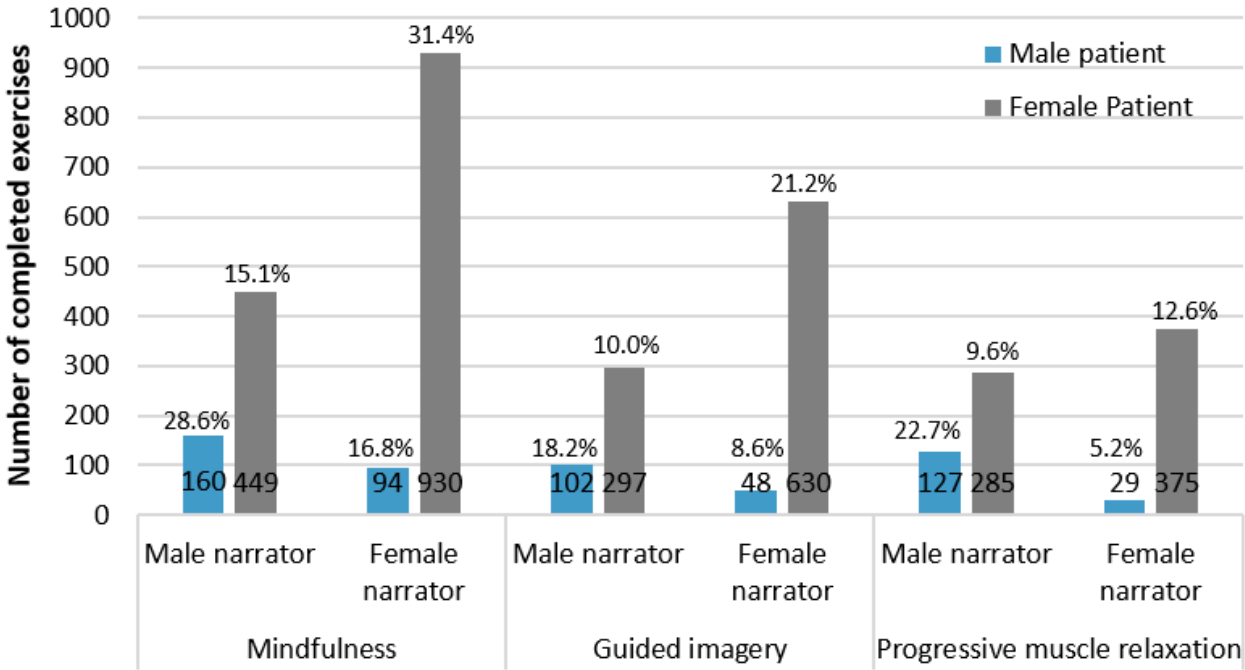


Figure 3. Completed exercises (3526) of all patients (N=100) over 20 weeks by type (mindfulness meditation, guided imagery, and progressive muscle relaxation), gender of patient (male and female), and sex of narrator (male and female). Percentages refer to the total number of exercises per gender.



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Implementation

A total of 5 health professionals took part in an interview: 2 female nursing experts (one from an inpatient unit and the other from an outpatient oncology unit), 2 female MBM psychologists, and 1 male oncologist. Interviews were conducted between January and March 2018 and lasted for an average of 45 minutes (SD 9.54). The qualitative analysis of the interviews yielded 4 themes: (1) general impression of the app, (2) suggestions for improvement, (3) implementation in standard care, and (4) experience with recommending the app to patients.

Overall, the general impression of the app was positive. For instance, the oncologist summarized his impression of the app as follows:

> *I think [the app] is a very helpful thing because it is relatively easy [to use]. You can test it. You can try it and if you like it, you can integrate it relatively easy into everyday life. I think it is very practical. It is a practical thing and if patients are interested, I also see that they take it up willingly.*

All health professionals perceived the app as appealing, clearly structured, and as a helpful supportive tool. In addition, the MBM psychologists liked the app as an addition to the 10-week face-to-face MBM course and appreciated the app as a good self-help tool complementing the course. The oncologist also stated that many patients with cancer look for something they can use to add to standard care and an app can provide a low threshold aid. As a negative aspect, a nursing expert stated that a smartphone is required and not every patient possesses such a device.

All health experts made various suggestions for improving the app. A shared opinion was that the content of the app (ie, number and variety of exercises) could be increased, as over an extended period, patients might get bored with a choice limited to 3 exercises. A nursing expert suggested that a new exercise could, for instance, be unlocked after completing the same exercise several times. An MBM psychologist suggested that every week, a different selection of exercises could be activated with alternating topics such as meditation, relaxation, self-compassion, or body exercises. In addition, the inclusion of exercises with different degrees of complexity was suggested. An MBM psychologist stated that exercises for beginners (eg, more detailed instructions, fewer moments of silence) as well as exercises for patients experienced in mindfulness and relaxation could be added. MBM psychologists and nursing experts also recommended that some exercises should be accompanied by soothing background music because longer periods of silence might be uncomfortable for some patients. They also recommended exercises with various lengths of time so that patients had more flexibility if they were facing time constraints or if they were too impatient for longer exercises. The oncologist mentioned that adding exercises specifically for sleep disorders might be a good addition to the app, especially for inpatients, because poor sleep in hospitals is very common. As an additional topic that could be added, he mentioned body exercises such as yoga. An MBM psychologist mentioned that an app mirroring the MBM course more closely would be great:

> *If I could make a wish, then I would say, it would be totally cool to have an accompanying Mind Body Medicine app. That is to say that a lot of exercises—not all of them—but a lot of exercises we do [could be added to the app]. Possibly also guided body exercises. That would be totally cool.*

The interviewees mentioned several factors that could influence the implementation of a mindfulness- and relaxation-based app into standard care. Both nursing experts and one of the MBM psychologists stated that the time point when the information of the app is delivered to the patient might be important. These health professionals mentioned that the patients were bombarded with information during the first consultation or during the first day when a patient enters the hospital and additional information about the app might overwhelm some patients. The outpatient nursing expert also mentioned that they are often limited because of time constraints during consultation hours:

> *On the one hand there are the concerns of the patients, which you have to discuss. But you also have a little bit of pressure, [to tell them] all relevant information. [...] And sometimes it's already two minutes before the end [of the consultation]. [...] And you can't just hand out the flyer. You also need to say a few words [about the app] and that's why I sometimes forgot [to mention the app]. Due to shortage of time.*

The nursing experts also mentioned that the nurses oftentimes forgot about the app because it is not part of standard care. Therefore, the nursing experts stated that it might be helpful to better inform the nurses about the app and setting up standards regarding the communication about the app, for example, when to inform the patients and how. In addition, the nursing experts stated that it might be helpful if they had a demonstration device at the oncology unit so that they could better explain the app to the patients. All interviewed health professionals further mentioned that patients with cancer are very diverse and that although some patients are very eager to try out various treatments, others are not. One MBM therapist also stated that not all patients perceive relaxation as important and that those patients might need some additional information which indicates why relaxation is good for them. All health professionals also stated that implementing such an app does not result in a lot of additional work for them and they appreciate the app, which they could recommend to suitable patients.

Regarding their experience with recommending the app to patients, health professionals shared the opinion that female patients are more drawn to mindfulness and relaxation exercises. Furthermore, the MBM therapists stated that patients who already practiced some form of relaxation or meditation often did not participate in the study. The MBM therapists also noticed that the composition of the MBM group had an influence on how many patients were willing to try out the app. For instance, if one patient was very motivated and expressed interest in the app, hesitant patients sometimes followed suit and were willing to try the app as well. One MBM therapist also noticed that many older people were willing to use the app:

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I was surprised that so many older patients had the app on their phone and also used the app regularly [...]. I had the impression, that it appeals to the young. [...]. But oftentimes, the older people have more time, because they don't work anymore.

Discussion

Principal Findings

In this study, we explored the feasibility of a mindfulness- and relaxation-based self-help app for patients with cancer. To evaluate the feasibility, we used the RE-AIM framework [37], and in this analysis, we focused on the framework dimensions effectiveness, adoption, and implementation. Our findings support the feasibility of this mHealth intervention. The results indicate that the intervention might have beneficial effects on patients' distress and quality of life. Furthermore, the mHealth intervention is accepted by the target population as well as by health professionals.

For the dimension effectiveness, we looked into pre-post effects. Our results suggest that the app might have the potential to reduce distress, fatigue, sleep disturbance, and anxiety as well as improve health-related quality of life and mindfulness. This is in line with a recent pilot study [47], in which a mobile mindfulness-based stress reduction program improved, among others, stress, anxiety, depression, sleep quality, quality of life, and mindfulness in patients with breast cancer with small to large effects. Furthermore, a recent randomized controlled trial conducted by Kubo et al [48] assessed the feasibility of a commercially available mindfulness program in which they targeted patients with cancer and their caregivers. This program leads to an increase in quality of life in patients with cancer with a medium effect size [48]. Similar to these findings, Rosen et al [49] reported that the quality of life of patients with breast cancer improved with a small effect size using a commercially available mindfulness course when compared with a control group.

As depressive symptoms and anxiety were not significantly reduced in the total sample in our study, we also looked at subsamples with higher HADS scores. In the high anxiety and high depression subsamples, anxiety and depression, respectively, decreased significantly over time. This might indicate that a mindfulness and relaxation mHealth intervention is especially beneficial for patients with cancer with higher emotional distress. This is also in line with a study by Barth et al [50], where highly distressed patients benefited most from psycho-oncological interventions. However, we did not find any group effects when comparing continuous app users with intervention dropouts. This might indicate that our definition of users and dropouts is not precise enough or that another variable than time spent practicing is responsible for changes in outcomes.

For adoption, our results showed that at week 20 of the intervention, 25 of 100 patients were using the app continuously. With 54 of 100 continuous app users at week 10 [36], this leads to a dropout rate of approximately 50% every 10 weeks. The 25 continuous app users practiced on average 3 to 5 times per week (median), which comes close to our initially stated recommendation of 5 exercises per week. We consider this a good adoption of the mHealth intervention because the intervention was set up as a self-care intervention without the involvement of a therapist or health professional. Mindfulness was the preferred exercise, followed by guided imagery and progressive muscle relaxation. However, mindfulness meditation exercises were also presented as the first choice in the app, whereas guided imagery was placed at the second position, and progressive muscle relaxation was placed at the third position. Therefore, the preference for mindfulness meditation could also be caused by the placement of the exercises in the app. These results regarding adoption are comparable with those of a study conducted by Kubo et al [48], in which patients with cancer received access to the commercially available mindfulness app Headspace (TM). In this study, 40 of 54 patients with cancer allocated to the intervention group completed the 8-week study, and 20 patients with cancer used the app on at least 50% of the days [48].

The results from the interviews with health professionals provide some insights into the implementation of a mindfulness and relaxation mHealth intervention into standard care. In general, all interviewed health professionals perceived the app as a helpful addition to standard care. The health professionals also suggested some improvements, which might increase the acceptance and long-term use of such mHealth interventions by patients. A suggested improvement shared by all health professionals is the increase in the content of the app, such as additional exercises or variations of the exercises. A statement about the implementation of the mHealth intervention given by several health professionals was the adequate provision of information. One of the interviewed MBM psychologists as well as the nursing experts stated that patients with cancer are, on the one hand, flooded with information, especially when they start their treatment. However, the provision of some information to the patients about a mHealth intervention is necessary, at least to let the patients know about the existing intervention. On the other hand, nursing experts also mentioned that nurses often forgot about the intervention, although they approve this kind of intervention. Therefore, a standardized procedure for informing patients about the mHealth intervention might facilitate the implementation of the intervention. In addition, health professionals such as nurses might have to be informed regularly about such interventions because it is not part of their standard treatment; therefore, they might forget about it, as seen in this study. Regarding the recruitment process, the health professionals made the observation that female patients were more interested in this mHealth intervention. This is also reflected by the gender ratio in this study's sample, with 76 female and 24 male patients with cancer, which is typical for complementary and alternative treatments [51-53]. This gender difference raises the question of whether an effort should be made to better recruit male patients with cancer for such an intervention. A nursing expert, for instance, mentioned during the interview that a focus on more technical aspects or facts could be more appealing to male patients.

Strengths, Limitations, and Future Directions

This study has several strengths and limitations. A strength of the study is the collection of objective data in the form of

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logging the exercise use for each patient over the course of 20 weeks. Therefore, data on using the app exercises were not biased through self-report. Another advantage of this study was the use of a mixed methods approach, which is recommended for the development of digital interventions [54].

A limitation of the study is that we did not have a control group. Therefore, the effectiveness of the app cannot be determined in this study because regression to the mean could have an impact on the improvement of well-being. Furthermore, we used paper-and-pencil questionnaires, which might have led to more missing data compared with web-based questionnaires [55]. However, this was compensated by using LMM analyses, which take into account all patients who provided baseline data. Another limitation is that we did not assess whether patients were practicing mindfulness and relaxation exercises without the app, which could have an effect on the assessed outcomes.

Therefore, future studies should investigate this topic with a randomized controlled trial to determine the effectiveness of a mindfulness and relaxation mHealth intervention. Our study provides some insights regarding the effects that might be expected in a similar study, which will be helpful to power future studies sufficiently. We also looked at aspects of implementing an mHealth intervention. All interviewed health professionals perceived such an mHealth intervention as a helpful addition to standard care, but as described earlier, they also stated barriers to the implementation of such an intervention, which should be investigated in future studies. Future studies could also investigate an mHealth intervention with more content than in this study app, as suggested during the interviews by health professionals. For instance, audio files with background music or exercises with variations in their duration could be added. In addition to mindfulness and relaxation exercises, physical exercise programs could be added. Physical exercise can have beneficial effects on symptoms of patients with cancer [56], and physical exercise has already been implemented in mHealth apps for patients with cancer [57].

Conclusions

The results of this observational feasibility study indicate that a mindfulness and relaxation app can be a feasible and an effective way to deliver a self-care intervention for patients with cancer. Our results indicate that such an intervention might be especially beneficial for highly distressed patients with cancer. The appeal of such an app could be increased with more diverse content, which might also positively affect the adherence of patients to such an intervention. The effectiveness and further aspects regarding the implementation of such an mHealth intervention should be investigated in a future randomized controlled trial.

Acknowledgments

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Conflicts of Interest

None declared.

References

1. Mehnert A, Brähler E, Faller H, Härter M, Keller M, Schulz H, et al. Four-week prevalence of mental disorders in patients with cancer across major tumor entities. J Clin Oncol 2014 Nov 01;32(31):3540-3546. [doi: 10.1200/JCO.2014.56.0086] [Medline: 25287821]
2. Mehnert A, Hartung TJ, Friedrich M, Vehling S, Brähler E, Härter M, et al. One in two cancer patients is significantly distressed: prevalence and indicators of distress. Psychooncology 2018 Jan;27(1):75-82. [doi: 10.1002/pon.4464] [Medline: 28568377]
3. Vehling S, Koch U, Ladehoff N, Schön G, Wegscheider K, Heckl U, et al. Prevalence of affective and anxiety disorders in cancer: systematic literature review and meta-analysis]. Psychother Psychosom Med Psychol 2012 Jul;62(7):249-258. [doi: 10.1055/s-0032-1309032] [Medline: 22585582]
4. Renovanz M, Soebianto S, Tsakmaklis H, Keric N, Nadji-Ohl M, Beutel M, et al. Evaluation of the psychological burden during the early disease trajectory in patients with intracranial tumors by the ultra-brief Patient Health Questionnaire for Depression and Anxiety (PHQ-4). Support Care Cancer 2019 Dec;27(12):4469-4477. [doi: 10.1007/s00520-019-04718-z] [Medline: 30904948]
5. Burg MA, Adorno G, Lopez ED, Loerzel V, Stein K, Wallace C, et al. Current unmet needs of cancer survivors: analysis of open-ended responses to the American Cancer Society Study of Cancer Survivors II. Cancer 2015 Feb 15;121(4):623-630. [doi: 10.1002/cncr.28951] [Medline: 25581252]
6. Faller H, Weis J, Koch U, Brähler E, Härter M, Keller M, et al. Utilization of professional psychological care in a large German sample of cancer patients. Psychooncology 2017 Apr;26(4):537-543. [doi: 10.1002/pon.4197] [Medline: 27327213]
7. Carlson LE, Zelinski E, Toivonen K, Flynn M, Qureshi M, Piedalue K, et al. Mind-body therapies in cancer: what is the latest evidence? Curr Oncol Rep 2017 Aug 18;19(10):67. [doi: 10.1007/s11912-017-0626-1] [Medline: 28822063]
8. Astin JA, Shapiro SL, Eisenberg DM, Forys KL. Mind-body medicine: state of the science, implications for practice. J Am Board Fam Pract 2003;16(2):131-147 [FREE Full text] [Medline: 12665179]

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9. Kwekkeboom KL, Cherwin CH, Lee JW, Wanta B. Mind-body treatments for the pain-fatigue-sleep disturbance symptom cluster in persons with cancer. J Pain Symptom Manage 2010 Jan;39(1):126-138 [FREE Full text] [doi: 10.1016/j.jpainsymman.2009.05.022] [Medline: 19900778]
10. Cramer H, Lauche R, Klose P, Lange S, Langhorst J, Dobos GJ. Yoga for improving health-related quality of life, mental health and cancer-related symptoms in women diagnosed with breast cancer. Cochrane Database Syst Rev 2017 Jan 03;1:CD010802 [FREE Full text] [doi: 10.1002/14651858.CD010802.pub2] [Medline: 28045199]
11. Haller H, Winkler MM, Klose P, Dobos G, Kümmel S, Cramer H. Mindfulness-based interventions for women with breast cancer: an updated systematic review and meta-analysis. Acta Oncol 2017 Dec;56(12):1665-1676. [doi: 10.1080/0284186X.2017.1342862] [Medline: 28686520]
12. Chen Z, Meng Z, Milbury K, Bei W, Zhang Y, Thornton B, et al. Qigong improves quality of life in women undergoing radiotherapy for breast cancer: results of a randomized controlled trial. Cancer 2013 May 01;119(9):1690-1698 [FREE Full text] [doi: 10.1002/cncr.27904] [Medline: 23355182]
13. Jeitler M, Jaspers J, von Scheidt C, Koch B, Michalsen A, Steckhan N, et al. Mind-body medicine and lifestyle modification in supportive cancer care: a cohort study on a day care clinic program for cancer patients. Psychooncology 2017 Dec;26(12):2127-2134. [doi: 10.1002/pon.4433] [Medline: 28370730]
14. Zhang J, Yang K, Tian J, Wang C. Effects of yoga on psychologic function and quality of life in women with breast cancer: a meta-analysis of randomized controlled trials. J Altern Complement Med 2012 Nov;18(11):994-1002. [doi: 10.1089/acm.2011.0514] [Medline: 22909345]
15. Spahn G, Choi K, Kennemann C, Lüdtke R, Franken U, Langhorst J, et al. Can a multimodal mind-body program enhance the treatment effects of physical activity in breast cancer survivors with chronic tumor-associated fatigue? A randomized controlled trial. Integr Cancer Ther 2013 Jul;12(4):291-300. [doi: 10.1177/1534735413492727] [Medline: 23766391]
16. Paul A, Cramer H, Lauche R, Altner N, Langhorst J, Dobos GJ. An oncology mind-body medicine day care clinic: concept and case presentation. Integr Cancer Ther 2013 Nov;12(6):503-507. [doi: 10.1177/1534735412473639] [Medline: 23329568]
17. Brebach R, Sharpe L, Costa DSJ, Rhodes P, Butow P. Psychological intervention targeting distress for cancer patients: a meta-analytic study investigating uptake and adherence. Psychooncology 2016 Aug;25(8):882-890. [doi: 10.1002/pon.4099] [Medline: 26893285]
18. Cohen A, Ianovski LE, Frenkiel S, Hier M, Zeitouni A, Kost K, et al. Barriers to psychosocial oncology service utilization in patients newly diagnosed with head and neck cancer. Psychooncology 2018 Dec;27(12):2786-2793. [doi: 10.1002/pon.4889] [Medline: 30216594]
19. Dilworth S, Higgins I, Parker V, Kelly B, Turner J. Patient and health professional's perceived barriers to the delivery of psychosocial care to adults with cancer: a systematic review. Psychooncology 2014 Jun;23(6):601-612. [doi: 10.1002/pon.3474] [Medline: 24519814]
20. Brown LF, Kroenke K, Theobald DE, Wu J, Tu W. The association of depression and anxiety with health-related quality of life in cancer patients with depression and/or pain. Psychooncology 2010 Jul;19(7):734-741 [FREE Full text] [doi: 10.1002/pon.1627] [Medline: 19777535]
21. Berry DL, Blonquist TM, Hong F, Halpenny B, Partridge AH. Self-reported adherence to oral cancer therapy: relationships with symptom distress, depression, and personal characteristics. Patient Prefer Adherence 2015;9:1587-1592 [FREE Full text] [doi: 10.2147/PPA.S91534] [Medline: 26604712]
22. Arcury TA, Gesler WM, Preisser JS, Sherman J, Spencer J, Perin J. The effects of geography and spatial behavior on health care utilization among the residents of a rural region. Health Serv Res 2005 Feb;40(1):135-155 [FREE Full text] [doi: 10.1111/j.1475-6773.2005.00346.x] [Medline: 15663706]
23. Ensor T, Cooper S. Overcoming barriers to health service access: influencing the demand side. Health Policy Plan 2004 Mar;19(2):69-79. [Medline: 14982885]
24. Waller A, Williams A, Groff SL, Bultz BD, Carlson LE. Screening for distress, the sixth vital sign: examining self-referral in people with cancer over a one-year period. Psychooncology 2013 Feb;22(2):388-395. [doi: 10.1002/pon.2102] [Medline: 22135205]
25. Eysenbach G. What is e-health? J Med Internet Res 2001 Jun;3(2):E20. [doi: 10.2196/jmir.3.2.e20] [Medline: 11720962]
26. van Heerden A, Tomlinson M, Swartz L. Point of care in your pocket: a research agenda for the field of m-health. Bull World Health Organ 2012 May 1;90(5):393-394 [FREE Full text] [doi: 10.2471/BLT.11.099788] [Medline: 22589575]
27. Mikolasek M, Berg J, Witt CM, Barth J. Effectiveness of mindfulness- and relaxation-based eHealth interventions for patients with medical conditions: a systematic review and synthesis. Int J Behav Med 2017 Jul 27. [doi: 10.1007/s12529-017-9679-7] [Medline: 28752414]
28. Fish J, Brimson J, Lynch S. Mindfulness interventions delivered by technology without facilitator involvement: what research exists and what are the clinical outcomes? Mindfulness (N Y) 2016;7(5):1011-1023 [FREE Full text] [doi: 10.1007/s12671-016-0548-2] [Medline: 27642370]
29. Spijkerman MP, Pots WT, Bohlmeijer ET. Effectiveness of online mindfulness-based interventions in improving mental health: a review and meta-analysis of randomised controlled trials. Clin Psychol Rev 2016 Apr;45:102-114 [FREE Full text] [doi: 10.1016/j.cpr.2016.03.009] [Medline: 27111302]

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30. McAlpine H, Joubert L, Martin-Sanchez F, Merolli M, Drummond KJ. A systematic review of types and efficacy of online interventions for cancer patients. Patient Educ Couns 2015 Mar;98(3):283-295. [doi: 10.1016/j.pec.2014.11.002] [Medline: 25535016]
31. Escriva Boulley G, Leroy T, Bernetière C, Paquienseguy F, Desfriches-Doria O, Préau M. Digital health interventions to help living with cancer: a systematic review of participants' engagement and psychosocial effects. Psychooncology 2018 Dec;27(12):2677-2686. [doi: 10.1002/pon.4867] [Medline: 30152074]
32. Tomlinson M, Rotheram-Borus MJ, Swartz L, Tsai AC. Scaling up mHealth: where is the evidence? PLoS Med 2013;10(2):e1001382 [FREE Full text] [doi: 10.1371/journal.pmed.1001382] [Medline: 23424286]
33. Matthew-Maich N, Harris L, Ploeg J, Markle-Reid M, Valaitis R, Ibrahim S, et al. Designing, implementing, and evaluating mobile health technologies for managing chronic conditions in older adults: a scoping review. JMIR Mhealth Uhealth 2016 Jun 09;4(2):e29 [FREE Full text] [doi: 10.2196/mhealth.5127] [Medline: 27282195]
34. Gagnon M, Ngangue P, Payne-Gagnon J, Desmartis M. m-Health adoption by healthcare professionals: a systematic review. J Am Med Inform Assoc 2016 Jan;23(1):212-220. [doi: 10.1093/jamia/ocv052] [Medline: 26078410]
35. Zhao Y, Ni Q, Zhou R. What factors influence the mobile health service adoption? A meta-analysis and the moderating role of age. Int J Inf Manage 2018 Dec;43:342-350. [doi: 10.1016/j.ijinfomgt.2017.08.006]
36. Mikolasek M, Witt CM, Barth J. Adherence to a mindfulness and relaxation self-care app for cancer patients: mixed-methods feasibility study. JMIR Mhealth Uhealth 2018 Dec 06;6(12):e11271 [FREE Full text] [doi: 10.2196/11271] [Medline: 30522990]
37. Glasgow RE, Vogt TM, Boles SM. Evaluating the public health impact of health promotion interventions: the RE-AIM framework. Am J Public Health 1999 Sep;89(9):1322-1327. [doi: 10.2105/ajph.89.9.1322] [Medline: 10474547]
38. Fischer F, Gibbons C, Coste J, Valderas JM, Rose M, Leplège A. Measurement invariance and general population reference values of the PROMIS Profile 29 in the UK, France, and Germany. Qual Life Res 2018 Apr;27(4):999-1014. [doi: 10.1007/s11136-018-1785-8] [Medline: 29350345]
39. Bonomi AE, Cella DF, Hahn EA, Bjordal K, Sperner-Unterweger B, Gangeri L, et al. Multilingual translation of the Functional Assessment of Cancer Therapy (FACT) quality of life measurement system. Qual Life Res 1996 Jun;5(3):309-320. [doi: 10.1007/bf00433915] [Medline: 8763799]
40. Cella DF, Tulsky DS, Gray G, Sarafian B, Linn E, Bonomi A, et al. The Functional Assessment of Cancer Therapy scale: development and validation of the general measure. J Clin Oncol 1993 Mar;11(3):570-579. [doi: 10.1200/JCO.1993.11.3.570] [Medline: 8445433]
41. Mehnert A, Müller D, Lehmann C, Koch U. [Die deutsche Version des NCCN Distress-Thermometers]. Z Psychol Psychiatr Psychother 2006 Jan;54(3):213-223. [doi: 10.1024/1661-4747.54.3.213]
42. Jacobsen PB, Donovan KA, Trask PC, Fleishman SB, Zabora J, Baker F, et al. Screening for psychologic distress in ambulatory cancer patients. Cancer 2005 Apr 01;103(7):1494-1502 [FREE Full text] [doi: 10.1002/cncr.20940] [Medline: 15726544]
43. Walach H, Buchheld N, Buttenmüller V, Kleinknecht N, Schmidt S. Measuring mindfulness—the Freiburg Mindfulness Inventory (FMI). Pers Individ Dif 2006 Jun;40(8):1543-1555. [doi: 10.1016/j.paid.2005.11.025]
44. Snaith RP. The hospital anxiety and depression scale. Health Qual Life Outcomes 2003;1:29 [FREE Full text] [doi: 10.1186/1477-7525-1-29] [Medline: 12914662]
45. Mehnert A, Herschbach P, Berg P, Henrich G, Koch U. [Fear of progression in breast cancer patients--validation of the short form of the Fear of Progression Questionnaire (FoP-Q-SF)]. Z Psychosom Med Psychother 2006;52(3):274-288. [doi: 10.13109/zptm.2006.52.3.274] [Medline: 17156600]
46. Mayring P. Qualitative Inhaltsanalyse: Grundlagen und Techniken. Basel: Beltz Pädagogik; 2010.
47. Lengacher CA, Reich RR, Ramesar S, Alinat CB, Moscoso M, Cousin L, et al. Feasibility of the mobile mindfulness-based stress reduction for breast cancer (mMBSR(BC)) program for symptom improvement among breast cancer survivors. Psychooncology 2018 Feb;27(2):524-531. [doi: 10.1002/pon.4491] [Medline: 28665541]
48. Kubo A, Kurtovich E, McGinnis M, Aghaee S, Altschuler A, Quesenberry C, et al. A randomized controlled trial of mHealth mindfulness intervention for cancer patients and informal cancer caregivers: a feasibility study within an integrated health care delivery system. Integr Cancer Ther 2019;18:1534735419850634 [FREE Full text] [doi: 10.1177/1534735419850634] [Medline: 31092044]
49. Rosen KD, Paniagua SM, Kazanis W, Jones S, Potter JS. Quality of life among women diagnosed with breast cancer: a randomized waitlist controlled trial of commercially available mobile app-delivered mindfulness training. Psychooncology 2018 Aug;27(8):2023-2030. [doi: 10.1002/pon.4764] [Medline: 29766596]
50. Barth J, Delfino S, Künzler A. Naturalistic study on the effectiveness of psycho-oncological interventions in cancer patients and their partners. Support Care Cancer 2013 Jun;21(6):1587-1595. [doi: 10.1007/s00520-012-1700-8] [Medline: 23299560]
51. Bishop FL, Lewith GT. Who uses CAM? A narrative review of demographic characteristics and health factors associated with CAM use. Evid Based Complement Alternat Med 2010 Mar;7(1):11-28 [FREE Full text] [doi: 10.1093/ecam/nen023] [Medline: 18955327]

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52. Reid R, Steel A, Wardle J, Trubody A, Adams J. Complementary medicine use by the Australian population: a critical mixed studies systematic review of utilisation, perceptions and factors associated with use. BMC Complement Altern Med 2016 Jun 11;16:176 [FREE Full text] [doi: 10.1186/s12906-016-1143-8] [Medline: 27289517]
53. Thomson P, Jones J, Evans JM, Leslie SL. Factors influencing the use of complementary and alternative medicine and whether patients inform their primary care physician. Complement Ther Med 2012;20(1-2):45-53. [doi: 10.1016/j.ctim.2011.10.001] [Medline: 22305248]
54. Michie S, Yardley L, West R, Patrick K, Greaves F. Developing and evaluating digital interventions to promote behavior change in health and health care: recommendations resulting from an international workshop. J Med Internet Res 2017 Jun 29;19(6):e232 [FREE Full text] [doi: 10.2196/jmir.7126] [Medline: 28663162]
55. Kongsved SM, Basnov M, Holm-Christensen K, Hjollund NH. Response rate and completeness of questionnaires: a randomized study of internet versus paper-and-pencil versions. J Med Internet Res 2007;9(3):e25 [FREE Full text] [doi: 10.2196/jmir.9.3.e25] [Medline: 17942387]
56. Nakano J, Hashizume K, Fukushima T, Ueno K, Matsuura E, Ikio Y, et al. Effects of aerobic and resistance exercises on physical symptoms in cancer patients: a meta-analysis. Integr Cancer Ther 2018 Dec;17(4):1048-1058 [FREE Full text] [doi: 10.1177/1534735418807555] [Medline: 30352523]
57. Haberlin C, O'Dwyer T, Mockler D, Moran J, O'Donnell DM, Broderick J. The use of eHealth to promote physical activity in cancer survivors: a systematic review. Support Care Cancer 2018 Jun 16. [doi: 10.1007/s00520-018-4305-z] [Medline: 29909476]

Abbreviations

FACT-G: Functional Assessment of Cancer Therapy–General
FMI: Freiburg Mindfulness Inventory
FoP-Q-SF: Fear of Progression Questionnaire-Short Form
HADS: Hospital Anxiety and Depression Scale
LMM: linear mixed model
MBM: mind-body medicine
mHealth: mobile health
PROMIS-29: 29-item Patient-Reported Outcomes Measurement Information System
RE-AIM: Reach, Effectiveness, Adoption, Implementation, and Maintenance

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Original Paper

A Mobile App to Improve Symptom Control and Information Exchange Among Specialists and Local Health Workers Treating Tanzanian Cancer Patients: Human-Centered Design Approach

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Abstract

Background: Improving access to end-of-life symptom control interventions among cancer patients is a public health priority in Tanzania, and innovative community-based solutions are needed. Mobile health technology holds promise; however, existing resources are limited, and outpatient access to palliative care specialists is poor. A mobile platform that extends palliative care specialist access via shared care with community-based local health workers (LHWs) and provides remote support for pain and other symptom management can address this care gap.

Objective: The aim of this study is to design and develop mobile-Palliative Care Link (mPCL), a web and mobile app to support outpatient symptom assessment and care coordination and control, with a focus on pain.

Methods: A human-centered iterative design framework was used to develop the mPCL prototype for use by Tanzanian palliative care specialists (physicians and nurses trained in palliative care), poor-prognosis cancer patients and their lay caregivers (patients and caregivers), and LHWs. Central to mPCL is the validated African Palliative Care Outcome Scale (POS), which was adapted for automated, twice-weekly collection of quality of life–focused patient and caregiver responses and timely review, reaction, and tracking by specialists and LHWs. Prototype usability testing sessions were conducted in person with 21 key informants representing target end users. Sessions consisted of direct observations and qualitative and quantitative feedback on app ease of use and recommendations for improvement. Results were applied to optimize the prototype for subsequent real-world testing. Early pilot testing was conducted by deploying the app among 10 patients and caregivers, randomized to mPCL use versus phone-contact POS collection, and then gathering specialist and study team feedback to further optimize the prototype for a broader randomized field study to examine the app's effectiveness in symptom control among cancer patients.

Results: mPCL functionalities include the ability to create and update a synoptic clinical record, regular real-time symptom assessment, patient or caregiver and care team communication and care coordination, symptom-focused educational resources, and ready access to emergency phone contact with a care team member. Results from the usability and pilot testing demonstrated that all users were able to successfully navigate the app, and feedback suggests that mPCL has clinical utility. User-informed recommendations included further improvement in app navigation, simplification of patient and caregiver components and language, and delineation of user roles.

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Conclusions: We designed, built, and tested a usable, functional mobile app prototype that supports outpatient palliative care for Tanzanian patients with cancer. mPCL is expressly designed to facilitate coordinated care via customized interfaces supporting core users—patients or caregivers, LHWs, and members of the palliative care team—and their respective roles. Future work is needed to demonstrate the effectiveness and sustainability of mPCL to remotely support the symptom control needs of Tanzanian cancer patients, particularly in harder-to-reach areas.

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KEYWORDS

mobile health; mHealth; user-centered design; palliative care; pain; cancer; sub-Saharan Africa; mobile phone

Introduction

Cancer is a growing public health concern in sub-Saharan Africa, with at least 500,000 annual deaths in recent years; a doubling of cancer incidence and mortality is projected by 2030 [1-4]. Although data for Africa as a whole are limited, a study in South Africa and Uganda showed unnecessary distress among late-stage patients with cancer who most often reported uncontrolled pain (87.5%), low energy (77.7%), sadness (75.9%), drowsiness (72.3%), and worry (69.6%), with pain as the most severe symptom [5].

Due to the limited pool of palliative care specialists and low public and private investment in cancer control, there is an urgent need for novel, sustainable, and community-based solutions to address inadequate specialty palliative care services throughout Africa [6-8], with a focus on the four pillars of the World Health Organization (WHO): (1) appropriate policies, (2) education (professional and lay), (3) drug availability, and (4) implementation throughout society [1,9]. These are only achievable with high-quality research to ensure that public health solutions are evidence-based, culturally sensitive, feasible, responsive, effective, and scalable [1].

With the increasing adoption of mobile technology, there is great potential to improve outpatient cancer symptom management through remote access to palliative care. In Tanzania, cell phone ownership increased from 10% in 2002 to 73% in 2015, and smartphone ownership increased from 8% to 13% between 2013 and 2017 [10]. Coupled with a projected further increase in smartphone ownership, mobile health (mHealth, ie, “the use of mobile and wireless devices to support the achievement of health objectives”) [11] promises to grow access to palliative care specialists (hereafter, specialists), resulting in improved symptom management among patients with cancer in Tanzania, our study setting, and other low-resource settings [12]. Although active (ie, mobile survey assessments and digital journaling) or passive (ie, wearables) collection of symptoms over time for a patient with cancer may be a feasible and reliable way of assessing quality of life remotely, there is limited knowledge about the effects of these emerging technologies relative to care coordination, with little effort in low-resource countries [13,14].

A systematic review of existing mobile and web apps focused on pain control in a range of medical conditions, including cancer, reported that although the number of such apps is growing, none of the apps described in scientific databases were available commercially. Furthermore, among the 283 pain control–focused apps identified in the 5 app stores (including Google Play and Apple App Store), scientific evidence of efficacy was nonexistent [15].

A more recent systematic review examined available full-text publications on mobile apps with the following characteristics: focused on cancer pain, downloaded and registered on either a mobile phone or computer, using a numeric scale to assess pain, reporting patient follow-up for more than a week, and available in English. Of the 13 studies reviewed, 5 were randomized controlled trials. The results of this review revealed that app-supported pain control is generally effective in the high-resource setting. Specifically, among the randomized controlled studies reviewed, patients who used the tested apps had less pain than patients without access to the apps. Other outcomes, such as quality of life, pain catastrophizing, and pain self-efficacy, were also improved in app users versus in those from control groups [16]. Existing mobile apps used in cancer pain management often offer a range of functions and specifications, including shared records, training, and real-time feedback. They educate patients about pain and enable documentation of the type of pain experienced as well as feedback regarding symptoms [16]. Importantly, mHealth facilitates pain management among individuals living in rural communities and supports control of other symptoms, including depression [17].

Few studies have examined mobile palliative care solutions in low-resource countries among those with noncommunicable diseases (NCDs), despite increasing awareness of the symptom control needs of patients with chronic diseases, including patients with cancer, and knowledge that by 2030, NCDs will be more prevalent than communicable diseases [12,18-30]. Limitations to previous studies include small sample sizes and varied follow-up times, including some as short as 14 days. There has been a call for larger samples and longer randomized controlled trials as well as further assessment of app functions most critical to symptom control [16]. Notably, previous studies have included limited involvement of health care providers in the design and development of apps, a limitation likely influencing the utility of these technologies [15,19,20]. In close partnership with Tanzanian target end users (physicians and nurses trained in palliative care, patients and lay caregivers [caregivers], and local health workers [LHWs]), we employed a human-centered design (HCD) framework to design, develop, and validate the usability of the mobile-Palliative Care Link (mPCL) prototype; a web and mobile app focused on symptom assessment and control for Tanzanian poor-prognosis patients

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with cancer that extends access to a limited pool of specialists through partnerships with community-based LHWs.

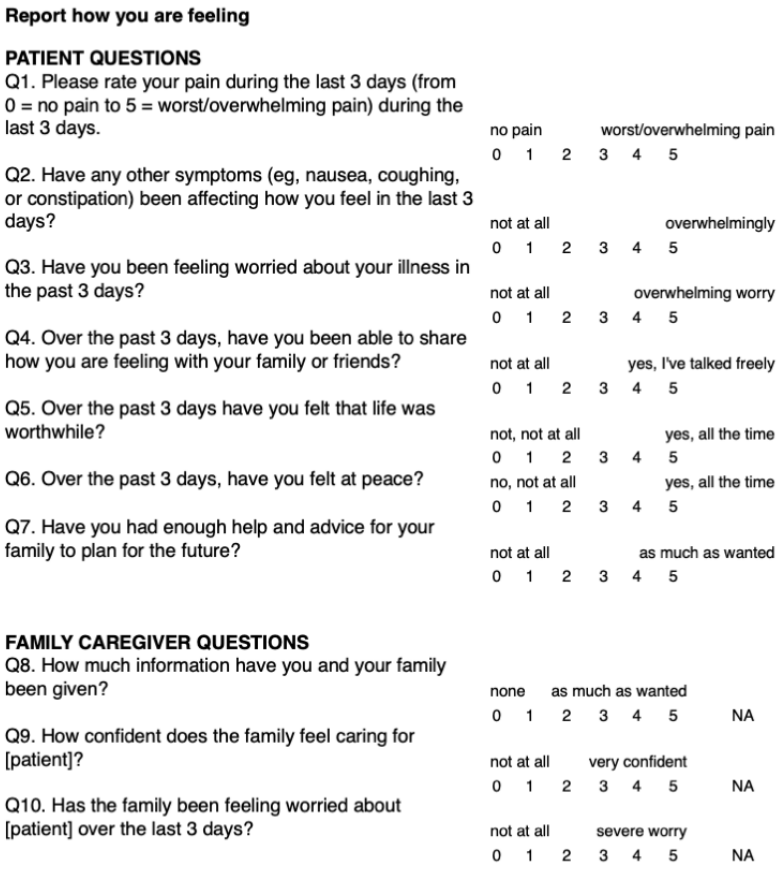
Methods

Overview

This study was approved by the Institutional Review Board of the Muhimbili University of Health and Allied Sciences (MUHAS, Dar es Salaam, Tanzania). Signed informed consent was obtained from all participants before enrollment into the study.

Using WHO palliative care pillars (policy, education, drug availability, and implementation) as a framework [9] and responses to the validated African Palliative Care Outcome Scale (POS; a 10-item quality of life–focused survey instrument) [31,32] as an outcome measure (Figure 1), we partnered with Dar es Salaam–based Tanzanian specialists (ie, palliative care–trained, Ocean Road Cancer Institute (ORCI)–affiliated oncology physicians and nurses), patients with cancer and caregivers, and LHWs to develop, pilot test, and validate the usability of the mPCL prototype. Located in Dar es Salaam, ORCI is the largest government-supported cancer center in Tanzania.

Figure 1. Palliative Care Outcome Scale of the mobile-Palliative Care Link app for a patient and caregiver (for display in Kiswahili). NA indicates that the caregiver is not present.



Stages of mPCL Development

The app design and development process consisted of six stages.

Stage 1: Establishing the Study Team

The multidisciplinary study team established to design and test mPCL included Tanzanian- and US-based partner institutions and organizations—MUHAS, ORCI, Maine Medical Center—and a social software enterprise Dimagi. Team members included Tanzanian and US palliative care specialists, health services researchers, software engineers and designers, and a user experience (UX) specialist (author RM). The team met remotely via videoconference on a monthly basis and communicated via email throughout the app design, development, and testing periods (Figure 2).

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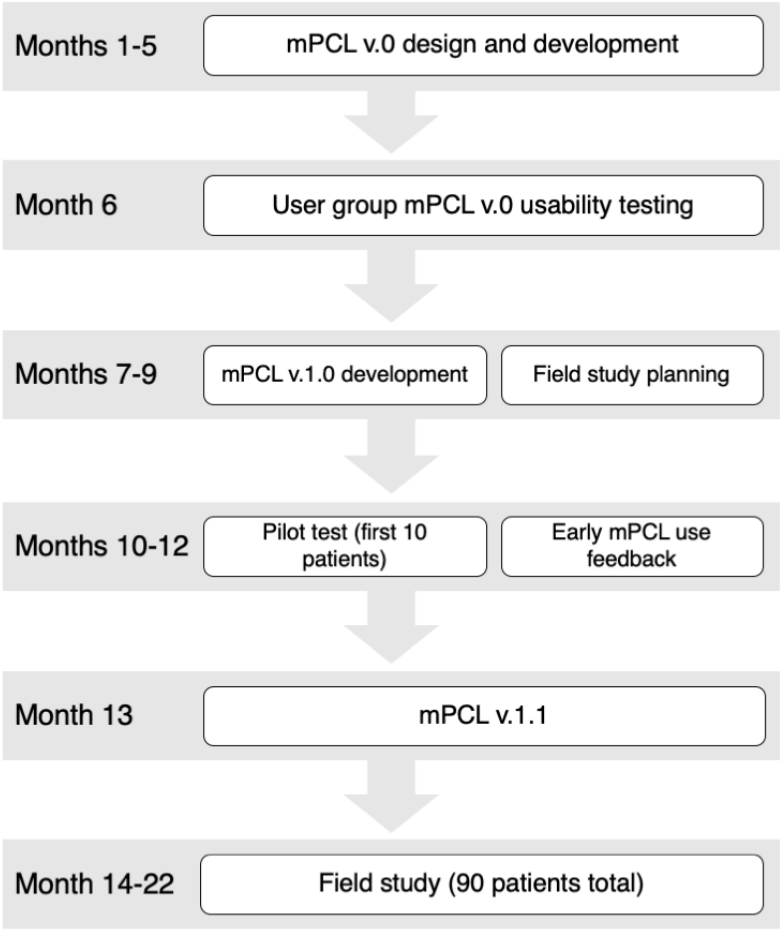
Figure 2. Design and development timeline of the mobile-Palliative Care Link app. Early app use feedback involved only specialists and study personnel; field study results are reported elsewhere.



Stage 2: Defining a Set of App Design Requirements

The study team defined 3 mPCL design requirements based on a proposed workflow that was endorsed by clinical study team members. Figure 3 shows the care communication and coordination app-facilitated workflow.

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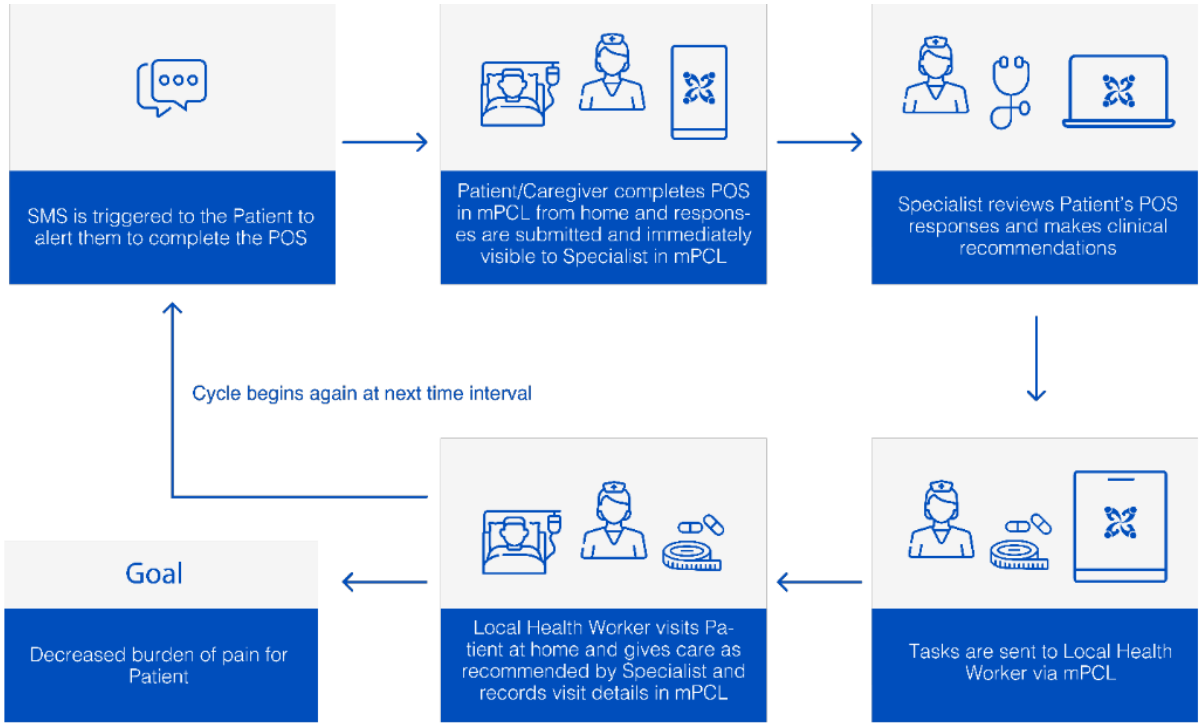
Figure 3. Design of the mPCL app focusing on the patient or caregiver and care team communication and care coordination. mPCL: mobile-Palliative Care Link; POS: Palliative Care Outcome Scale.



Design requirements were as follows:

Requirement 1: Streamlined and timely collection of patient self-reported symptoms. Central to mPCL's utility is its ability to regularly and in real time assess the patient's quality of life (with a focus on pain control) through scheduled, twice-weekly POS delivery and response collection, including 7 patient-focused items and 3 caregiver-completed items (Figure 1). Permission was secured to adapt this survey instrument for mobile use.

Requirement 2: Interdisciplinary care coordination. Following a patient-centric, interdisciplinary system of care coordination, mPCL was designed for access and use by the patient or caregiver and key members of the patient's clinical care team to deliver responsive, high-quality community-based palliative care services. We define these roles as follows:

1. Specialists include hospital-based specialist physicians (oncologists trained in palliative care) and palliative care nurses (hereafter referred to as nurses). The specialist physician's primary tasks are to generate a shared synoptic clinical record and palliative care plan, review POS results, and oversee the patient's care. Nurses support the development of the synoptic clinical record, conduct visits with the patient or caregiver in coordination with the LHW, and serve as a liaison between all care team members as well as an emergency contact for patients or caregivers. As such, both specialist physicians and nurses play a role in creating synoptic clinical records in mPCL. The clinical record and care plan can be viewed by other members of the care team and can be updated at any time by the specialist based on POS responses and input from the nurse, LHW, and patient or caregiver. Specialist physicians have the exclusive ability to prescribe, supply, and make adjustments to morphine and other medications critical to pain and other symptom management.
2. The community-based LHW, located in close proximity to the patient's or caregiver's home, assists with regular remote assessment, monitoring, and management of the patient's symptoms via in-person visits recorded in the form of mPCL follow-up interactions and through mPCL communication or care coordination in partnership with other team members, thereby providing frontline care based on direct ongoing specialist guidance and the needs of the patient.
3. The cancer patient receiving outpatient, home-based palliative care as well as their caregiver, responsible for providing in-home patient support, can access and use the app to complete the 10-item POS and submit results to mPCL's cloud-based server for subsequent review by the LHW and review or action by a specialist. Additional patient-centric design specifications include a set of low-literacy educational resources developed in Kiswahili (Tanzania's primary language) with a focus on the causes and management of common late-stage cancer symptoms.

Requirement 3: Symptom response–focused communication between the care team and patient or caregiver. Shared access to POS results, an evolving synoptic clinical record and palliative care plan, and follow-up notes by care team members on interactions with the patient or caregiver allow for: (1) timely communication to support patient-centered care plan decision making in response to an LHW's in-person assessment of the patient experiencing escalating symptoms or other needs, (2) coordination of care to implement changes to the care plan, and (3) important updates regarding changes in patient status (ie, hospitalization or death). mPCL also provides patients with ready access emergency phone contact with a specialist or LHW

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in the event of rapidly escalating symptoms or acute changes in clinical status.

Stage 3: Defining User Requirements

In accordance with HCD methodology, user characteristics and needs were gathered and analyzed to create a set of user requirements before app development [33]. The first step in doing this was to create a set of user personas. Each persona presented a summary of the key characteristics, background, and needs of a representative user from each user group. The personas were developed by a subset of the study team and reviewed by all team members, including those in Tanzania who had the closest understanding of prospective app users. After the personas were complete, a set of user stories was created. Each user story described how one or more users (represented by the personas) would use the app, either on their own or together. The user stories functioned as a means to clearly and concisely define how the app would be used by each user group. As with the personas, the user stories were reviewed by all team members.

Stage 4: Creating the App Prototype, mPCL v.0

The app prototype, mPCL v.0, was designed and built to directly support the core requirements defined in Stage 2, summarized above. The process of designing and creating the prototype involved (1) drafting the data architecture, (2) creating display pages and input forms to populate with content, and (3) defining custom user interfaces and permissions for types of users based on their specific roles and tasks. Periodic technical reviews and audits were conducted internally by Dimagi to ensure app design optimization and to verify technical requirements for data collection and analysis, for example, configuring unique user names and updating a change in medication. The back and front ends of the functional prototype were built and prepared by Dimagi staff with feedback from clinical team members and the team's UX specialist. mPCL was developed on CommCare; Dimagi's open-source, secure, cloud-based case management platform that allows end users to collect data and deliver interventions via custom-built mobile and web apps. This enabled the team to rapidly iterate the design and prepare a functional prototype for testing and use [34].

Stage 5: Expert UX Review

Once the prototype was complete, an expert review was conducted by the UX specialist. The goal of this review was to identify and fix areas where the app was not in compliance with established UX best practices. The UX specialist ascertained areas of improvement and suggested changes. These changes were reviewed by team members and implemented into an updated version of the app. Key improvements included reorganizing the workflow in the app to make it easier for specialists and LHWs to access patient information, changes to the set of data shown for each user group to ensure availability of all essential information, and updates to labels and terminology to improve clarity and ease of use.

Stage 6: Testing the Prototype

Usability and pilot testing were conducted with target end users, whereby the mPCL prototype was iterated and further developed after each phase of testing.

Usability Test

mPCL v.0 usability was assessed in individualized in-person usability testing sessions conducted by the UX specialist with participants representing target end users. Two site visits in Tanzania were led by US study team members, in collaboration with MUHAS and ORCI partners, to conduct in-person prototype usability testing and then train end users on the system just before the pilot test. The goals of usability testing were to (1) validate the design of mPCL and identify any remaining design issues, (2) uncover opportunities for system improvement, and (3) learn about the target user's behaviors and prototype app interactions [35]. mPCL v.0 usability testing was conducted with a diverse sample of patients, LHWs, and specialists. Potential participants were identified and recruited by ORCI-based study team members. The eligibility criteria for patients included adult ORCI inpatients with known untreatable cancer. Specialists included ORCI-based oncologists and a palliative care nurse. LHWs were eligible to participate if they were within 50 km of ORCI and had experience caring for ORCI patients. Written informed consent was obtained from all study candidates before the usability testing session.

Usability testing sessions occurred in person in a private space at ORCI. Testing for patients and LHWs was conducted in Kiswahili, with a translator. Testing for specialists was conducted in English. Patients were first briefly trained by a study team member on the basic use of mPCL. They were then asked to use an mPCL-equipped study smartphone to perform the following tasks to assess usability: (1) access educational resources, (2) complete and submit POS responses, and (3) contact a care team member. Specialist physicians were asked to use an mPCL-equipped tablet to (1) set up a mock patient's synoptic clinical record, including a discharge palliative care plan; (2) review POS results; (3) enter follow-up patient notes, including changes in care plan; and (4) exchange notes with an LHW. These notes were intended to document requests for in-person assessment, collect additional clinical information, convey treatment recommendations and care plan changes. The nurse was asked to (1) register a mock patient into mPCL and enter relevant sociodemographic and clinical information into the synoptic clinical record, (2) complete the POS, (3) record a note documenting an interaction with the patient, (4) review the patient's POS results and medications, and (5) update the individual's contact information. LHWs were asked to use a study mPCL-equipped smartphone to (1) review a mock patient record, including POS results and (2) exchange notes with a mock specialist and patient regarding the patient's assessment and symptom control. All usability testing participants were observed performing the predefined tasks and all issues that arose in performing the tasks (eg, missteps in navigating through the app to perform a task and errors entering data) were documented. Recorded usability issues and participants' recommendations for changes to the prototype design were reviewed and considered by the study team. At the end of the usability testing, all participants completed a verbally administered survey that assessed users' perceived mPCL ease or difficulty of use. A set of recommendations was derived from usability testing feedback to inform the iteration of a more robust and user-validated mPCL prototype. App modifications

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ultimately accepted and employed were based on feasible design decisions with the goal of maximizing usability. The final mPCL v.1.0 prototype was then used in the subsequent pilot test.

Pilot Test

As part of a larger prospective field study of the system, cancer patients were enrolled and consented upon planned discharge to home from ORCI and randomized to either the mPCL intervention or twice-weekly phone collection of POS responses by an ORCI-based clinician team member. Here, we describe the pilot testing used to inform the final version of mPCL (v.1.1), deployed and tested in the field study. A full description of the field study and its outcomes will be reported elsewhere (manuscript in preparation). In brief, patient eligibility for both the pilot test and field study included (1) an adult ORCI inpatient with known untreatable cancer, being discharged to home, (2) a 4-month life expectancy or greater per specialist physician assessment, (3) residence within 50 km of ORCI for medication access, (4) caregiver available to support outpatient care for the illness duration, (5) an LHW consented to support the patient's outpatient care for the test's duration (up to 4 months post discharge), and (6) completed primary school education. Intervention patients lacking personal smartphones were loaned an Android device with the mPCL app preinstalled and available for use during the 4-month study period, and those with reliable access to their own personal smartphone were provided the option to install and use the mPCL app on their own device. An ORCI information technology specialist working directly with the study team assisted patients with the preparation and maintenance of devices for study purposes (ie, acquisition of SIM cards and installation of mPCL) and served as the first point of contact to respond to any emergent technical issues over the course of the study. For specialists, mPCL was accessible from their office-based computers as a web app as well as their smartphones as a web or native mobile app. LHWs had the option to either use their own mPCL-enabled smartphones or an Android device provided for use during the study with the mPCL mobile app preinstalled.

Real-time feedback and input regarding mPCL use as well as study process or procedure problems were requested via email and during regular team meetings from specialists (physicians and nurse), and ORCI-based study personnel during the 2-month pilot test period. Within this time, a total of 10 patients were enrolled and randomized to mPCL versus phone contact. At the end of the 2-month pilot test period, patient recruitment was held for close to a month during which mPCL use feedback and pilot test process recommendations were compiled, analyzed and used to iterate on and finalize the app prototype, mPCL v 1.1, for further field study.

Results

mPCL v.0 Usability Testing

A total of 21 potential target end users participated in mPCL v.0 usability testing: 7 patients and caregivers, 8 specialists, and 6 LHWs. Of the 7 patients who participated, 6 were women (1 man), and none of them reported any secondary school education or spoke English. Patients' ages ranged from 34 to 64 years, and 2 patients or their caregivers owned an Android smartphone, 4 owned a mobile phone, and 1 did not own a phone. Among specialists, 7 physicians and 1 nurse participated, and 6 of them were women (2 men). Specialists had 4-14 years of clinical experience, were English speaking, and owned Android smartphones. The LHW participants included 4 women and 2 men with 4-14 years of clinical experience; all owned Android smartphones. All LHWs were fluent in Kiswahili, with a few also conversant in tribal languages, and reported limited English language proficiency.

Open-ended user feedback and usability issues identified during usability tests were itemized and reviewed by the mPCL study team for optimization of mPCL v.0 to mPCL v.1.0. This included review of direct feedback from users on role-specific tasks and navigation of custom interfaces, designed for each user role. Design component improvement recommendations were subsequently reviewed, validated and acted upon. Examples of user task performance improvement recommendations prompting app optimization included (1) reformatting the POS assessment for patients and caregivers to display individual items one at a time instead of all on one page, making it easier for those not accustomed to navigating a touchscreen; (2) adding more comprehensive clinical data for collection by specialists, specifically providing more detail on the patient's current and historical medications; (3) adding more information on the patient's social history to the clinical record (ie, family support resources, such as their living situation and nutritional support); (4) translating all information displayed to LHWs into Kiswahili to make the app easier to use for those with limited English language proficiency; and (5) adding the individual patient's cancer type and stage to the patient list display for easier identification. Other emergent themes in user feedback that were acted upon included the need for clearer delineation of user roles and tasks and related user permissions (eg, creation of follow-up notes by a specialist physician and patient enrollment and registration by a nurse) and clarification of POS data collection and monitoring (eg, reminder schedule and modality to prompt patients to submit POS assessments, and notification mechanisms to alert the care team of a new POS submission). As summarized in Table 1, the perception of mPCL's usability for tasks performed ranged from a low degree of ease and acceptability (3 out of 4) to a very high degree of ease and acceptability (1 out of 4). In general, respondents found mPCL easy to use, with an average usability score of 2 and below for any given task. Of particular note, all LHWs (6 out of 6) reported a high degree of ease and acceptability for time spent reviewing the clinical record and the POS assessments. Several respondents remarked that they anticipated that ease of use and acceptability would improve with increased experience using the app.

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Table 1. Prototype usability test survey results among patients, specialists, and local health workers (n=21).

Survey item by user group	Response[a]		Number of responses to survey items, *n*(%)
	Mean (SD)	Range	
Patients (*n*=7)			
Ease or difficulty of POS[b] completion	1.9 (0.9)	1-3	7 (100)
Acceptability of time to complete POS	1.3 (0.76)	1-3	7 (100)
Ease or difficulty of using educational materials	1.6 (0.79)	1-3	7 (100)
Ease or difficulty of making emergency phone calls	1.2 (0.41)	1-2	6 (86)
Specialists (*n*=8)			
Ease or difficulty of creating a clinical record	1.5 (0.53)	1-2	8 (100)
Acceptability of time spent creating a clinical record	1.3 (0.49)	1-2	8 (100)
Ease or difficulty of reviewing a clinical record	1.1 (0.35)	1-2	8 (100)
Acceptability of time spend reviewing a clinical record	1.3 (0.49)	1-2	7 (88)
Ease or difficulty of reviewing POS	1.6 (0.55)	1-2	5 (63)
Local health workers (*n*=6)			
Ease or difficulty of reviewing a clinical record	1.3 (0.82)	1-3	6 (100)
Acceptability of time spent reviewing a clinical record	1 (0.0)	1-1	6 (100)
Ease or difficulty of reviewing POS	2 (0.63)	1-3	6 (100)
Acceptability of time spent reviewing POS	1 (0.0)	1-1	6 (100)
Ease or difficulty of recording a patient interaction	1.8 (0.5)	1-2	4 (67)

[a]All survey item responses were scored from 1 to 4, with 1=very high degree of ease or acceptability and 4=very low degree of ease or acceptability.
[b]POS: Palliative Care Outcome Scale.

mPCL v.1.0 Pilot Test

During the 2-month mPCL pilot test period, 4 specialist physicians, 1 nurse, 5 LHWs, and 10 patients who were randomized to mPCL use versus phone-contact POS collection were enrolled. Specialists, including a subset of mPCL users who were also study team members (coauthors TN, BM, HM, and MN) were asked to provide real-time feedback on issues or questions related to either mPCL v.1.0 use or study processes and procedures, in preparation for the subsequent field study. Table 2 summarizes examples of issues identified; some of this feedback required immediate resolution, whereas other feedback was addressed at the end of the pilot test period.

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Table 2. Examples of mPCL pilot test feedback and corresponding actions taken.

Issue identified	Action taken
CommCare failed to recognize installation codes necessary to install the mPCL[a] app on a study phone	ORCI[b]-based team instructed on resolution
CommCare failed to install updates	ORCI-based team instructed on resolution
LHWs[c] and patients unknowingly uninstalled mPCL or reset cellular internet settings	ORCI-based information technology support team member engaged to address issues on demand
Study nurse could not complete the mPCL clinical record if the cancer stage was not known	"Unknown" was added as a response selection
Patients requested to use their own personal SIM cards rather than using SIM card provided by study	Personal SIM cards were allowed and used with study phones, with participant's permission
ORCI study team noted variability in the ease of training patients on the use of mPCL	Procedure established to capture data on patient's mPCL training ease or difficulty (eg, number of times patient training repeated and specific challenges encountered during training)
Difficulty for the patient to select which care team member they wished to contact by phone in emergency setting (ie, nurse, LHW, or specialist)	mPCL adjusted to allow the patient to more easily select the desired care team member
Patients completed more than one Palliative Care Outcome Scale in a given day	Feedback provided to patient that they were submitting duplicate surveys, including a reminder that they could contact a care team member by phone in the event of escalating symptoms

[a]mPCL: mobile-Palliative Care Link.

[b]ORCI: Ocean Road Cancer Institute.

[c]LHWs: local health workers.

mPCL v1.1 Prototype Finalization

The mPCL v1.1 prototype functionalities summarized below were focused on real-time symptom assessment and care coordination, with the primary aim of effective symptom management and maintenance of quality of life. For the purpose of the mPCL field study, we defined and validated 4 individual mPCL user groups with interfaces, access, and permissions to functionalities specific to each group's roles and tasks in managing study patients: specialist physician, nurse, LHW, and patient or caregiver. Specifically, a nurse was determined to be the only user group with the ability to register a new study patient in mPCL via the Enroll New Patient module. Additional tasks assigned to the nurse to support field study-specific activities (eg, ability to drop a patient from the study) were built and validated via the pilot test, in preparation for the subsequent field study. Field study-specific surveys for each user group were directly included and disseminated to users through the app (Figure 4 shows the screenshots of user interfaces).

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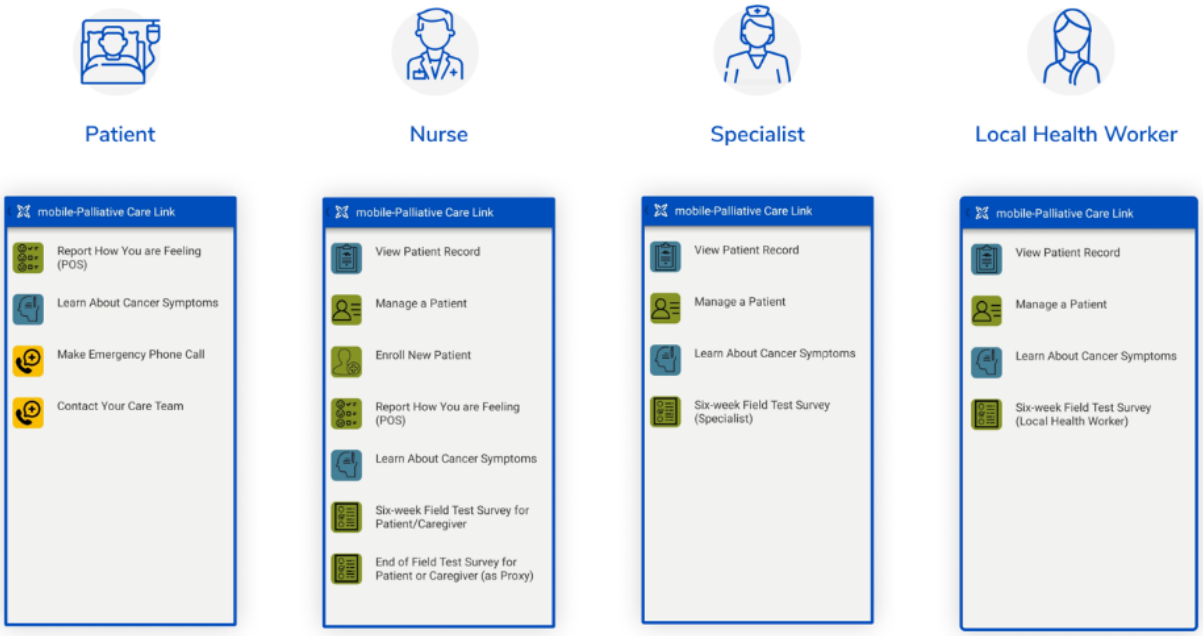
Figure 4. Four separate interfaces for four different user roles (from left to right): patient or caregiver, nurse, specialist physician, and local health worker.



POS

The core priority of mPCL is adequate pain control based on patients' self-reported POS scores. The 10 Likert-scaled POS items are included in the app as a survey form, with single-choice response options ranked from 0 to 5, corresponding to symptom severity. The assessment is displayed in Kiswahili and designed to collect responses directly from patients and their caregivers. Scores are automatically available for review by the clinical care team upon synchronization of data on mPCL-enabled devices connected to the CommCare cloud server back-end. Through mPCL, patients are reminded via SMS text message to complete the POS on a twice-weekly basis, with results immediately accessible to the specialist, nurse, and LHW for timely tracking and response, as needed. Flags signifying escalating symptom scores were built into the app for more immediate attention from the care team (Figure 5).

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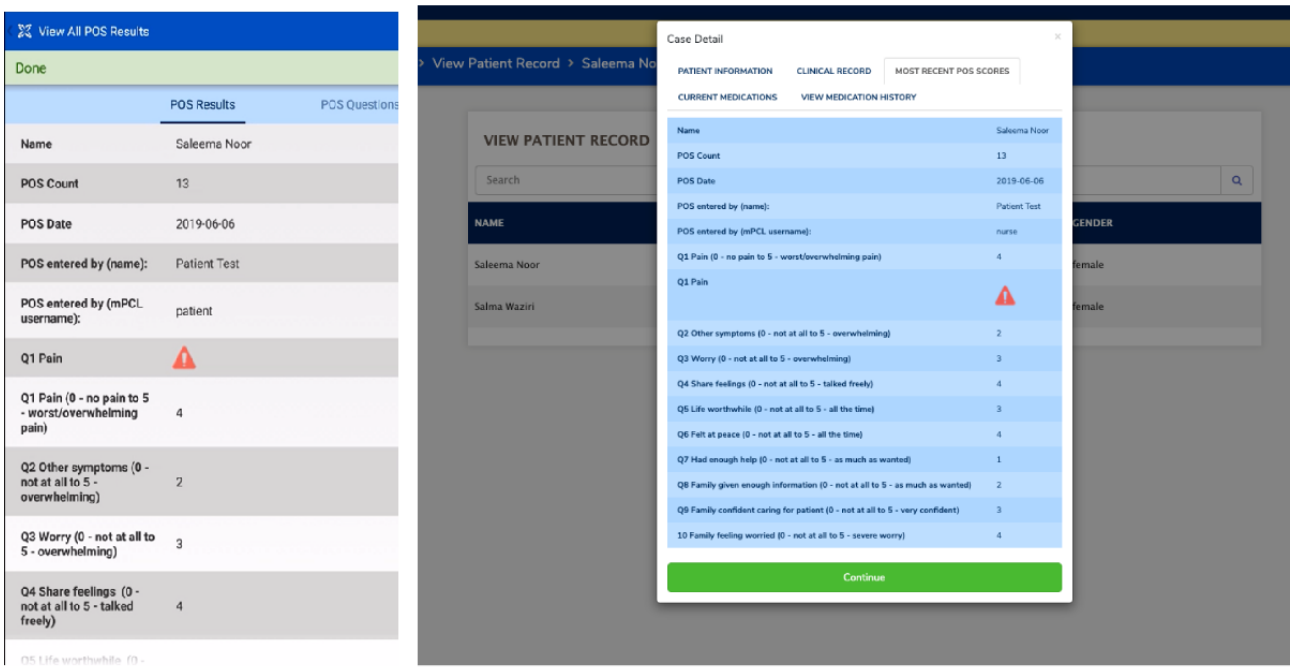
Figure 5. Palliative care Outcome Scale responses (mock patient) as viewed in the mobile app on a smartphone (left) and on the web app (right) by the specialist. A red triangle icon is displayed to alert the care team to reported pain scores that are above the set threshold.



Synoptic Clinical Record and Palliative Care Plan

A series of templated forms allow specialists to create and share access to a synoptic clinical record and discharge palliative care plan that includes the patient's basic demographic information, social history, disease type and stage, noncancer comorbidities, a summary of previous cancer treatments, essential imaging and laboratory results, and an outpatient palliative care plan, including discharge medications and allergies. The synoptic clinical record facilitates clinical and social history data collection by a specialist physician and nurse immediately following inpatient hospital discharge of the patient to home for ongoing palliative care coordination. This record is available to both the specialist physician and nurse with read or write access and LHW with read access (Figure 6 shows the examples of parts of the clinical record that are viewable to care team users).

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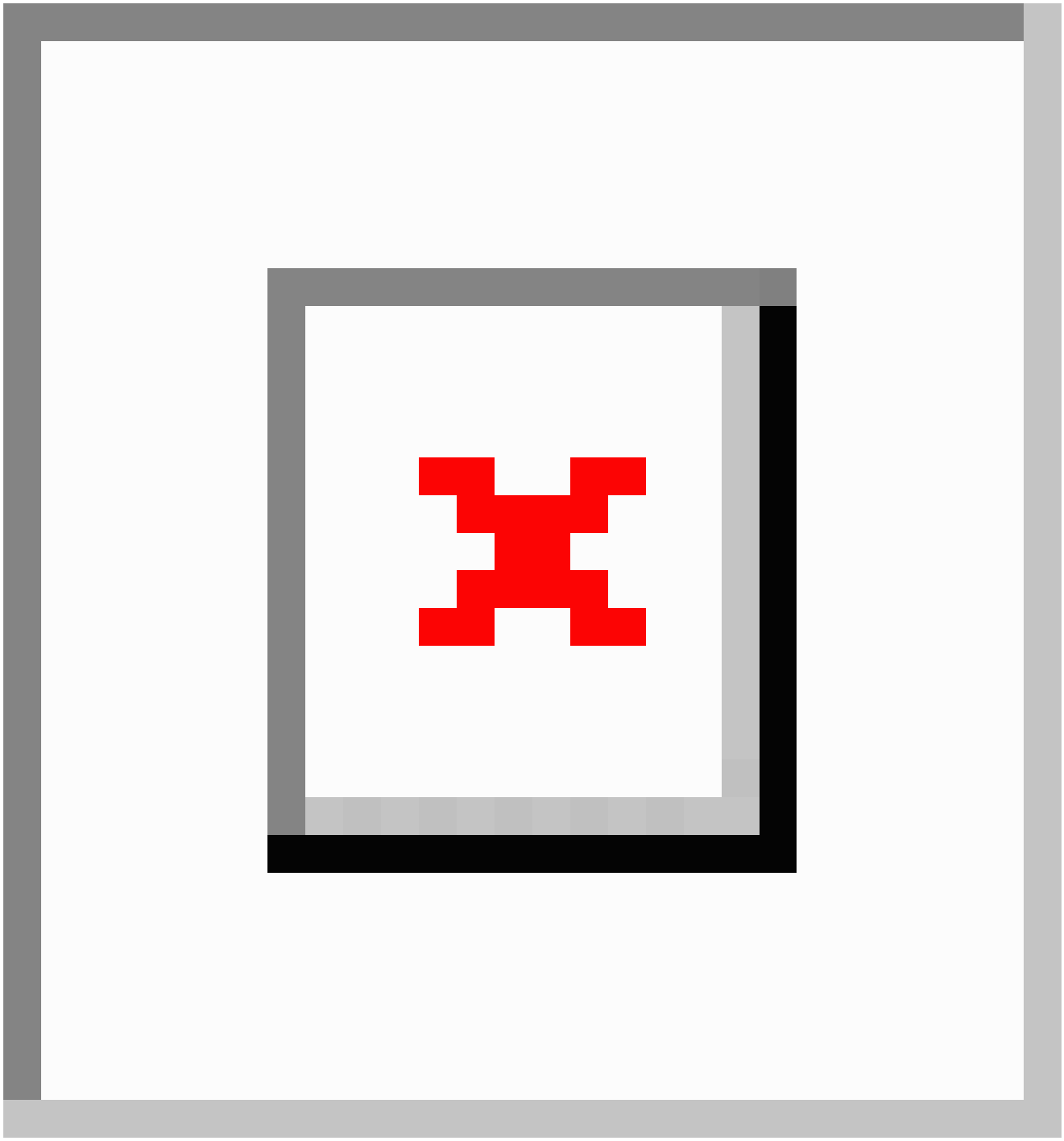
Figure 6. Clinician web app view of patient information (top) and clinical record of the mock patient record (bottom).



Follow-Up Patient Interaction

Postdischarge changes in clinical status, including any communication with or in-home assessment of the patient, readmissions, clinic visits, medication adjustments, or death are recorded in mPCL by a member of the care team using clinical follow-up form templates. This clinical documentation is intended for communication and care coordination among care team members and to update the patient's clinical record and alert other care team members of important changes in clinical status.

SMS Text Messaging and Reminders

One-way SMS text messaging is enabled and programmable through the app to support, for example, scheduled reminders to complete the POS or other study survey instruments.

Educational Module

Basic educational information, adapted from publicly available, web-based resources [36,37], was developed to improve the patients' and caregivers' awareness of the causes and management of a wide range of late-stage cancer symptoms (ie, pain, nausea, constipation, and shortness of breath). Through the support of a US-based literacy expert, the educational module was developed at a primary school reading level and then translated into Kiswahili with the assistance of MUHAS

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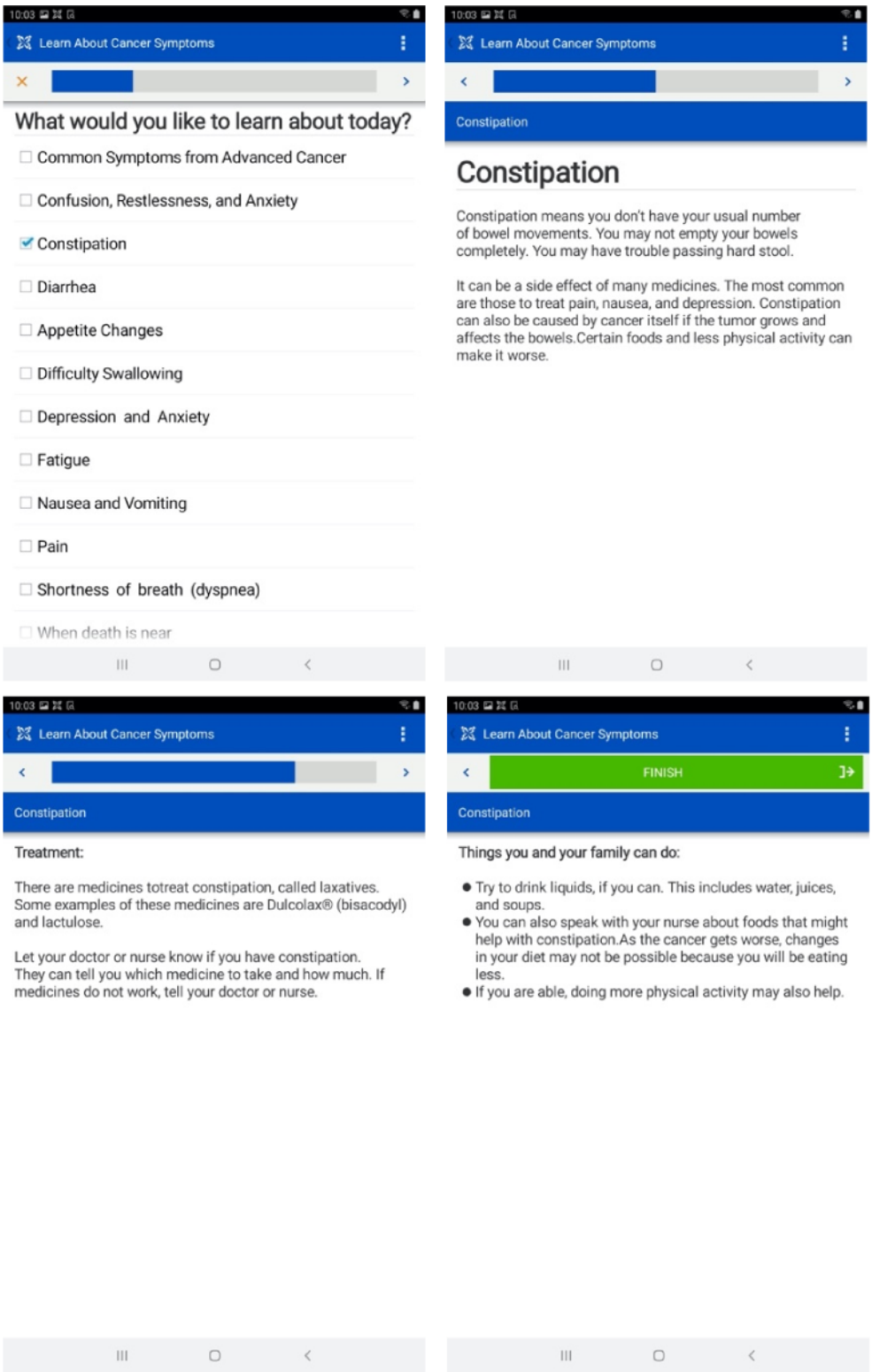
or ORCI study team members and input from patient or caregiver usability test participants (Figure 7).

Figure 7. Example screenshots of the patient symptom-focused educational resource (displayed in Kiswahili for patients). Patients are able to select specific content areas they would like to learn more about.



Emergency Contact

An emergency contact module was built to enable patients or caregivers to directly connect with a member of the care team via phone (Figure 8).

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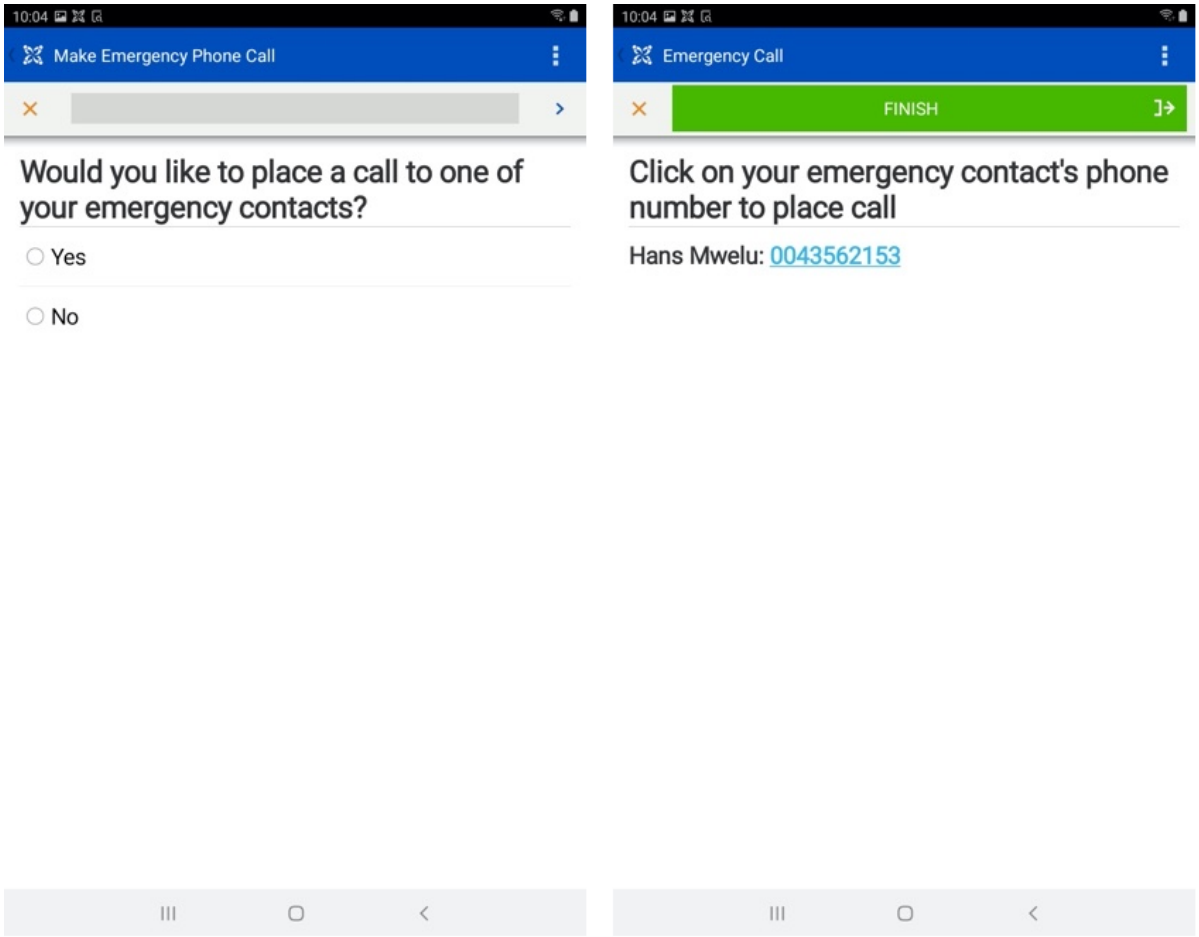
Figure 8. Screenshots of the emergency contact module. When the patient clicks Yes on the first screen of the module (left), they are advanced to the next screen (right), where they can click on a hyperlink to directly call the designated emergency contact.



Discussion

Principal Findings

Here, we describe mPCL HCD and development processes. This secure, patient-centered web and mobile app is focused on extending the reach of a limited pool of specialist clinicians. Specifically, mPCL facilitates real-time symptom collection and reporting for direct communication between patients or caregivers and their clinical care team members, and LHW-specialist care coordination to support prompt and effective community-based symptom control. Through the work described here we show that mPCL is usable and feasible for executing and fulfilling tasks specific to and expected of each user role.

Although this is not the first mobile app dedicated to cancer-related pain and other symptom control, to our knowledge; this is the first such system developed expressly to support palliative care in low-resource settings using a community-based framework of care. Critical to the mPCL design process was input collected directly from potential target end users to inform prototype iterations before finalization of a version deployed in a real-world clinical setting. Although smartphone ownership and connectivity have greatly increased across Tanzania, more of this growth is among younger, more educated, and affluent populations [10], and the use of a smartphone app to deliver a symptom control intervention at a population level in Tanzania has only recently emerged as an area of exploration for researchers and developers. As such, a full awareness and understanding of the target population's context is first needed to build a usable app in terms of access to technologies and resources, ability to adopt and effectively use the intervention, and preferences regarding design, to include a careful assessment of the cultural competency of the app in different populations and settings, especially those facing the greatest socioeconomic and geographic barriers to care.

As with mPCL, individual apps can offer a wide range of functions and specifications, such as educational resources, diaries, reminders, treatment recommendations, and real-time communication with health care providers. There is a need for comprehensive reporting and testing of these individual functions and features to examine which components are most helpful in symptom control. Furthermore, standardized quantification of patient-reported symptoms can be lacking or

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limited in apps. There has been a call for standardized protocols and tools for pain (and other symptom) assessment, as this would strengthen future mHealth studies and allow investigators to synthesize and compare results of individual studies in a range of settings and populations [18]. Here, we designed and demonstrated the usability of an app directly addressing pain and other symptoms (physical and emotional) using a validated patient- and caregiver-focused tool (ie, the African POS). We assessed the POS and other mPCL functions, as well as user-focused features among representatives of all target user groups.

Cancer-related pain is a global issue, with the greatest concern among those in underresourced settings where access to specialists and other resources, including medications, is limited or nonexistent. mPCL is focused on pain and other acute and chronic late-stage symptoms, directly linked to quality of life, among patients with cancer from a low-resource sub-Saharan African country. The design of an interface and functionalities specific to the role of and usability tested among each member of the palliative care team promises to address some of the limitations cited in previous work in this area. Critical to the utility and usability of mPCL was attention to the unique cultural, sociodemographic, and educational experiences (including language proficiencies) and backgrounds of patients and their caregivers. We adopted a rigorous HCD approach with active engagement and participation of patients and caregivers throughout the app design process—a technique that is viewed as essential to the adoption and ultimate effectiveness (herein, reflected in improved quality of life among patients with cancer) of new technologies in low-resource settings [38-40].

Core to mPCL functionality is the scheduled delivery and collection of patient symptoms and quality of life indicators made available real time to all care team members. This functionality promises to deliver a prompt response to escalating symptoms. The clinician end users viewed immediate access to the synoptic clinical record and follow-up notes, as well as functions focused on user group communication and care coordination, as critical. The generation and tracking of the synoptic clinical record were not found to be cumbersome among the specialists who participated in both initial usability testing and early pilot testing and users perceived the clinical information to be up to date. In line with previous literature revealing that real-time communication improves outcome relative to adequate pain control, access to emergency phone contact with a care team member was seen as an essential component of mPCL [16].

Notably, both patients and LHWs reported the importance of the educational module in improving awareness of anticipated late-stage, cancer-associated symptoms as well as an understanding of the basic means to control these symptoms. Although these resources were directed at the patient and caregiver, LHWs reported that this information was informative for them personally and they believed that it supported them in their care of patients with cancer.

Conclusions

Here, we describe the design and development of a mobile app aimed at extending the reach of a limited pool of specialists, dedicated to symptom control and improved quality of life among late-stage cancer patients in low-resource settings. We followed an HCD framework with direct engagement of all target end user groups—specialists (physicians and nurses), LHWs, and patients and caregivers—to design the prototype. The central focus of the app was real-time symptom monitoring (using a validated scale) and communication. Usability testing revealed general app acceptance, and early pilot testing showed the app to be usable and feasible in the setting of a single urban cancer institute. Our broader, randomized field study will provide further evidence regarding the clinical utility of mPCL. Additional questions related to this work include the generalizability of mPCL to other geographic settings and in settings with less access to symptom control medications and other support resources. As mobile technologies continue to grow and evolve in low-resource settings such as Tanzania, the field of cancer medicine can greatly benefit from an understanding of how to build patient-centric tools optimized for remote symptom monitoring and tracking as well as effective and efficient care coordination. Furthermore, rigorous studies of the use of tools such as mPCL in practice will be critical to understanding how they can be widely adopted and scaled.

Acknowledgments

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Authors' Contributions

The coauthors of this paper include the following individuals who were active contributors to the study and the app design and development team: HM served as the study nurse on the project and reviewed and provided input to the manuscript on the role of nurses. MN was a coinvestigator on the project. She directly supported all ORCI-based study activities and reviewed and provided input to the manuscript on the role of specialist physicians. JM served as the primary technical focal point on this project and reviewed and provided input to the manuscript on the deployment of mPCL in the pilot study. As a PI, TN contributed to the conception of the project, and oversaw all study activities at ORCI. He reviewed and provided input to the manuscript. BM served as the study coordinator throughout the project period and reviewed and provided input to the manuscript on methods and results. SM was the lead PI; she conceived of mPCL and oversaw the overall project. She contributed significantly to the initial draft and the development of the manuscript. RM led UX design and usability and pilot data collection and analyses. He contributed

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significantly to the initial draft and the development of the manuscript. EQ actively contributed to the design and development of the app and assisted with the generation of figures. KL led the design and development of the app and assisted with editing portions of the manuscript and generation of figures. YH served as a PI, oversaw the app design and development, and contributed significantly to the initial draft and development of the manuscript. SS managed the project timeline and design of the app and assisted with editing portions of the manuscript and generation of figures.

Conflicts of Interest

KL, EQ, YH, SS are involved in the design and development of the mobile application described in this paper and are employed by the organization whose revenue depends on the open source platform on which the mobile application was built. No other conflicts have been declared.

References

1. Harding R, Selman L, Powell RA, Namisango E, Downing J, Merriman A, et al. Research into palliative care in sub-Saharan Africa. Lancet Oncol 2013 Apr;14(4):e183-e188. [doi: 10.1016/S1470-2045(12)70396-0] [Medline: 23561750]
2. Sung H, Ferlay J, Siegel RL, Laversanne M, Soerjomataram I, Jemal A, et al. Global cancer statistics 2020: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. CA Cancer J Clin 2021 Feb 04 [FREE Full text] [doi: 10.3322/caac.21660] [Medline: 33538338]
3. Kanavos P. The rising burden of cancer in the developing world. Ann Oncol 2006 Jun;17 Suppl 8:viii15-viii23 [FREE Full text] [doi: 10.1093/annonc/mdl983] [Medline: 16801335]
4. Parkin DM, Sitas F, Chirenje M, Stein L, Abratt R, Wabinga H. Part I: Cancer in indigenous Africans--burden, distribution, and trends. Lancet Oncol 2008 Jul;9(7):683-692. [doi: 10.1016/S1470-2045(08)70175-X] [Medline: 18598933]
5. Harding R, Selman L, Agupio G, Dinat N, Downing J, Gwyther L, et al. The prevalence and burden of symptoms amongst cancer patients attending palliative care in two African countries. Eur J Cancer 2011 Jan;47(1):51-56. [doi: 10.1016/j.ejca.2010.08.003] [Medline: 20822896]
6. Grant L, Downing J, Namukwaya E, Leng M, Murray SA. Palliative care in Africa since 2005: good progress, but much further to go. BMJ Support Palliat Care 2011 Sep;1(2):118-122. [doi: 10.1136/bmjspcare-2011-000057] [Medline: 24653220]
7. Powell RA, Harding R, Namisango E, Katabira E, Gwyther L, Radbruch L, et al. Palliative care research in Africa: consensus building for a prioritized agenda. J Pain Symptom Manage 2014 Feb;47(2):315-324 [FREE Full text] [doi: 10.1016/j.jpainsymman.2013.03.022] [Medline: 23870840]
8. Powell RAH, Harding R, Namisango E, Katabira E, Gwyther L, Radbruch L, et al. Palliative care research in Africa: consensus building for a prioritized agenda. J Pain Symptom Manage 2014 Feb;47(2):315-324. [doi: 10.1016/j.jpainsymman.2013.03.022]
9. Stjernswärd J, Foley KM, Ferris FD. The public health strategy for palliative care. J Pain Symptom Manage 2007 May;33(5):486-493. [doi: 10.1016/j.jpainsymman.2007.02.016] [Medline: 17482035]
10. Silver L, Johnson C. Majorities in sub-Saharan Africa own mobile phones, but smartphone adoption is modest. Washington, DC: PEW Research Center; 2018. URL: https://www.pewresearch.org/global/2018/10/09/majorities-in-sub-saharan-africa-own-mobile-phones-but-smartphone-adoption-is-modest/ [accessed 2021-02-12]
11. New horizons for health through mobile technologies. Based on the findings of the second global survey on eHealth Global Observatory for eHealth series - Volume 3. World Health Organization. 2011. URL: https://www.who.int/goe/publications/goe_mhealth_web.pdf [accessed 2021-02-21]
12. Hazin R, Qaddoumi I. Teleoncology: current and future applications for improving cancer care globally. Lancet Oncol 2010 Feb;11(2):204-210. [doi: 10.1016/s1470-2045(09)70288-8]
13. Hall CS, Fottrell E, Wilkinson S, Byass P. Assessing the impact of mHealth interventions in low- and middle-income countries--what has been shown to work? Glob Health Action 2014;7:25606 [FREE Full text] [Medline: 25361730]
14. Mutebi M, Bhatia R, Salako O, Rubagumya F, Grover S, Hammad N. Innovative use of mHealth and clinical technology for oncology clinical trials in Africa. JCO Glob Oncol 2020 Jun;6:948-953 [FREE Full text] [doi: 10.1200/JGO.19.00191] [Medline: 32614724]
15. de la Vega R, Miró J. mHealth: a strategic field without a solid scientific soul. a systematic review of pain-related apps. PLoS One 2014;9(7):e101312 [FREE Full text] [doi: 10.1371/journal.pone.0101312] [Medline: 24999983]
16. Zheng C, Chen X, Weng L, Guo L, Xu H, Lin M, et al. Benefits of mobile apps for cancer pain management: systematic review. JMIR Mhealth Uhealth 2020 Jan 23;8(1):e17055 [FREE Full text] [doi: 10.2196/17055] [Medline: 32012088]
17. Kroenke K, Theobald D, Wu J, Norton K, Morrison G, Carpenter J, et al. Effect of telecare management on pain and depression in patients with cancer: a randomized trial. J Am Med Assoc 2010 Jul 14;304(2):163-171 [FREE Full text] [doi: 10.1001/jama.2010.944] [Medline: 20628129]
18. Thurnheer SE, Gravestock I, Pichierri G, Steurer J, Burgstaller JM. Benefits of mobile apps in pain management: systematic review. JMIR Mhealth Uhealth 2018 Oct 22;6(10):e11231 [FREE Full text] [doi: 10.2196/11231] [Medline: 30348633]
19. Rosser BA, Eccleston C. Smartphone applications for pain management. J Telemed Telecare 2011;17(6):308-312. [doi: 10.1258/jtt.2011.101102] [Medline: 21844177]

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20. Portelli P, Eldred C. A quality review of smartphone applications for the management of pain. Br J Pain 2016 Aug;10(3):135-140 [FREE Full text] [doi: 10.1177/2049463716638700] [Medline: 27583140]
21. Bloomfield GS, Vedanthan R, Vasudevan L, Kithei A, Were M, Velazquez EJ. Mobile health for non-communicable diseases in Sub-Saharan Africa: a systematic review of the literature and strategic framework for research. Global Health 2014;10:49 [FREE Full text] [doi: 10.1186/1744-8603-10-49] [Medline: 24927745]
22. Chib A, van Velthoven MH, Car J. mHealth adoption in low-resource environments: a review of the use of mobile healthcare in developing countries. J Health Commun 2015;20(1):4-34. [doi: 10.1080/10810730.2013.864735] [Medline: 24673171]
23. Brinkel J, Krämer A, Krumkamp R, May J, Fobil J. Mobile phone-based mHealth approaches for public health surveillance in sub-Saharan Africa: a systematic review. Int J Environ Res Public Health 2014 Nov;11(11):11559-11582 [FREE Full text] [doi: 10.3390/ijerph111111559] [Medline: 25396767]
24. Aranda-Jan CB, Mohutsiwa-Dibe N, Loukanova S. Systematic review on what works, what does not work and why of implementation of mobile health (mHealth) projects in Africa. BMC Public Health 2014;14:188 [FREE Full text] [doi: 10.1186/1471-2458-14-188] [Medline: 24555733]
25. Bastawrous A, Armstrong MJ. Mobile health use in low- and high-income countries: an overview of the peer-reviewed literature. J R Soc Med 2013 Apr;106(4):130-142. [doi: 10.1177/0141076812472620] [Medline: 23564897]
26. Obasola OI, Mabawonku I, Lagunju I. A review of e-health interventions for maternal and child health in sub-Sahara Africa. Matern Child Health J 2015 Aug;19(8):1813-1824. [doi: 10.1007/s10995-015-1695-0] [Medline: 25652059]
27. Namisango E, Ntege C, Luyirika EBK, Kiyange F, Allsop MJ. Strengthening pharmaceutical systems for palliative care services in resource limited settings: piloting a mHealth application across a rural and urban setting in Uganda. BMC Palliat Care 2016 Feb 19;15:20 [FREE Full text] [doi: 10.1186/s12904-016-0092-9] [Medline: 26895882]
28. Agarwal S, Perry HB, Long L, Labrique AB. Evidence on feasibility and effective use of mHealth strategies by frontline health workers in developing countries: systematic review. Trop Med Int Health 2015 Aug;20(8):1003-1014 [FREE Full text] [doi: 10.1111/tmi.12525] [Medline: 25881735]
29. Folaranmi T. mHealth in Africa: challenges and opportunities. Perspect Public Health 2014 Jan;134(1):14-15. [doi: 10.1177/1757913913514703] [Medline: 24395839]
30. Vasudevan L, Ostermann J, Moses SM, Ngadaya E, Mfinanga SG. Patterns of mobile phone ownership and use among pregnant women in Southern Tanzania: cross-sectional survey. JMIR Mhealth Uhealth 2020 Apr 08;8(4):e17122 [FREE Full text] [doi: 10.2196/17122] [Medline: 32267240]
31. Harding R, Selman L, Agupio G, Dinat N, Downing J, Gwyther L, et al. Validation of a core outcome measure for palliative care in Africa: the APCA African Palliative Outcome Scale. Health Qual Life Outcomes 2010 Jan 25;8:10 [FREE Full text] [doi: 10.1186/1477-7525-8-10] [Medline: 20100332]
32. POS: Palliative Outcome Scale. African Palliative Care Association. 2012. URL: http://pos-pal.org/ [accessed 2021-02-12]
33. Harte R, Glynn L, Rodríguez-Molinero A, Baker PM, Scharf T, Quinlan LR, et al. A human-centered design methodology to enhance the usability, human factors, and user experience of connected health systems: a three-phase methodology. JMIR Hum Factors 2017 Mar 16;4(1):e8 [FREE Full text] [doi: 10.2196/humanfactors.5443] [Medline: 28302594]
34. Dimagi I. CommCare Mobile/web application software. Dimagi, Inc. URL: http://dimagi.com [accessed 2021-02-12]
35. Nielsen J. Usability engineering 1st ed. In: 362 p. Germany: Kaufmann; Nov 11, 1994:1-362.
36. Toward the end of life: what you and your family can expect. Memorial Sloan Kettering Cancer Center. URL: https://www.mskcc.org/cancer-care/patient-education/towards-end-life [accessed 2021-02-12]
37. Physical changes as you near the end of life. American Cancer Society. 2020. URL: https://www.cancer.org/treatment/end-of-life-care/nearing-the-end-of-life/physical-symptoms.html [accessed 2021-02-12]
38. Adam M, McMahon SA, Prober C, Bärnighausen T. Human-centered design of video-based health education: an iterative, collaborative, community-based approach. J Med Internet Res 2019 Jan 30;21(1):e12128. [doi: 10.2196/12128]
39. Birnbaum F, Lewis D, Rosen RK, Ranney ML. Patient engagement and the design of digital health. Acad Emerg Med 2015 Jun;22(6):754-756 [FREE Full text] [doi: 10.1111/acem.12692] [Medline: 25997375]
40. Henderson VA, Barr KL, An LC, Guajardo C, Newhouse W, Mase R, et al. Community-based participatory research and user-centered design in a diabetes medication information and decision tool. Prog Community Health Partnersh 2013;7(2):171-184 [FREE Full text] [doi: 10.1353/cpr.2013.0024] [Medline: 23793248]

Abbreviations

HCD: human-centered design
LHW: local health worker
mHealth: mobile health
mPCL: mobile-Palliative Care Link
MUHAS: Muhimbili University of Health and Allied Sciences
NCD: noncommunicable disease
ORCI: Ocean Road Cancer Institute
POS: Palliative Care Outcome Scale

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UX: user experience
WHO: World Health Organization

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Original Paper

Effect of Collaborative Review of Electronic Patient-Reported Outcomes for Shared Reporting in Breast Cancer Patients: Descriptive Comparative Study

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Abstract

Background: Digital monitoring of treatment-related symptoms and self-reported patient outcomes is important for the quality of care among cancer patients. As mobile devices are ubiquitous nowadays, the collection of electronic patient-reported outcomes (ePROs) is gaining momentum. So far, data are lacking on the modalities that contribute to the quantity and quality of ePROs.

Objective: The objective of our study was to compare the utilization of two versions of a subsequently employed mobile app for electronic monitoring of PROs and to test our hypothesis that a shared review of symptoms in patient-physician collaboration has an impact on the number of data entries.

Methods: The Consilium Care app engages cancer patients to standardize reporting of well-being and treatment-related symptoms in outpatient settings. For descriptive comparison of the utilization of two slightly different app versions, data were obtained from an early breast cancer trial (version 1 of the app, n=86) and an ongoing study including patients with advanced disease (version 2 of the app, n=106). In both app versions, patients and doctors were allowed to share the information from data entries during consultations. Version 2 of the app, however, randomly selected symptoms that required a detailed and shared regular patient-doctor review in order to focus on the collection and appropriate interpretation regarding awareness and guidance for severity grading. The numbers and types of symptom entries, satisfaction with both app versions, and patients' perceived effects during consultations were included for analysis.

Results: Symptom severity grading was performed according to the Common Terminology Criteria for Adverse Events (CTCAE) using a horizontal slider and was indicated in descriptive terminology in both apps, while a graphical display facilitated the illustration of symptom history charts. In total, 192 patients electronically reported 11,437 data entries on well-being and 33,380 data entries on individual symptoms. Overall, 628 (of 872 intended) requested patient-doctor symptom reviews were performed in version 2 of the app. Both the amount of data entries per patient and day for well-being (version 1 vs version 2: 0.3 vs 1.0; $P<.001$) and symptoms (version 1 vs version 2: 1.3 vs 1.9; $P=.04$) appeared significantly increased in version 2 of the app. Overall satisfaction with both app versions was high, although version 2 of the app was perceived to be more helpful in general.

Conclusions: Version 2 of the app showed much better results than version 1 of the app. A request for collaborative patient-doctor symptom review is likely to affect the number of digital symptom data entries. This app shows high potential to improve the patient-doctor experience.

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Trial Registration: ClinicalTrials.gov NCT02004496; https://clinicaltrials.gov/ct2/show/NCT02004496 and ClinicalTrials.gov NCT03578731; https://clinicaltrials.gov/ct2/show/NCT03578731

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KEYWORDS

cancer; Consilium Care; smartphone app; eHealth; electronic patient-reported outcomes; Common Terminology Criteria for Adverse Events

Introduction

Despite the considerable progress of cancer treatment in recent decades, shortcomings still remain in patient self-management and communication with doctors. Most patients are motivated to spend time and effort in documenting their symptoms for shared reporting with physicians during consultations. However, the collection of electronic patient-reported outcomes (ePROs) is now becoming widespread, since mobile health solutions harbor the potential to improve symptom documentation regarding treatment pathways and facilitate communication between stakeholders [1,2]. To meet these requirements, mobile apps have been designed and tested with input from patients, nurses, and doctors and have gained attention with respect to improving efficacy and safety data in oncology trials and drug discovery studies [3-5]. The benefit of digital patient monitoring during immunotherapy in cancer has been demonstrated in terms of a more efficient symptom assessment and patient-doctor communication, as well as a decreased need for telephone consultations [6-8]. Integrating ePROs for symptom monitoring during routine cancer care has also been associated with increased survival due to early responsiveness to symptoms, longer tolerance, and continuation of chemotherapy, as well as a potential reduction in follow-up costs [9,10]. Recent studies have explored patient compliance rates, with the use of symptom alerts emphasizing the impact of structured graphical displays on outcome reporting [3,4]. Consequently, several digital platforms are now implementing ePROs that allow cancer patients to capture symptoms in a timely and structured manner and to share data with treatment teams. Some platforms also apply automatic algorithms, which indicate alert notifications to patients and treatment centers if symptoms worsen [2,11,12]. We previously reported on the efficacy of the Consilium Care mobile smartphone app in a randomized clinical trial demonstrating that its use could stabilize daily functional activity and well-being of breast cancer patients in collaboration with their physicians [1]. Currently, efforts using version 2 of the Consilium Care app are being made to demonstrate the reliability of electronically captured patient-reported symptom entries upon shared reporting with physicians in routine cancer care for the early detection of critical symptoms [13].

In this study, we describe and compare the functionality and utility of two consecutively developed and slightly different Consilium Care app versions for collecting ePROs and test our hypothesis that a requested review of symptoms in a patient-physician collaboration would impact the frequency or number of digital data entries.

Methods

In order to compare the functionality and utility of both Consilium Care smartphone apps (designed and intended for clinical outcome research), we referred to a cohort of breast cancer patients receiving systemic therapy, demonstrated baseline characteristics, and indicated systemic treatment regimens. Version 1 of the app was previously used in a prospective randomized controlled trial (NCT02004496), while the recently modified version 2 of the app is still being applied in an observational study [1,13]. The observational trial cohort (version 2 of the app) was included in this comparison study since information on utility became available from a subset of breast cancer patients, while the greater part of the participants in this study were treated for cancer of the lung, colon, and prostate, and lymphoma. Eligible participants for both trials were recruited consecutively and without preselection. Recording of well-being and symptoms usually started on the day of the initiation or change of anticancer treatment and continued during an observational period of 6 weeks for version 1 of the app and 12 weeks for version 2 of the app.

Both versions of the Consilium Care app were developed to continuously record symptoms and treatment side effects in cancer patients according to the Common Terminology Criteria for Adverse Events (CTCAE) [10] but were not designed to send questionnaires to patients. Data entry displays for patients in both apps provided similar functions, although they were presented in a slightly different manner. Version 1 of the app collected data on the recording of symptoms, well-being, and activities of daily living. However, the concept for a presumably more modern and user-centered design of version 2 of the app presented a greater range of available symptoms and was implemented with the help of doctors, nurses, and patients.

Graphical displays for entering well-being, symptoms and corresponding grading, private notes, and medications, as well as the “time line” of the patient history of symptoms in both app versions are shown in Figure 1. A horizontal slider on a visual analog scale could be moved to indicate symptom severity and category according to the CTCAE, as displayed below (version 1 of the app) or above (version 2 of the app) the slider. Thirty symptoms were available to indicate severity, onset, and duration in version 1 of the app, and 52 symptoms were available for the same indications in version 2 of the app [1,8]. The first five categories were presented as a visual analog scale, while the sixth category, death, was omitted. Depending on the patient’s input, frequently reported symptoms were either displayed as “favorites” (version 1 of the app) or “last used” (version 2 of the app) (Figure 1).

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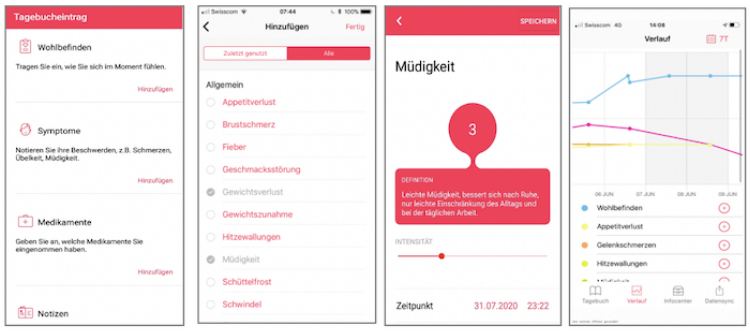
Figure 1. Different graphical displays of the two app versions. CTCAE: Common Terminology Criteria for Adverse Events.

Version 1

Entrance screen facilitates selection of symptoms and favorites, well-being, and private notes. Symptoms are presented in alphabetical order and provided with colors. Data entries "Eingabe" is equipped with date and time stamp. Movement of a slider indicates symptom severity (percentage), and descriptive terminology according to CTCAE (below slider). Colors of the timeline for the history of symptoms (well-being: green, symptoms: different blue tones, diary entries: red, chemotherapy cycle: violet, diagnosis list: yellow). Date of symptom entry and terminology is displayed on bottom.

Version 2

Entrance screen facilitates selection of well-being, symptoms, medication and private notes. Symptoms are displayed as "last used" or can be selected from an organ related list. Symptom entries (eg, fatigue) is equipped with date and time stamp. Movement of a slider indicates symptom severity and category with descriptive terminology according to CTCAE (above slider). Colors of the timeline for the history of symptoms (well-being: blue, symptoms: different colors; diary entries, diagnosis and chemotherapy cycles are indicated separately); navigation line and date of symptom entry on bottom.



Patients could also add private notes or additional symptoms and any medical measures undertaken as free text in version 1 of the app and in a more structured manner in version 2 of the app. In addition, patients indicated their daily functional activities according to the Eastern Cooperative Oncology Group (ECOG) performance status, and information for self-care (derived from the Swiss Cancer League) was displayed by the app depending on the severity of symptoms upon data entry (not shown). The history of recorded data was displayed automatically in both Consilium Care versions in the form of a graph (Figure 1) [4]. Patients were assigned to medical oncology visits every 3 weeks for shared reporting, which were preferentially scheduled on days of chemotherapeutic interventions. During consultation visits, nurses and doctors reminded the participants to use the app. If indicated, patients using version 2 of the app also received push notifications every 3 days to remind them of the need for data entry. Furthermore, at regular intervals, version 2 of the app randomly selected two patient-reported symptoms that were entered during the past 20 days. Patients and doctors were then prompted to perform a detailed and shared review of these symptoms, in order to focus on the collection and appropriate interpretation regarding awareness and guidance for symptom severity grading. Up to four such reviews with two symptoms each were planned according to the scheduled visits. At the end of each observational period, participants were asked to complete a questionnaire on paper reviewing the utility of the app and satisfaction with it in order to evaluate the quality of care and the relationship between the patient and physician during the course of treatment. The rating was completed after study participation using a 5-point Likert scale with scores ranging from 1 (agree not at all) to 5 (agree very strongly).

Both versions of the Consilium Care app were available on the most common platforms (Apple App Store or Google Play Store). After loading the app, a QR scanner was available to decode the patients' personalized QR code. The participating centers were responsible for data entry into the electronic data capture (EDC) system. Patient data were stored in a designated ISO 27001-certified data center. ePRO data were synchronized between the smartphone app and the databank accordingly. For each patient's convenience, a summary of diagnostic work-up, treatment medications, and the contact information of the respective treatment center were displayed on both app versions.

For descriptive analysis, categorical variables were presented as frequencies and percentages. Differences between groups were assessed using Pearson chi-square test. Age was presented as mean (SD). The numbers of entries per patient and day were not normally distributed and hence were reported as medians with IQR. The Mann-Whitney test was performed to compare groups. Two-sided P values ≤.05 were considered statistically significant. There was no adjustment for multiple testing. All statistical analyses were performed using R version 4.0.0 (R Foundation for Statistical Computing).

The research complies with the guidelines for human studies and was conducted ethically in accordance with the World Medical Association Declaration of Helsinki. We state that all participants provided written informed consent to publish their data. Both study protocols (NCT02004496 and NCT03578731) were approved by the local ethics committee on human research.

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Results

Baseline Characteristics

Between December 2013 and July 2015, 86 breast cancer patients using version 1 of the app completed all study visits, while for version 2 of the app, data from a subset of 106 patients were available for analysis upon recruitment from November 2018 to October 2019. For descriptive comparison, baseline characteristics as distributed between both patient groups are displayed in Table 1. The mean age of the patients using version 1 of the app was 52 years, and that of the patients using version 2 of the app was 56 years (Table 1). All 86 patients using version 1 of the app were treated for early stage disease, and two-thirds (n=54, 63%) of these patients were treated in an adjuvant setting. In contrast, about half (n=56, 53%) of the patients using version 2 of the app received treatment for advanced disease with noncurative intention. In patients using version 1 of the app, a total of seven distinct chemotherapeutic agents in six different chemotherapy regimens were administered (Figure 2), whereas a much greater variety of 16 distinct antitumoral agents, including antihormones, CDK4/6 inhibitors, and immunotherapies, were applied in patients using version 2 of the app. During the ePRO reporting period, the most frequent chemotherapy regimens applied in early stage breast cancer were epirubicin/cyclophosphamide (n=32), paclitaxel/trastuzumab (n=19), and paclitaxel/carboplatin (n=12). In contrast, for users of version 2 of the app, the most commonly used therapeutic regimens were antihormones ± CDK4/6 inhibitors (n=25), carbo-docetaxel-Herceptin/Perjeta (n=13), docetaxel-endoxan (n=13), and checkpoint inhibitors (n=11) (Figure 2). Owing to more advanced disease stages and neoadjuvant regimens, CDK4/6 inhibitors and anti-HER2 antibodies were among the most applied drugs in the patient cohorts.

Table 1. Patient demographics.

Characteristic	Consilium Care app		*P* value
	Version 1 (n=86)	Version 2 (n=106)	
Age (years), mean (SD)	52 (11)	56 (12)	.002
Female, n (%)	85 (99%)	106 (100%)	0.45
Male, n (%)	1 (1%)	0 (0%)	
Intention, n (%)			
Adjuvant	54 (63%)	34 (32%)	<.001
Neoadjuvant	32 (37%)	16 (15%)	<.001
Noncurative	0 (0%)	56 (53%)	<.001
Breast cancer	86 (100%)	106 (100%)	1.0
Well-being entries (total), n	1430	10,007	
Per patient	16	94	
Per patient and day, median (IQR)	0.3 (0.02-0.8)	1.0 (0.8-1.2)	<.001
Symptom entries (total), n	9271	24,109	
Per patient	107	227	
Per patient and day, median (IQR)	1.3 (0.6-3.0)	1.9 (1.1-3.5)	.038

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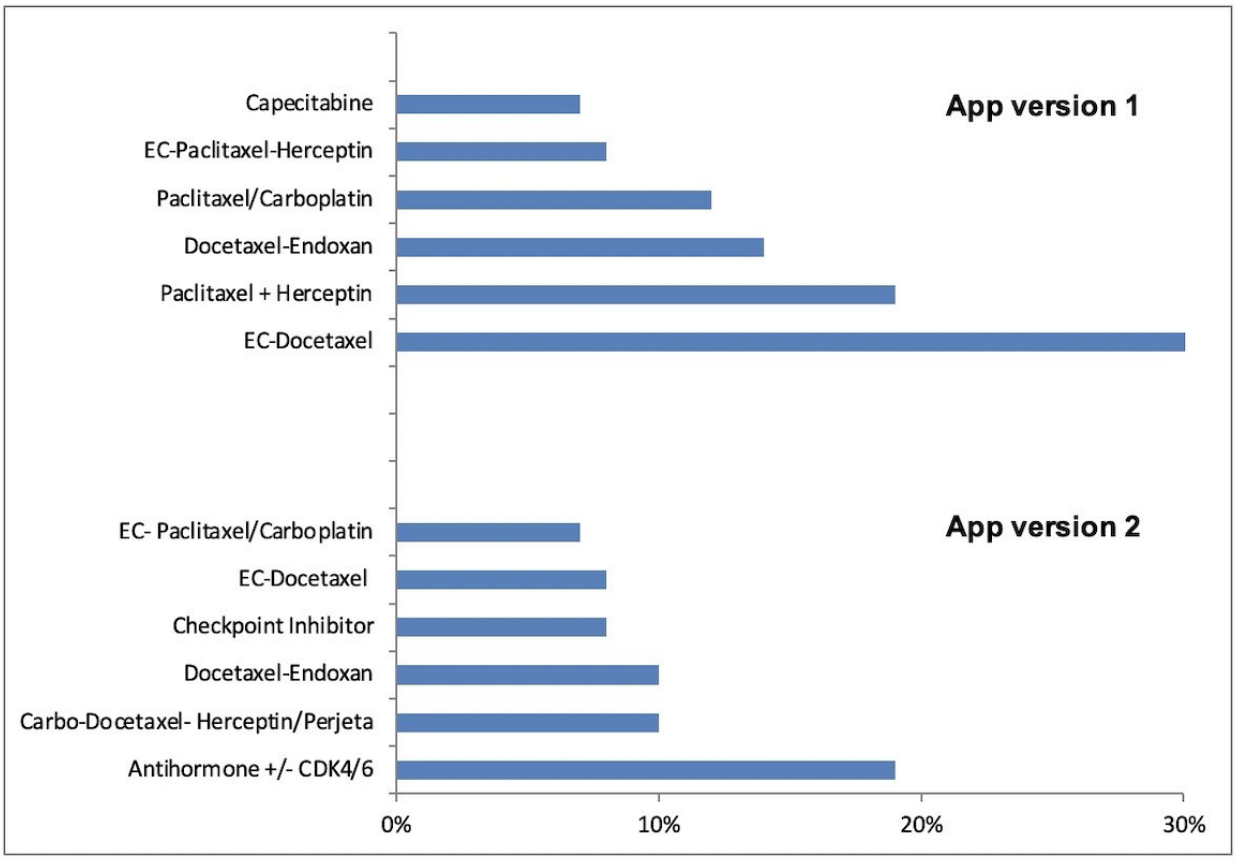
Figure 2. Frequency of the most commonly applied anticancer therapies during Consilium app use.



Well-Being and Symptoms

Since neither of the Consilium Care versions was designed to send questionnaires, reporting on well-being and symptoms was primarily performed on the patient's individual motivation, although push notifications were sent every 3 days if indicated. Overall, a high absolute amount of data entries on well-being and symptoms was captured in both versions of the app. Regarding well-being, a total of 11,437 data entries were reported, of which 1430 entries were derived from 86 patients using version 1 of the app during an observational period of 6 weeks (average of 41 days), while 10,007 data entries were derived from 106 patients using version 2 of the app during an observational period of 12 weeks (average of 91 days). Considering the time point of treatment (neo/adjuvant vs noncurative), we found that noncurative patients statistically entered more well-being data (median [IQR]: neo/adjuvant, 1.0 [IQR 0.5-1.1] and noncurative, 1.1 [IQR 0.9-1.4]; $P<.001$). However, both patient groups (curative and noncurative) using version 2 of the app reported their well-being more than twice as often as early stage breast cancer patients using version 1 of the app (version 1 vs version 2: 0.3 vs 1.0; $P<.001$) (Table 1). Since both app versions displayed the input control for well-being in a similar manner, this observation seemed unlikely to be associated with design features, but could be attributed to the effects of shared reporting.

In summary, all 192 patients generated a large absolute number (33,380) of electronically reported symptoms and side-effects (9271 in version 1 and 24,109 in version 2), suggesting easy use of control panels and sliders in both app versions. From the 106 patients using version 2 of the app, a total of 628 (of 872 intended) patient-doctor shared reviews were performed on randomly selected symptoms that had been entered during the previous 20 days of the respective period. Since the number of reported symptoms per patient and day appeared significantly higher in users of version 2 of the app (version 1 vs version 2: 1.3 vs 1.9; $P=.038$), the implementation of a request for shared symptom review was likely to have stimulated an increase in the frequency or number of symptom data entries.

The most commonly reported symptom in both groups was fatigue, although this was indicated twice as often (37% vs 18%) in the group of early stage breast cancer (version 1 of the app). This slightly younger and supposedly more fit patient group also frequently reported symptoms, including hair loss, headache, taste disorder, nausea, and abdominal pain (Figure 3), while users of version 2 of the app frequently reported symptoms, including taste disorder, dry mouth, nausea, hot flashes, and joint pain. Unfortunately, owing to the heterogeneity of drugs and limited information on dosage, we were not able to analyze potential associations of symptoms with the applied treatment regimens and settings (eg, adjuvant vs noncurative).

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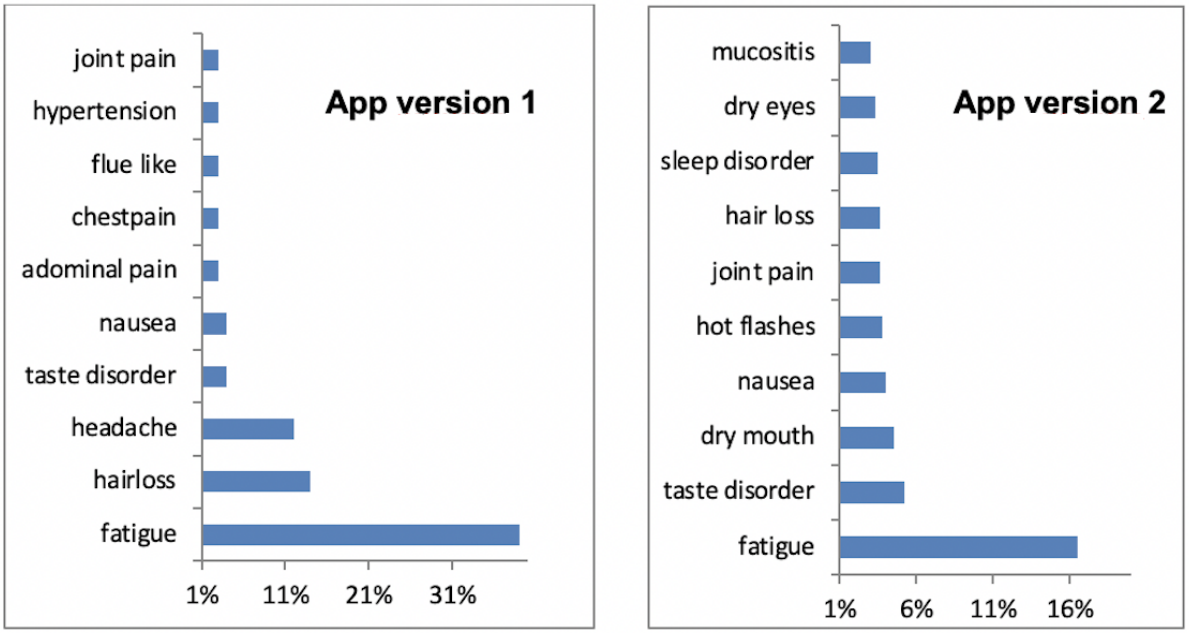
Figure 3. Most frequently reported side-effects in both app versions.



Utility of the Smartphone App Versions

Questionnaires from all patients included in the prospective trial were available for rating version 1 of the app, and questionnaires from 67 patients were available for rating version 2 of the app. No patient died or was censored from analysis. Overall satisfaction with both app versions was high. In our experience, the vast majority of patients were able to use both app versions intuitively to report their symptoms, although a few elderly individuals and nonapp users in particular required instructions from a nurse or physician. According to the answers received from the patient questionnaires (Table 2), both app versions were rated helpful, although version 2 of the app was a clear favorite among users (*P*=.003). Patients in both groups also stated that the app had a positive effect on their doctor visits and that the symptoms were encountered for shared review. Importantly, nearly all patients felt reassured that their personal data were treated confidentially and stated that they would recommend the easy-to-use Consilium Care app version 2 to other patients (Table 2). Although not statistically significant, version 2 of the app appeared to be more helpful for dealing with the symptoms of illness (*P*=.057). Of note, no technical issues or data safety concerns were raised during the course of this study.

Table 2. Comparison of the usability of the two smartphone app versions.

Statement	Good and very good agreement with the statement, % of patients		*P* value
	Version 1 (n=86)	Version 2 (n=67)	
I find the app helpful	62 (72%)	61 (91%)	.003
The app is easy to use	N/A[a]	66 (99%)	N/A[a]
The app helps me deal with the symptoms of my illness	53 (62%)	51 (76%)	.057
The app has had a positive effect on doctor visits	69 (80%)	54 (81%)	.96
My records were taken into account by the doctor during consultations	81 (94%)	60 (90%)	.29
My symptoms are taken seriously by the doctor	84 (98%)	65 (97%)	1.0
I believe that my personal data will be treated confidentially	84 (98%)	67 (100%)	.50
I would recommend the app to other patients	84 (98%)	65 (97%)	1.0

[a]N/A: not applicable.

Discussion

In this article, we demonstrated that collaborative patient-doctor symptom review was likely to affect the number of digital symptom data entries. This finding adds to the increasing published data on the effects of electronic symptom reporting of patients undergoing systemic anticancer therapy [2-7]. Several studies have also reported high compliance rates with patient-reported outcomes in oncology trials, improved accuracy, and completeness of data, as well as positive effects during

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routine cancer treatment [3-5]. Recent findings in breast and prostate cancer patients undergoing radiotherapy, however, indicated that the acceptance and possible benefits of a mobile app might be higher in younger or less fit patients [14]. Likewise, in our study, the recording of well-being during systemic treatment seemed to be more important to the patient group with presumably advanced cancer stages and less fit patients, who needed and expected improved disease control.

The high amount of data entries and answers from the patient questionnaires (Table 2) suggested a considerable ease of use of the Consilium Care app associated with possible benefits for self-empowerment. As a result of inputs from doctors, nurses, and patients at different ages and cancer entities for the development process of version 2 of the app, we designed and implemented automatic reminders (push notifications) and refined the operation for the structured assessment of side-effects and quality of life, as well as symptom history charts, as these are important functions of a mobile app [4,15,16].

Personal communication from patients further indicated a great interest in alert functions, which should be displayed based on data input, and an intrinsic willingness to share this information with the treatment team. Although several patients and doctors showed interest in entering vital data (eg, glucose, blood pressure, and weight), this feature has not yet been implemented in either app version. Previously, in version 1 of the app, we had shown that the use of the Consilium Care app had the potential to stabilize the daily functional activity of cancer patients and that more distinct symptom entries were received from those users who shared reporting with their doctors [1]. Patients using version 2 of the app obviously indicated higher amounts of distinct symptoms (P=.038; Table 1) and indeed reported on their well-being every single day. Therefore, it is likely that the implementation of a request for shared symptom review, as integrated in version 2 of the app, might have positively affected the frequency and number of digital symptom data entries [15,17]. However, owing to several limitations of this study, the treatment context, applied medication schedules, and differences in the number of available symptoms could not be evaluated in more detail for the interpretation of symptom entries.

Since almost all patients stated that they would recommend the app to other patients (Table 2), the general aspects of usability obviously did not negatively affect the patient rating of either app version. Our assumption that patients would positively encounter the intended “fresh look” of the interface and design in version 2 of the app, however, was currently not tested in a specific questionnaire and thus cannot be attributed to an increased number of symptom data entries [4]. In an ongoing observational study, we are investigating how far collaborative symptom reviews might affect both the quality and severity grading of symptoms, as well as reliability of data entries in association with patient outcomes [13]. However, in general, patients rated version 2 of the app as being more helpful, although a considerable benefit in dealing specifically with the symptoms of illness was not demonstrated (Table 2).

As mentioned, neither version of the app was equipped to send questionnaires, and calls from nurse specialists were not intended. We can only speculate regarding how far occasional push notifications, ample choice of symptoms, and listing of frequently selected “favorites” or “last used” symptoms might have influenced patients’ motivation and input selection, as unfortunately, we did not include these variables in our end-of-study assessment [18,19]. However, the increasingly careful symptom recording provided by ePROs, along with improved symptom management in routine outpatient care, demonstrated a reduction in both unplanned hospitalizations and disease burden [2]. In their study, Basch et al [2] asked patients to report (between regular visits and upon weekly email prompts) on 12 common symptoms available for grading on a 5-point scale from 0 (not present) to 4 (disabling) based on clinical criteria (CTCAE). Data from 441 patients contributed to a total of 84,212 individually reported symptoms during a mean period of 7.4 months. Of note, when considering these numbers, a total of more than 250,000 symptom entries would have resulted from our patient cohort, although it cannot be ruled out that patient motivation for reporting may decrease over time. Due to the descriptive characteristic of our study, we were unable to determine a definite pattern in symptom recording with respect to the duration of the observational period (6 vs 12 weeks). On a personal communication level, most of the physicians who explored the Consilium Care app confirmed that, in particular, the summative picture of a timeline history for symptoms could provide more information than a thousand numbers [4]. Most of the patients also indicated that their use of the app had a positive effect on doctor visits with a focus on the evaluation of symptoms.

As patients frequently reported cognitive impairments, the diary characteristic of apps in general might appear helpful to frequently capture and recall disease-related information [17]. Interestingly, users of version 1 of the app indicated their fatigue on almost 6 of 7 days per week, potentially related to a pronounced effect of menopausal symptoms after chemotherapy, while users of version 2 of the app, who had a presumably more severe disease course, indicated their well-being every single day, a finding that could be associated with a lack of wording for cognitive needs in the available CTCAE [17].

In summary, recent published data indicate that efforts in patient-centered design and usability of mobile apps could contribute to the essential collection and communication of high-quality patient-reported outcome data for the timely management of treatment-related side-effects and toxicities [18]. There is a need to further explore how far the range of available symptoms or the intention for shared symptom review may affect the frequency or number of reliable data entries. In the context of increasingly complex cancer therapies, the growing use of oral anticancer drugs, and COVID-19–related efforts to provide remote care, implementation strategies for patient communication and adherence [19] should be iteratively challenged in clinical practice.

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Acknowledgments

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Authors' Contributions

Guarantor of the integrity of the study: AT, ME, and MB; study concept and design: AT and ME; literature review: AT, ME, and MB; clinical studies: AT, MM, and BB; experimental studies/data analysis: ME, BS, and AT; statistical analysis: ME and BS; manuscript preparation: AT, ME, MB, and BS; manuscript editing: MB, AT, ME, and BS. Final approval of the manuscript was provided by all authors.

Conflicts of Interest

AT is the initiator and stock owner of Mobile Health AG, a startup company that operates the Consilium Care smartphone app. AT also serves as a chief medical officer for the startup company. MB is an employee of Mobile Health.

References

1. Egbring M, Far E, Roos M, Dietrich M, Brauchbar M, Kullak-Ublick GA, et al. A Mobile App to Stabilize Daily Functional Activity of Breast Cancer Patients in Collaboration With the Physician: A Randomized Controlled Clinical Trial. J Med Internet Res 2016 Sep 06;18(9):e238 [FREE Full text] [doi: 10.2196/jmir.6414] [Medline: 27601354]
2. Basch E, Deal AM, Kris MG, Scher HI, Hudis CA, Sabbatini P, et al. Symptom Monitoring With Patient-Reported Outcomes During Routine Cancer Treatment: A Randomized Controlled Trial. J Clin Oncol 2016 Feb 20;34(6):557-565 [FREE Full text] [doi: 10.1200/JCO.2015.63.0830] [Medline: 26644527]
3. Basch E. High Compliance Rates With Patient-Reported Outcomes in Oncology Trials Submitted to the US Food and Drug Administration. J Natl Cancer Inst 2019 May 01;111(5):437-439. [doi: 10.1093/jnci/djy183] [Medline: 30561701]
4. Snyder C, Smith K, Holzner B, Rivera YM, Bantug E, Brundage M, PRO Data Presentation Delphi Panel. Making a picture worth a thousand numbers: recommendations for graphically displaying patient-reported outcomes data. Qual Life Res 2019 Feb;28(2):345-356 [FREE Full text] [doi: 10.1007/s11136-018-2020-3] [Medline: 30306533]
5. Basch E, Dueck AC. Patient-reported outcome measurement in drug discovery: a tool to improve accuracy and completeness of efficacy and safety data. Expert Opin Drug Discov 2016 Aug;11(8):753-758. [doi: 10.1080/17460441.2016.1193148] [Medline: 27310432]
6. Iivanainen S, Alanko T, Peltola K, Konkola T, Ekström J, Virtanen H, et al. ePROs in the follow-up of cancer patients treated with immune checkpoint inhibitors: a retrospective study. J Cancer Res Clin Oncol 2019 Mar;145(3):765-774 [FREE Full text] [doi: 10.1007/s00432-018-02835-6] [Medline: 30666409]
7. Trojan A, Huber U, Brauchbar M, Petrausch U. Consilium Smartphone App for Real-World Electronically Captured Patient-Reported Outcome Monitoring in Cancer Patients Undergoing anti-PD-L1-Directed Treatment. Case Rep Oncol 2020;13(2):491-496 [FREE Full text] [doi: 10.1159/000507345] [Medline: 32518544]
8. Schmalz O, Jacob C, Ammann J, Liss B, Iivanainen S, Kammermann M, et al. Digital Monitoring and Management of Patients With Advanced or Metastatic Non-Small Cell Lung Cancer Treated With Cancer Immunotherapy and Its Impact on Quality of Clinical Care: Interview and Survey Study Among Health Care Professionals and Patients. J Med Internet Res 2020 Dec 21;22(12):e18655 [FREE Full text] [doi: 10.2196/18655] [Medline: 33346738]
9. Basch E, Deal AM, Dueck AC, Scher HI, Kris MG, Hudis C, et al. Overall Survival Results of a Trial Assessing Patient-Reported Outcomes for Symptom Monitoring During Routine Cancer Treatment. JAMA 2017 Jul 11;318(2):197-198 [FREE Full text] [doi: 10.1001/jama.2017.7156] [Medline: 28586821]
10. Lizée T, Basch E, Trémolières P, Voog E, Domont J, Peyraga G, et al. Cost-Effectiveness of Web-Based Patient-Reported Outcome Surveillance in Patients With Lung Cancer. J Thorac Oncol 2019 Jun;14(6):1012-1020 [FREE Full text] [doi: 10.1016/j.jtho.2019.02.005] [Medline: 30776447]
11. Licqurish SM, Cook OY, Pattuwage LP, Saunders C, Jefford M, Koczwara B, et al. Tools to facilitate communication during physician-patient consultations in cancer care: An overview of systematic reviews. CA Cancer J Clin 2019 Nov;69(6):497-520 [FREE Full text] [doi: 10.3322/caac.21573] [Medline: 31339560]
12. Calvert M, Kyte D, Mercieca-Bebber R, Slade A, Chan A, King MT, the SPIRIT-PRO Group, et al. Guidelines for Inclusion of Patient-Reported Outcomes in Clinical Trial Protocols: The SPIRIT-PRO Extension. JAMA 2018 Feb 06;319(5):483-494. [doi: 10.1001/jama.2017.21903] [Medline: 29411037]
13. Efficacy of the "Consilium" Smartphone App for Detecting Symptoms and Treatment Side Effects in Cancer Patients (APP-2). ClinicalTrials.gov. URL: https://clinicaltrials.gov/ct2/show/NCT03578731 [accessed 2021-02-26]
14. El Shafie RA, Weber D, Bougatf N, Sprave T, Oetzel D, Huber PE, et al. Supportive Care in Radiotherapy Based on a Mobile App: Prospective Multicenter Survey. JMIR Mhealth Uhealth 2018 Aug 30;6(8):e10916 [FREE Full text] [doi: 10.2196/10916] [Medline: 30166275]

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15. Kessel KA, Vogel MM, Schmidt-Graf F, Combs SE. Mobile Apps in Oncology: A Survey on Health Care Professionals' Attitude Toward Telemedicine, mHealth, and Oncological Apps. J Med Internet Res 2016 Nov 24;18(11):e312 [FREE Full text] [doi: 10.2196/jmir.6399] [Medline: 27884810]
16. Giordano FA, Welzel G, Siefert V, Jahnke L, Ganslandt T, Wenz F, et al. Digital Follow-Up and the Perspective of Patient-Centered Care in Oncology: What's the PRObLem? Oncology 2020;98(6):379-385 [FREE Full text] [doi: 10.1159/000495294] [Medline: 30517946]
17. Reeve BB, McFatrich M, Pinheiro LC, Freyer DR, Basch EM, Baker JN, et al. Cognitive Interview-Based Validation of the Patient-Reported Outcomes Version of the Common Terminology Criteria for Adverse Events in Adolescents with Cancer. J Pain Symptom Manage 2017 Apr;53(4):759-766 [FREE Full text] [doi: 10.1016/j.jpainsymman.2016.11.006] [Medline: 28062347]
18. Di Maio M, Basch E, Bryce J, Perrone F. Patient-reported outcomes in the evaluation of toxicity of anticancer treatments. Nat Rev Clin Oncol 2016 May 20;13(5):319-325. [doi: 10.1038/nrclinonc.2015.222] [Medline: 26787278]
19. Hershman DL, Unger JM, Hillyer GC, Moseley A, Arnold KB, Dakhil SR, et al. Randomized Trial of Text Messaging to Reduce Early Discontinuation of Adjuvant Aromatase Inhibitor Therapy in Women With Early-Stage Breast Cancer: SWOG S1105. J Clin Oncol 2020 Jul 01;38(19):2122-2129 [FREE Full text] [doi: 10.1200/JCO.19.02699] [Medline: 32369401]

Abbreviations

CTCAE: Common Terminology Criteria for Adverse Events
ePRO: electronic patient-reported outcome

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Original Paper

Electronic Health Record Portal Use by Family Caregivers of Patients Undergoing Hematopoietic Cell Transplantation: United States National Survey Study

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Abstract

Background: As family caregivers of patients undergoing hematopoietic cell transplantation have multifaceted caregiving responsibilities (such as medical, household, financial) of long duration, they also have multiple physical, social, psychological, and informational needs.

Objective: This study explored the prevalence of electronic health record patient portal use by family caregivers for managing both their own and their hematopoietic cell transplantation care recipient's health, as well as potential factors associated with portal use.

Methods: An electronic caregiver health survey, first developed via cognitive interviewing methods of hematopoietic cell transplantation caregivers, was distributed nationally (in the United States) by patient advocacy organizations to family caregivers of hematopoietic cell transplantation patients. It was used to assess self-reported caregiver demographics, caregiving characteristics, depression and anxiety with the Patient Health Questionnaire–4, coping with the Brief COPE, and caregiver portal use to manage care recipient's and their own health.

Results: We found that 77% of respondents (720/937) accessed electronic health record patient portals for their care recipients, themselves, or both. Multivariate models indicated use of care recipient electronic health record portals by caregivers was more likely with young, White, married, low-income caregivers caring for a parent, residing with the care recipient, and experiencing more caregiver depression. Caregiver use of their own electronic health record portal was more likely with young, White, high-income caregivers caring for a parent and experiencing chronic medical conditions of their own. Partially due to multicollinearity, anxiety and coping did not contribute independently to this model.

Conclusions: Findings from the survey could open avenues for future research into caregiver use of technology for informational support or intervention, including wearables and mobile health.

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KEYWORDS

hematopoietic stem cell transplantation; caregiver; mobile apps; questionnaire; survey; app; cancer; electronic health record; EHR; online portal; transplant; stem cell; management

Introduction

Caregivers of Patients Undergoing Hematopoietic Cell Transplantation

Hematopoietic cell transplantation is a high-risk but potentially curative therapy for life-threatening blood diseases [1-3]. Hematopoietic cell transplantation patients require a committed informal family caregiver or care partner (relative or friend) to provide unpaid assistance for long durations [4]. Caregivers of hematopoietic cell transplantation patients [5] perform complex medical tasks, transport and accompany patients during appointments, manage medications, monitor vital signs and fluid intake, assist with activities of daily living, and provide emotional support [6,7]. Caregivers experience immense psychological and physical risks resulting from the stresses of managing the care recipients' as well as their own needs [8].

Caregiving demands often exceed the resources available to caregivers [7]. In particular, patients undergoing hematopoietic cell transplantation require caregiving for an extended time, and demands vary based on stage of disease at diagnosis, treatment intensity, and possible treatment complications [4]. If caregivers have to relocate with their care recipient to be close to the transplant center, financial toxicity and social isolation may further compound care demands [9]. Caregiving has also been described as a rewarding and positive experience; however, ensuring quality of life among caregivers of hematopoietic cell transplantation patients requires broad consideration of their physical, social, psychological, and spiritual demands and needs [4].

Informational Needs of Caregivers and Patient Portal Utilization

Caregivers of hematopoietic cell transplantation patients have significant needs for information about their care recipient's laboratory results, appointments, health conditions, or treatment regimens [4,10-12]. These data are available through electronic health record portals, a secure online website allowing patients access to their personal health information [10]. Caregivers may use their care recipient's patient portal to help them with role demands, such as managing medications, keeping up-to-date with medical diagnoses and treatments, and communicating with health care providers [13,14]. Use of the patient portal can support caregivers in managing their own and their care recipient's health [13,15]. However, little is known about hematopoietic cell transplantation caregivers' uptake of their own portal use (self) and use of their care recipient's portal. Information accessed via the patient portal can be critical for reducing caregiver role ambiguity and anxiety, increasing engagement in care, and meeting information needs among hematopoietic cell transplantation caregivers [10].

The purpose of this study was to learn more about family caregivers' use of electronic health record patient portals. Building on inpatient and outpatient interviews, we developed a survey to be distributed nationally (in the United States) to family caregivers of hematopoietic cell transplantation patients—the National Caregiver Health Survey [3,16,17]. We drew upon a nationally representative sample to (1) characterize hematopoietic cell transplantation caregivers; (2) describe their mental health and coping behaviors; and (3) examine the relationship between caregiver characteristics, mental health and coping, and caregiver self and care recipient portal use.

Methods

Study

The survey is part of a larger multiphase project and was developed through cognitive interviews with hematopoietic cell transplantation caregivers, using verbal probing and think-aloud techniques [3,10,17-25].

Sampling Frames

The sampling frames were email distribution lists from the National Bone Marrow Transplant Link (nBMTLINK) and Blood and Marrow Transplant Information Network (BMT InfoNet); both are nonprofit patient advocacy organizations in the United States devoted to serving transplant patients and family caregivers. With institutional review board approval, the nBMTLINK and BMT InfoNet advertised and provided access (ie, through hyperlinks) to the survey in their electronic newsletters and through email distribution lists. All listed members were presumed to have been sampled. Recruitment into the lists was voluntary and opt-in. Total counts of members in the lists and noncoverage of the target population were unknown. Additional survey responses were obtained by distributing a study brochure that contained the survey URL and QR code at BMT InfoNet's Celebrating a Second Chance at Life Survivorship Symposium (May 2-5 2019, Orlando, Florida). A waiver of informed consent documentation was obtained, and information about the survey was provided on the first screen.

Potential Error

Although there is no sampling error in a census (ie, all members of the email lists were sampled), there were other sources of potential error in surveys, such as nonresponse and measurement errors. The survey was implemented by the Center for Survey Research at Indiana University (LY); cognitive interview techniques [3] were used to minimize error in the development of the questionnaire.

Data Collection

The survey was programmed for web administration in Qualtrics (Qualtrics XM) software. The field period was May 2 to June 30, 2019. Eligibility criteria included being an unpaid informal caregiver of an hematopoietic cell transplantation recipient, an adult, and able to complete the survey online in English. A US $20 gift card was offered to respondents for survey completion. The survey duration was approximately 16 minutes.

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Survey Components

The survey included 5 components: (1) caregiver characteristics (age, gender, race, ethnicity, marital status, educational status, employment, annual household income, relationship with care recipient, and caregiver medical conditions, for example, high blood pressure, heart disease, diabetes, arthritis, asthma, mental health disorder, cancer); (2) caregiving characteristics, responsibilities, and life experiences posttransplant (eg, care recipient's age, gender, timing of transplant, transplant type, and transplant source, stem cell donor relationship, care duration, care burden, whether residing with the care recipient, whether caring for others in addition to the hematopoietic cell transplantation patient); (3) use of information technology, including the patient portal; (4) depression and anxiety; and (5) coping strategies [3]. For items 4 and 5, the Patient Health Questionnaire (PHQ-4), and Brief COPE were incorporated [26,27].

The PHQ-4 screens has depression and anxiety subscales consisting of 2 items each [26,28]. Respondents rate symptoms of depressed mood (eg, having little interest or pleasure in doing things) and anxiety (eg, not being able to stop or control worrying), over the past 2 weeks on a scale from 0 (not at all), to 3 (nearly every day). Subscale scores range from 0 to 6 with a cut-off score of 3, suggestive of clinically significant depressive or anxiety disorders, respectively. Higher scores indicate worse depression and anxiety, with Cronbach α=.85 when measured in a large general population sample [29].

Brief COPE is a 28-item instrument used to assess 14 different coping strategies: self-distraction, active coping, denial, alcohol and drug use, use of emotional support, use of instrumental support, behavioral disengagement, venting, positive reframing, planning, use of humor, acceptance, and religion [30]. The author provides permission to choose or adapt selected scales for use. Thus, based on cognitive interviews of hematopoietic cell transplantation caregivers, 16 items were included in the final survey [3]. Factor analysis yielded a set of 4 unique coping factors. The mean response to the component items in each factor served as each caregiver's score for that factor.

Statistical Analysis

We summarized continuous variables with means and standard deviations, and we summarized categorical variables with percentages. Logistic regression models were fit in 3 stages. First, we assessed the univariate and multivariate association of caregiver characteristics with use of the health care portal for the care recipient's health. The multivariate model was determined by entering all variables at once and then removing one variable at a time (backward selection) until all remaining variables were statistically significant (ie, had odds ratios with 95% confidence intervals that excluded the value of 1.0). Second, we assessed univariate and multivariate associations of caregiver mental health measures with use of the health care portal for the care recipient's health using the same approach. Third, we combined all the variables from the two multivariate models into a single combined multivariate model and further reduced variables with backward selection. These three modeling approaches were also repeated with the outcome changed to the caregiver's use of a health care portal for their own health. The fit of all multivariate models was summarized by area under the curve (AUC), which ranges from 0.5 for a random model to 1.0 for a perfect model and quantifies how well the fitted logistic regression probabilities discriminate among caregivers who use the portal and caregivers who do not. Data were analyzed using R (version 3.6.02) in R Studio (version 1.2.5033).

Results

Caregiver Demographics

A flow diagram of the survey respondents (N=948) is shown in Figure 1, and demographics are summarized in Table 1. Note that percentages are based on denominators that vary from the overall sample size of 948 due to missing data. The median age of the study population was 40 years (range 18-89 years). Most caregivers identified as female (620/944, 65.7%), were married (823/943, 87.3%), were employed (743/940, 79.0%), were White (746/940, 79.4%), were of non-Hispanic ethnicity (783/941, 83.2%), were college educated (665/945, 70.4%), and had annual household income greater than $50,000 (623/872, 71.4%). Caregiver relationships to care recipients were parent (311/946, 32.9%), adult child (274/946, 28.9%), spouse (257/946, 27.1%), and other (104/946, 11.1%; eg, grandparent, cousin, friend).

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Figure 1. Flow diagram outlining number of eligible and responding participants to survey, as well as number of participants included in analysis.

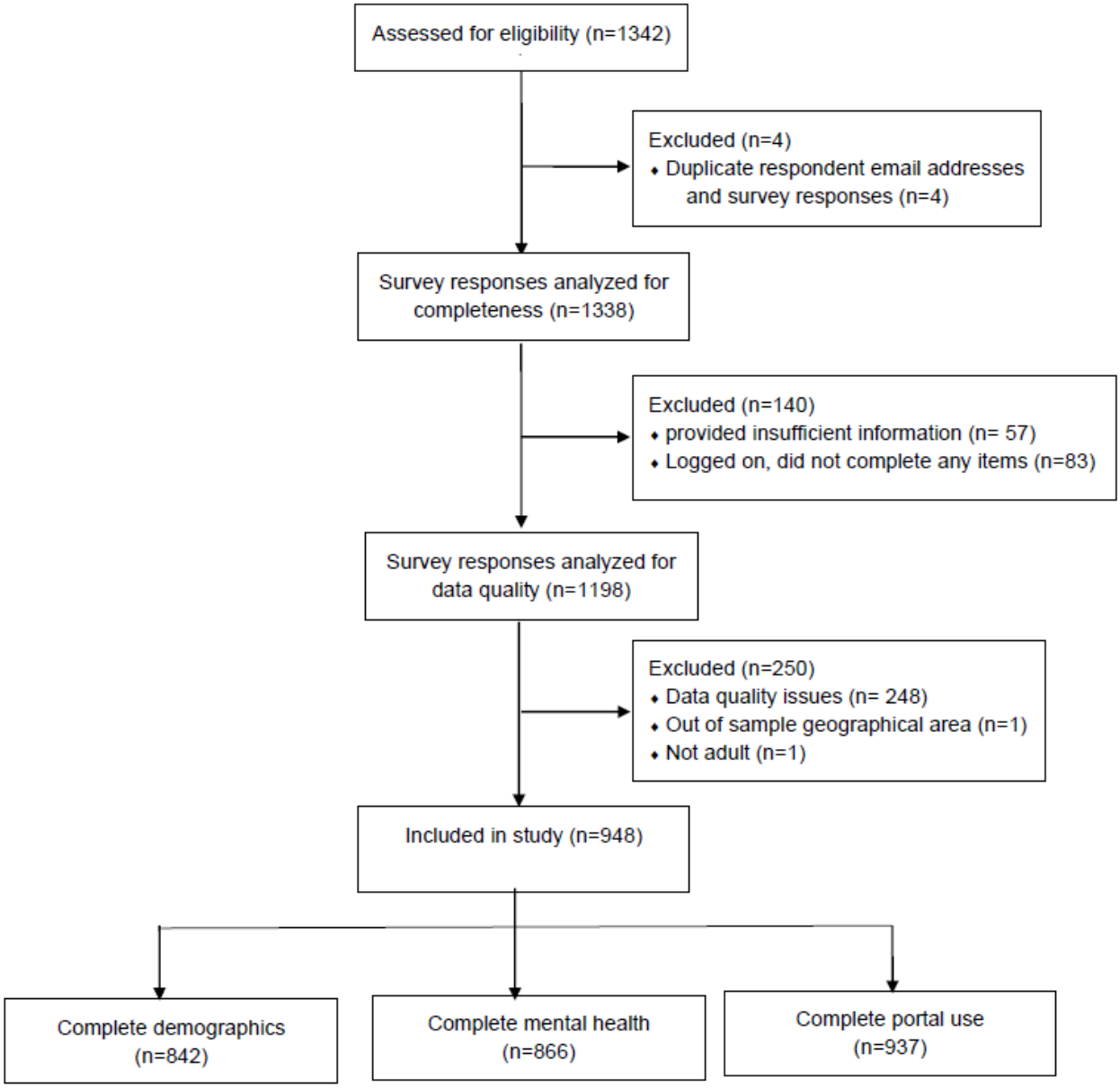

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Table 1. Summary of caregiver demographics and caregiving characteristics.

Variables	Participants (excluding missing data)
Age (years), n (%)	
≤40 years	479 (50.7)
>40 years	465 (49.3)
Gender, n (%)	
Male	324 (34.2)
Female	620 (65.7)
Income, n (%)	
≤$50,000	249 (28.5)
$50,001-$99,999	373 (42.8)
≥$100,000	250 (28.7)
Race, n (%)	
White	746 (79.4)
Other[a]	194 (20.6)
Ethnicity, n (%)	
Hispanic	158 (16.8)
Non-Hispanic	783 (83.2)
Marital status, n (%)	
Married	823 (87.3)
Unmarried	120 (12.7)
Employment status, n (%)	
Employed	743 (79.0)
Unemployed	197 (21.0)
Education, n (%)	
Some college or less	280 (29.6)
College degree or more	665 (70.4)
Caregiver relation to recipient, n (%)	
Parent	311 (32.9)
Child	274 (28.9)
Spouse	257 (27.1)
Other	104 (11.1)
Donor relationship, n (%)	
Related donor	476 (51.0)
Unrelated donor	328 (35.1)
Patient themselves	130 (13.9)
Caregiver supporting another individual, n (%)	
Yes	644 (68.1)
No	301 (31.9)
Care duration, n (%)	
≤6 months	443 (46.9)
>6 months	501 (53.1)
Care burden, n (%)	
≤20 hours/week	343 (36.4)

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Variables	Participants (excluding missing data)
20-40 hours/week	376 (39.9)
>40 hours/week	224 (23.7)
Caregiver lives with recipient, n (%)	
Yes	786 (83.4)
No	156 (16.6)
Caregiver medical conditions, mean (SD)	1.2 (1.3)

[a]The race variable was a multiple choice question in our survey; however, since the majority of respondents were White, during analysis, we used only dummy code White/non-White.

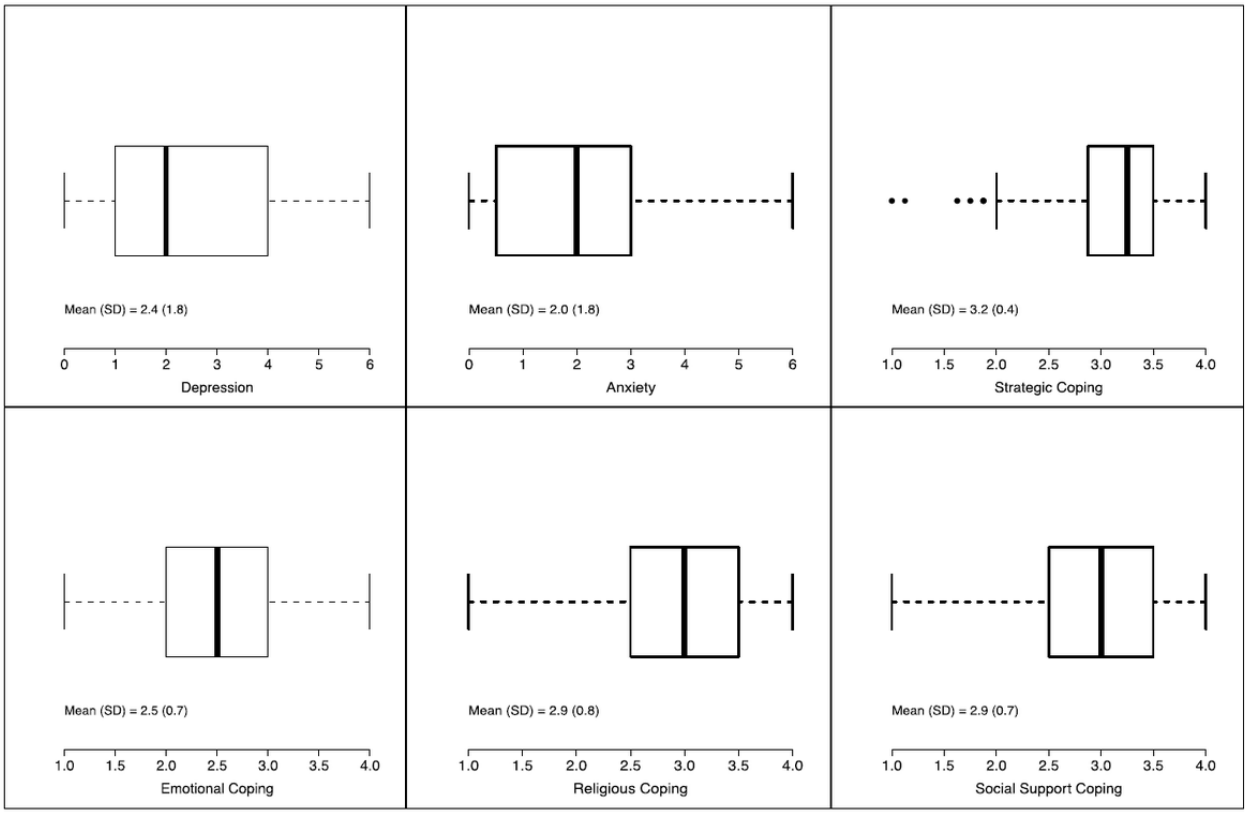
Caregiving Responsibilities and Characteristics

The majority of caregivers supported another individual in addition to the care recipient (644/945, 68.1%) and resided in the same household as the care recipient (786/942, 83.4%). Care demands varied from ≤20 hours per week (343/943, 36.4%), through 20 to 40 hours per week (376/943, 39.9%), to >40 hours per week (224/943, 23.7%). Duration of caregiving was almost evenly split between ≤6 months (443/944, 46.9%) and >6 months (501/944, 53.1%). Two-thirds of caregivers (629/948, 66.4%) indicated they had at least one chronic medical condition.

Caregiver Mental Health

Caregiver mental health variables are summarized in Figure 2; 28.6% of caregivers (259/904) exceeded the cut-off score of 3 for clinically significant depression, and 21.5% (194/903) exceeded the cut-off score of 3 for clinically significant anxiety. The means of the 4 coping scales ranged from 2.5 to 3.0, suggesting the 4 coping processes were used sometimes by the average caregiver.

Figure 2. Summary of caregiver mental health characteristics.



Care Recipient Demographics

Care recipient demographics are summarized in Table 2. Most (658/944, 69.7%) were adults and 63.3% (598/945) were male; 50.9% (476/934) received a transplant from a related donor, 35.1% (328/934) from an unrelated donor, and 13.9% (130/934) received an autologous transplant. Cell sources for the transplants varied among bone marrow (470/935, 50.3%), peripheral blood (113/935, 37.6%), and cord blood (113/935, 12.1%).

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Table 2. Summary of care recipient characteristics.

Variables	Participants, n (%)
Age (years) (n=944)	
<18 years	286 (30.3)
≥18 years	658 (69.7)
Gender (n=945)	
Male	598 (63.3)
Female	347 (36.7)
Timing of transplant (n=945)	
≤6 months	234 (24.8)
7 months-1 year	197 (20.8)
1-2 years	164 (17.3)
2-3 years	188 (20.0)
>3 years	162 (17.1)
Transplant type (n=935)	
Bone marrow cells	470 (50.3)
Cord blood cells	113 (12.1)
Peripheral blood stem cells	352 (37.6)

Health Care Portal Usage

Caregivers (597/937, 64%) accessed a health care portal for information regarding their care recipient's health, 49% (463/937) accessed a health care portal for checking their own health information; 36.2% (340/937) accessed a health care portal for checking both (ie, self as well as care recipient's), while 23.1% (217/937) did not access a portal for either purpose.

We report univariate correlations between demographics, mental health variables, and caregiver access of health care portals for their care recipients in Multimedia Appendix 1.

Caregiver Factors Associated With Use of Care Recipient's Health Care Portal

In the multivariate model of caregiver demographics, care recipient portals were more likely to be accessed by White caregivers, 40 years old or younger, married, earning an income less than $50 000, caring for their parent, and living with their care recipient (Figure 3A; AUC 0.885). In the multivariate model of caregiver mental health variables, care recipients' portals were more likely to be accessed by caregivers with higher depression, anxiety, and emotional coping (Figure 3B, AUC 0.668). However, in the final multivariate model that included both caregiver demographics and mental health variables, caregiver depression was the only mental health variable that remained associated with caregiver use of the care recipient portal while controlling for caregiver demographics (Figure 4; AUC 0.856).

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Figure 3. Multivariate odds ratios (dots) and 95% confidence intervals (bars) for (A) caregiver characteristics and (B) mental health for the use of a care recipient's health portal. CG: caregiver.

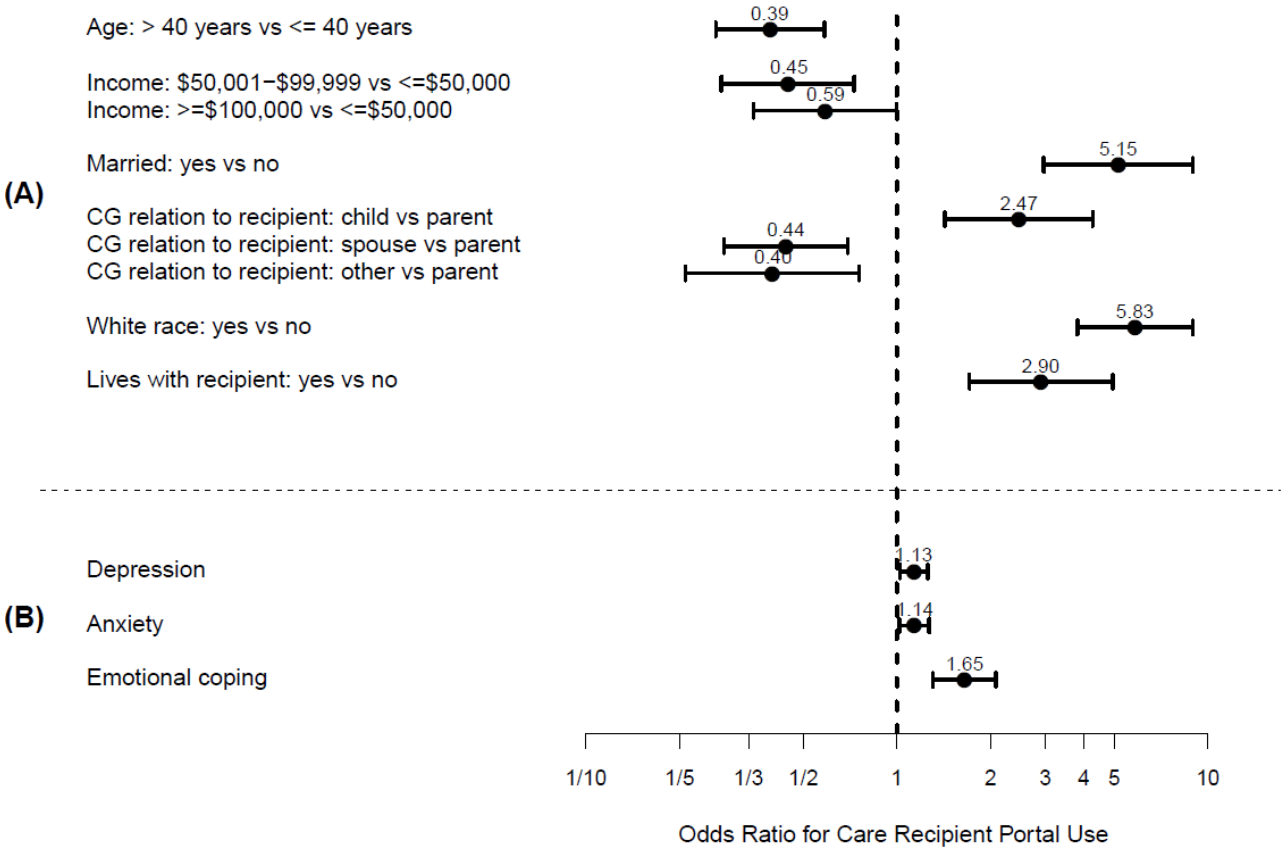
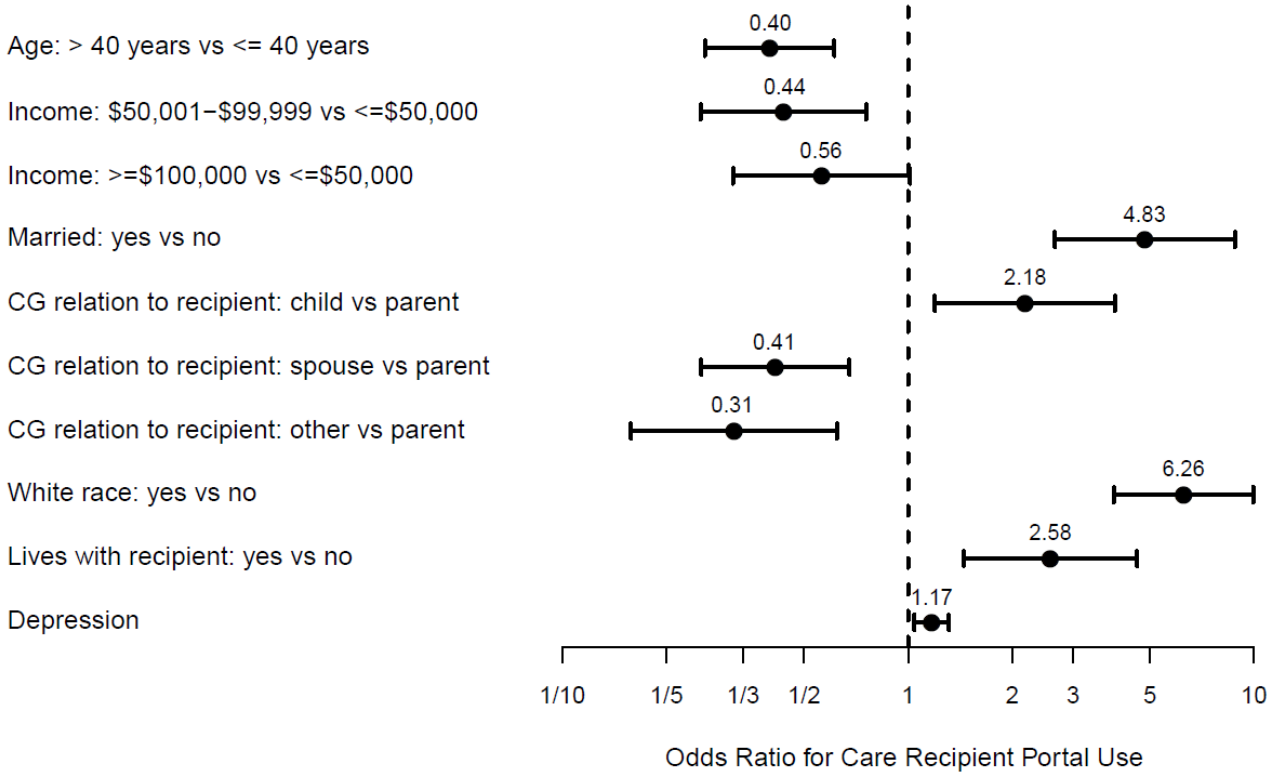


Figure 4. Multivariate odds ratios (dots) and 95% confidence intervals (bars) for combined caregiver characteristics and mental health for the use of a care recipient's health portal.



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Caregiver Factors Associated With Use of Caregiver's Health Care Portal

In the multivariate model of caregiver demographics, caregivers' use of their own health care portal was more likely among White caregivers, age 40 years or younger, without a college degree, with high income (>$50,000), with care duration <6 months, and an increased number of medical comorbidities (Figure 5A; AUC 0.823). In the multivariate model of caregiver mental health variables, self-portal use was more likely with greater strategic and social support coping (Figure 5B; AUC 0.624). However, in the final multivariate model, lack of college degree, care duration, and strategic and social support coping were no longer associated with portal use (Figure 6; AUC 0.790) partially due to multicollinearity. Specifically, higher anxiety was correlated with shorter duration of caregiving, and increased use of social support coping was correlated with higher levels of education.

Figure 5. Multivariate odds ratios (dots) and 95% confidence intervals (bars) for (A) caregiver characteristics and (B) mental health for the use of a caregiver's own health portal.

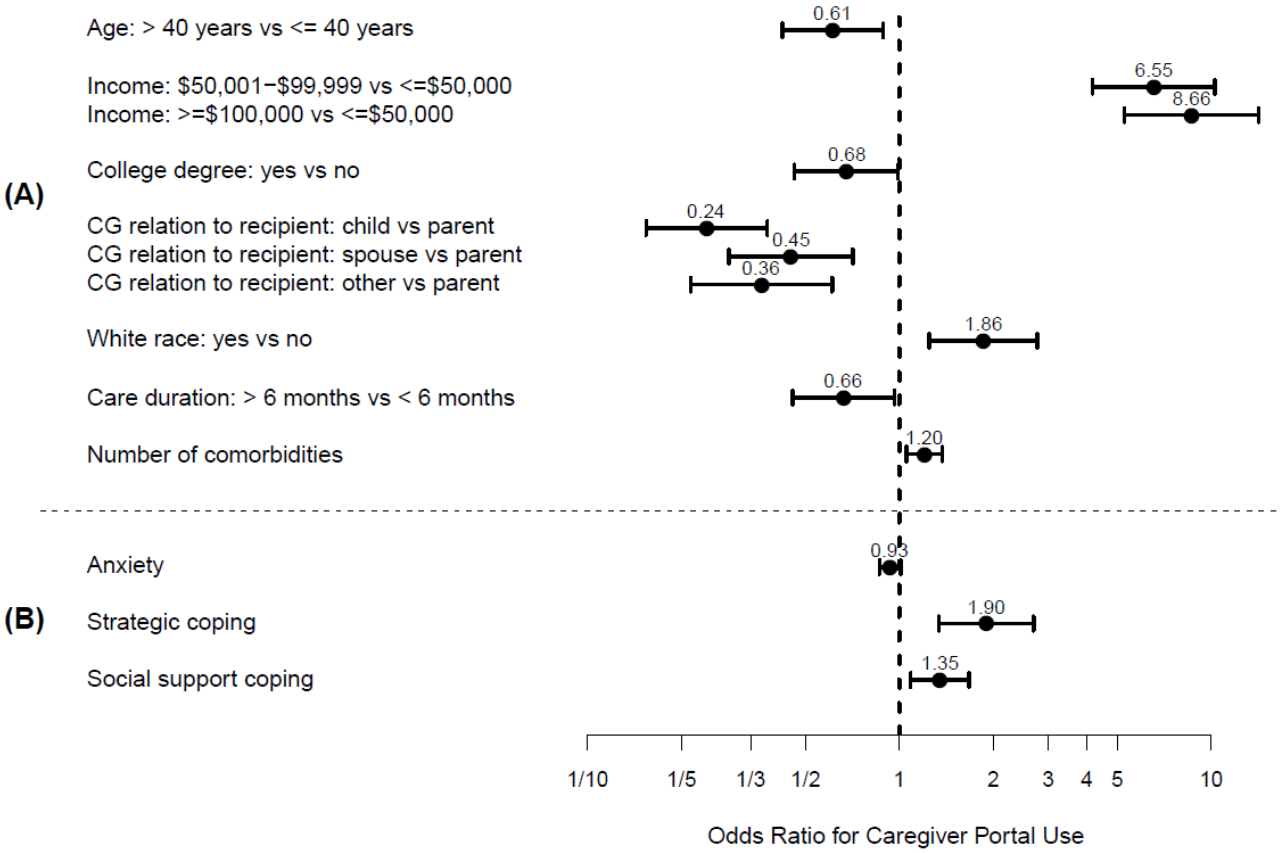

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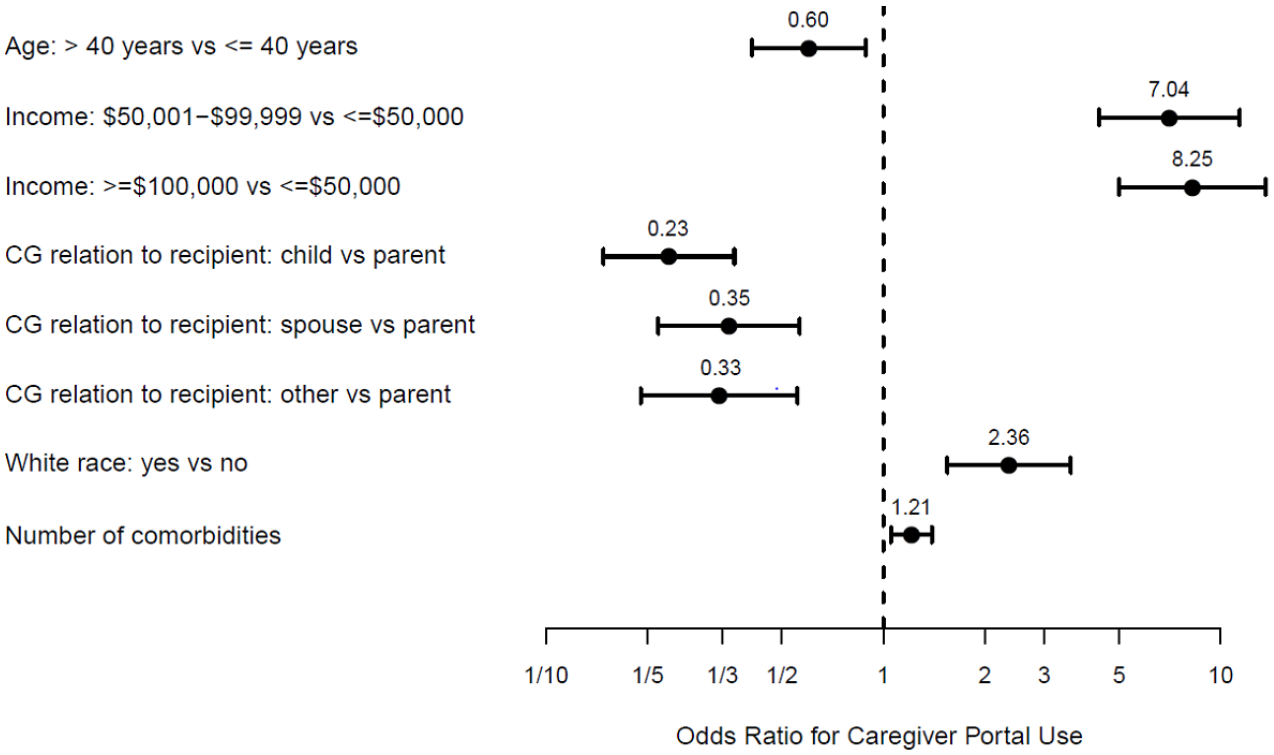
Figure 6. Multivariate odds ratios (dots) and 95% confidence intervals (bars) for combined caregiver characteristics and mental health for the use of a caregiver's own health portal.



Discussion

To our knowledge, this study of more than 900 caregivers from a national US sample is the largest published sample of hematopoietic cell transplantation caregivers surveyed to date focused on caregivers' use of their own and their care recipients' health portal [3,24,25,31]. Our study highlights hematopoietic cell transplantation caregiver demographics, mental health, coping behaviors, caregiving characteristics, and care recipient characteristics. We explored the relationship between caregiver characteristics, mental health and coping, and caregiver portal use for self as well as care recipient. Caregiver demographics—mostly female, married, White, employed, educated, and non-Hispanic—were consistent with those in a recently published single-institution, cross-sectional analysis of hematopoietic cell transplantation caregivers [32].

Caregivers in our sample experienced significant burden. Nearly two-thirds supported their care recipient for >20 hours a week and more than half supported their care recipient for over 6 months. These data support the findings of previously published studies [6,11,33] that have reported high levels of distress, depression, and anxiety in the hematopoietic cell transplantation caregiving population and the demands that caregivers must juggle across the hematopoietic cell transplantation trajectory. In addition, two-thirds of caregivers in our sample had at least 1 chronic condition, indicating additional challenges that may impact self-care or their own health.

The patient portal is expected to support patients and their families in managing their health and the health of their care recipient. In this sample, approximately two-thirds of caregivers accessed their care recipient's portal, but nearly one-quarter of caregivers reported never accessing the portal for themselves or the care recipient. These estimates deviate from the findings of previous studies [13,14,34] that reported low caregiver access to the care recipient's patient portal. Recent work in breast cancer suggests increased caregiver registration for the patient portal through a structured process of establishing a shared visit agenda and clarifying expectations about the role of family caregivers through a communication intervention, called Sharing in Care [35]. Such studies may allow us to examine strategies that are effective in supporting caregivers and engaging them in activities that may promote self-care as well as their care recipient. How self-care practices as well as quality of care provided by the caregiver influences subsequent patient outcomes remains a critical question in the field.

Our study provides insight into factors that may impact caregiver portal use of the care recipient. Being young, married, White, an adult child caregiver, and residing in the same household as the care recipient increased likelihood of caregiver portal use of the care recipient. These factors help identify where certain strategies could be targeted in future research (eg, older age, single, non-White, parent or other caregiver, separate living residences). It was encouraging that income was not a barrier to accessing the care recipient's portal. Interestingly, caregivers who reported higher depression scores were also more likely to use the portal for their care recipient. Our group previously found that among users of a health information technology system (Roadmap 1.0), hematopoietic cell transplantation caregivers of adult care recipients who perceived Roadmap 1.0 to be more useful were those who reported lower quality of life and more fatigue, depression, and distress [23]. We speculated that caregivers who were struggling with the caregiving process may have consequently been more reliant on repeated viewing of the health information technology system to reaccess information that they may not have comprehended well or

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recalled effectively. Surprisingly, in the multivariate models, duration of caregiving, care burden in hours per week, and complexity of hematopoietic cell transplantation, indicated by type of hematopoietic cell transplantation, did not influence caregivers accessing their care recipient portal, despite the association on the univariate level. This suggests that the characteristics of caregivers themselves drive the care recipient portal use.

In addition to examining portal use for the care recipient, we were also interested in factors associated with self-portal use. We found that older hematopoietic cell transplantation caregivers, non-White, low income, adult children or spouses of care recipients, or those with chronic medical conditions may be at risk for not adopting self-portal use. Thus, an evidence-based understanding of the landscape of caregiving characteristics and portal use may allow us to effectively design and develop novel interventions systems (eg, mobile health apps, wearable sensors) that complement or integrate within existing patient portals and further enhance user operability. In this age of rapid technological advances, evolving use of health information technology (eg, telehealth), new therapeutic regimens, and increased demands placed on patients and families in the outpatient setting, it is an opportune and exciting time to develop health information technology systems that may support family caregivers and enhance their preparedness for the caregiving process—for themselves and for care recipients. Importantly, health care systems may need to develop structured processes to train patients and families in using technologies, such as self and care recipient portal use. Such interventions may have the potential to facilitate engagement with the patient portal among caregivers themselves, thereby enabling them to also support their care recipient.

Major strengths of this study include having a large well-characterized hematopoietic cell transplantation caregiver population derived from a national sample and contributing novel information about portal access by caregivers. The survey was developed with rigorous research methodology conducted in hematopoietic cell transplantation patients and caregivers, including think-aloud and verbal probing approaches [3,16,17]. Nonetheless, we recognize the limitations of the study, which include the cross-sectional design. The findings may not be generalizable across the trajectory of hematopoietic cell transplantation care. Although we attempted to control for time since transplant in our analyses, caregiver burden may be subject to changing challenges across different time points. Additionally, the respondents may inherently be less burdened, by having the time or energy to complete a survey (ie, care recipient is doing well posttransplant). Selection bias may have also been influenced by those who were adept at completing a web-based online survey. Importantly, while this caregiver population was from a national sample, the generalizability of the findings is limited to hematopoietic cell transplantation caregivers who were female, White, non-Hispanic, married, employed, high income, and educated. Finally, the survey was only conducted in English, which may have restricted non-English speaking, reading, or writing caregivers.

Our findings highlight the intensive burden placed on hematopoietic cell transplantation caregivers, impact of mental health, and coping strategies used. We anticipate that the findings will inform future research around caregiver use of and attitudes toward different types of technology (eg, wearables and mobile health). For instance, future studies could characterize hematopoietic cell transplantation caregivers' use of these different types and reasons for engaging with such tools. Future work could also examine whether caregivers are likely to use a tool to help manage their own well-being and what such a tool would look like. While examination of caregiver use of other technology tools has been pursued in other contexts, little is known about use among hematopoietic cell transplantation caregivers. Understanding factors that support adoption of technology (eg, electronic health record portal use) will be critical in upcoming years as newer systems are developed and newer care delivery approaches are integrated in health care systems (eg, telehealth, telemedicine).

Acknowledgments

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Authors' Contributions

VG contributed to writing the original draft, data curation, data analysis, and visualization, as well as reviewing and editing the manuscript. MR contributed to writing the original draft, data curation, data analysis, and visualization, as well as reviewing and editing the manuscript. FH contributed to data analysis and reviewing and editing the manuscript. LY contributed to survey formatting and distribution, data management, data analysis, and data interpretation, as well as reviewing and editing the manuscript. TB contributed to writing the original draft, data curation, data analysis, and visualization, as well as reviewing and editing the manuscript. SWC contributed to data curation, investigation, methodology, data analysis, resources, supervision, visualization, and writing the original draft, as well as reviewing and editing the manuscript.

Conflicts of Interest

None declared.

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Multimedia Appendix 1
Univariate odds ratios (dots) and 95% confidence intervals (bars).
[PNG File , 73 KB - cancer_v7i1e26509_app1.png]

References

1. Copelan EA. Hematopoietic stem-cell transplantation. N Engl J Med 2006 Apr 27;354(17):1813-1826. [doi: 10.1056/nejmra052638]
2. Laudenslager ML, Simoneau TL, Kilbourn K, Natvig C, Philips S, Spradley J, et al. A randomized control trial of a psychosocial intervention for caregivers of allogeneic hematopoietic stem cell transplant patients: effects on distress. Bone Marrow Transplant 2015 Aug 11;50(8):1110-1118 [FREE Full text] [doi: 10.1038/bmt.2015.104] [Medline: 25961767]
3. Kedroske J, Koblick S, Chaar D, Mazzoli A, O'Brien M, Yahng L, et al. Development of a national caregiver health survey for hematopoietic stem cell transplant: qualitative study of cognitive interviews and verbal probing. JMIR Form Res 2020 Jan 23;4(1):e17077 [FREE Full text] [doi: 10.2196/17077] [Medline: 32012037]
4. Gemmill R, Cooke L, Williams AC, Grant M. Informal caregivers of hematopoietic cell transplant patients: a review and recommendations for interventions and research. Cancer Nurs 2011;34(6):E13-E21 [FREE Full text] [doi: 10.1097/NCC.0b013e31820a592d] [Medline: 21242762]
5. AARP, National Alliance on Caregiving. Caregiving in the United States. AARP. 2020. URL: https://www.aarp.org/content/dam/aarp/ppi/2020/05/full-report-caregiving-in-the-united-states.doi.10.26419-2Fppi.00103.001.pdf [accessed 2020-12-05]
6. Simoneau TL, Mikulich-Gilbertson SK, Natvig C, Kilbourn K, Spradley J, Grzywa-Cobb R, et al. Elevated peri-transplant distress in caregivers of allogeneic blood or marrow transplant patients. Psychooncology 2013 Sep 25;22(9):2064-2070 [FREE Full text] [doi: 10.1002/pon.3259] [Medline: 23440998]
7. Applebaum AJ, Bevans M, Son T, Evans K, Hernandez M, Giralt S, et al. A scoping review of caregiver burden during allogeneic HSCT: lessons learned and future directions. Bone Marrow Transplant 2016 Nov 13;51(11):1416-1422 [FREE Full text] [doi: 10.1038/bmt.2016.164] [Medline: 27295270]
8. Bevans M, Sternberg EM. Caregiving burden, stress, and health effects among family caregivers of adult cancer patients. JAMA 2012 Jan 25;307(4):398-403 [FREE Full text] [doi: 10.1001/jama.2012.29] [Medline: 22274687]
9. Applebaum FR, Forman SJ, Negrin RS, Blume KG, editors. Hematopoetic Cell Transplantation, fourth ed. Oxford, England: Blackwell Publishing; 2004.
10. Kaziunas E, Hanauer D, Ackerman M, Choi S. Identifying unmet informational needs in the inpatient setting to increase patient and caregiver engagement in the context of pediatric hematopoietic stem cell transplantation. J Am Med Inform Assoc 2016 Jan;23(1):94-104 [FREE Full text] [doi: 10.1093/jamia/ocv116] [Medline: 26510878]
11. Cooke L, Grant M, Eldredge DH, Maziarz RT, Nail LM. Informal caregiving in hematopoietic blood and marrow transplant patients. Eur J Oncol Nurs 2011 Dec;15(5):500-507 [FREE Full text] [doi: 10.1016/j.ejon.2011.01.007] [Medline: 21306952]
12. Williams LA. Whatever it takes: informal caregiving dynamics in blood and marrow transplantation. Oncol Nurs Forum 2007 Jun 15;34(2):379-387. [doi: 10.1188/07.onf.379-387]
13. Iott B, Raj M, Platt J, Anthony D. Family caregiver access of online medical records: findings from the Health Information National Trends Survey. J Gen Intern Med 2020 Dec 02 [FREE Full text] [doi: 10.1007/s11606-020-06350-8] [Medline: 33269423]
14. Wolff JL, Darer JD, Larsen KL. Family caregivers and consumer health information technology. J Gen Intern Med 2016 Jan 27;31(1):117-121 [FREE Full text] [doi: 10.1007/s11606-015-3494-0] [Medline: 26311198]
15. Wolff J, Berger A, Clarke D, Green J, Stametz R, Yule C, et al. Patients, care partners, and shared access to the patient portal: online practices at an integrated health system. J Am Med Inform Assoc 2016 Nov;23(6):1150-1158. [doi: 10.1093/jamia/ocw025] [Medline: 27026614]
16. Kedroske J, Koblick S, Chaar D, Mazzoli A, O'Brien M, Yahng L, et al. Development of a national caregiver health survey for hematopoietic stem cell transplant: qualitative study of cognitive interviews and verbal probing. JMIR Form Res 2020 Jan 23;4(1):e17077 [FREE Full text] [doi: 10.2196/17077] [Medline: 32012037]
17. Chaar D, Shin JY, Mazzoli A, Vue R, Kedroske J, Chappell G, et al. A mobile health app (Roadmap 2.0) for patients undergoing hematopoietic stem cell transplant: qualitative study on family caregivers' perspectives and design considerations. JMIR Mhealth Uhealth 2019 Oct 24;7(10):e15775 [FREE Full text] [doi: 10.2196/15775] [Medline: 31651402]
18. Collins D. Pretesting survey instruments: an overview of cognitive methods. Qual Life Res 2003 May;12(3):229-238. [doi: 10.1023/a:1023254226592] [Medline: 12769135]
19. Kaziunas E, Buyuktur A, Jones J, Choi S, Hanauer D, Ackerman M. Transition and reflection in the use of health information: the case of pediatric bone marrow transplant caregivers. 2015 Presented at: 18th ACM Conference on Computer Supported Cooperative Work & Social Computing; March 14-18; Vancouver, British Columbia.
20. Maher M, Kaziunas E, Ackerman M, Derry H, Forringer R, Miller K, et al. User-centered design groups to engage patients and caregivers with a personalized health information technology tool. Biol Blood Marrow Transplant 2016 Feb;22(2):349-358 [FREE Full text] [doi: 10.1016/j.bbmt.2015.08.032] [Medline: 26343948]

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21. Runaas L, Hanauer D, Maher M, Bischoff E, Fauer A, Hoang T, et al. BMT Roadmap: a user-centered design health information technology tool to promote patient-centered care in pediatric hematopoietic cell transplantation. Biol Blood Marrow Transplant 2017 May;23(5):813-819 [FREE Full text] [doi: 10.1016/j.bbmt.2017.01.080] [Medline: 28132870]
22. Runaas L, Hoodin F, Munaco A, Fauer A, Sankaran R, Churay T, et al. Novel health information technology tool use by adult patients undergoing allogeneic hematopoietic cell transplantation: longitudinal quantitative and qualitative patient-reported outcomes. JCO Clin Cancer Inform 2018 Dec(2):1-12. [doi: 10.1200/cci.17.00110]
23. Fauer AJ, Hoodin F, Lalonde L, Errickson J, Runaas L, Churay T, et al. Impact of a health information technology tool addressing information needs of caregivers of adult and pediatric hematopoietic stem cell transplantation patients. Support Care Cancer 2019 Jun 20;27(6):2103-2112 [FREE Full text] [doi: 10.1007/s00520-018-4450-4] [Medline: 30232587]
24. Shin JY, Kang TI, Noll RB, Choi SW. Supporting caregivers of patients with cancer: a summary of technology-mediated interventions and future directions. Am Soc Clin Oncol Educ Book 2018 May(38):838-849. [doi: 10.1200/edbk_201397]
25. Shin JY, Choi SW. Online interventions geared toward increasing resilience and reducing distress in family caregivers. Curr Opin Support Palliat Care 2020 Mar;14(1):60-66 [FREE Full text] [doi: 10.1097/SPC.0000000000000481] [Medline: 31842019]
26. Kroenke K, Spitzer RL, Williams JB, Löwe B. An ultra-brief screening scale for anxiety and depression: the PHQ–4. Psychosomatics 2009 Nov;50(6):613-621. [doi: 10.1016/s0033-3182(09)70864-3]
27. Kershaw T, Northouse L, Kritpracha C, Schafenacker A, Mood D. Coping strategies and quality of life in women with advanced breast cancer and their family caregivers. Psychology & Health 2007 Feb;19(2):139-155. [doi: 10.1080/08870440310001652687]
28. Spitzer RL, Kroenke K, Williams JB. Validation and utility of a self-report version of PRIME-MD: the PHQ primary care study. Primary Care Evaluation of Mental Disorders. Patient Health Questionnaire. JAMA 1999 Nov 10;282(18):1737-1744. [doi: 10.1001/jama.282.18.1737] [Medline: 10568646]
29. Löwe B, Wahl I, Rose M, Spitzer C, Glaesmer H, Wingenfeld K, et al. A 4-item measure of depression and anxiety: validation and standardization of the Patient Health Questionnaire-4 (PHQ-4) in the general population. J Affect Disord 2010 Apr;122(1-2):86-95. [doi: 10.1016/j.jad.2009.06.019] [Medline: 19616305]
30. Carver CS. You want to measure coping but your protocol's too long: consider the brief COPE. Int J Behav Med 1997 Mar;4(1):92-100. [doi: 10.1207/s15327558ijbm0401_6] [Medline: 16250744]
31. Grossman MR, Zak DK, Zelinski EM. Mobile apps for caregivers of older adults: quantitative content analysis. JMIR Mhealth Uhealth 2018 Jul 30;6(7):e162 [FREE Full text] [doi: 10.2196/mhealth.9345] [Medline: 30061093]
32. Jamani K, Onstad LE, Bar M, Carpenter PA, Krakow EF, Salit RB, et al. Quality of life of caregivers of hematopoietic cell transplant recipients. Biol Blood Marrow Transplant 2018 Nov;24(11):2271-2276 [FREE Full text] [doi: 10.1016/j.bbmt.2018.06.015] [Medline: 29935213]
33. Von Ah D, Spath M, Nielsen A, Fife B. The caregiver's role across the bone marrow transplantation trajectory. Cancer Nursing 2016;39(1):E12-E19. [doi: 10.1097/ncc.0000000000000242]
34. Wolff JL, Darer JD, Berger A, Clarke D, Green JA, Stametz RA, et al. Inviting patients and care partners to read doctors' notes: OpenNotes and shared access to electronic medical records. J Am Med Inform Assoc 2017 Apr 01;24(e1):e166-e172 [FREE Full text] [doi: 10.1093/jamia/ocw108] [Medline: 27497795]
35. Wolff JL, Aufill J, Echavarria D, Heughan J, Lee KT, Connolly RM, et al. Sharing in care: engaging care partners in the care and communication of breast cancer patients. Breast Cancer Res Treat 2019 Aug 4;177(1):127-136 [FREE Full text] [doi: 10.1007/s10549-019-05306-9] [Medline: 31165374]

Abbreviations

AUC: area under the curve
BMT InfoNet: Blood and Marrow Transplant Information Network
nBMTLINK: National Bone Marrow Transplant Link
PHQ: Patient Health Questionnaire

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Original Paper

Development and Early Feasibility of Chatbots for Educating Patients With Lung Cancer and Their Caregivers in Japan: Mixed Methods Study

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Abstract

Background: Chatbots are artificial intelligence–driven programs that interact with people. The applications of this technology include the collection and delivery of information, generation of and responding to inquiries, collection of end user feedback, and the delivery of personalized health and medical information to patients through cellphone- and web-based platforms. However, no chatbots have been developed for patients with lung cancer and their caregivers.

Objective: This study aimed to develop and evaluate the early feasibility of a chatbot designed to improve the knowledge of symptom management among patients with lung cancer in Japan and their caregivers.

Methods: We conducted a sequential mixed methods study that included a web-based anonymized questionnaire survey administered to physicians and paramedics from June to July 2019 (phase 1). Two physicians conducted a content analysis of the questionnaire to curate frequently asked questions (FAQs; phase 2). Based on these FAQs, we developed and integrated a chatbot into a social network service (phase 3). The physicians and paramedics involved in phase I then tested this chatbot (α test; phase 4). Thereafter, patients with lung cancer and their caregivers tested this chatbot (β test; phase 5).

Results: We obtained 246 questions from 15 health care providers in phase 1. We curated 91 FAQs and their corresponding responses in phase 2. In total, 11 patients and 1 caregiver participated in the β test in phase 5. The participants were asked 60 questions, 8 (13%) of which did not match the appropriate categories. After the β test, 7 (64%) participants responded to the postexperimental questionnaire. The mean satisfaction score was 2.7 (SD 0.5) points out of 5.

Conclusions: Medical staff providing care to patients with lung cancer can use the categories specified in this chatbot to educate patients on how they can manage their symptoms. Further studies are required to improve chatbots in terms of interaction with patients.

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KEYWORDS

cancer; caregivers; chatbot; lung cancer; mixed methods approach; online health; patients; symptom management education; web-based platform

Introduction

Distress among patients with cancer and their caregivers has received increasing attention from medical staff. Early palliative care (EPC) from the time of diagnosis has been shown to have a positive impact on quality of life [1]. Through EPC, patients and their caregivers gain experience in several areas, including prompt and personalized symptom management [2].

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Nonetheless, patient education remains a problem for health care providers [3]. Advancements in health care increase the amount of information that needs to be provided during patient education. Consequently, burnout among health care providers involved in EPC has become a problem [4].

Chatbots are artificial intelligence (AI)–driven programs that interact with people [5] through text messages and outputs on cellphone- or web-based platforms [6]. A simple rendition of this system involves a user entering text and AI predicting the corresponding predefined category and then sending the response corresponding to that category to the user. Considering the potential of this system to substitute the conversational mode of education that humans use and to save on labor, this technology has attracted increasing attention. Several chatbots are currently available for patients with breast cancer [7,8]; however, no chatbots are available for those with lung cancer and their caregivers. In this study, we aimed to develop and evaluate the early feasibility of a chatbot designed to answer questions of patients with lung cancer and their caregivers on a web-based platform whenever they experience unfamiliar symptoms; this would help them improve their knowledge of symptom management.

Methods

Study Design

To develop a chatbot for patients with lung cancer, we used a sequential mixed methods approach (Table 1) [9]. We adopted this approach because of the lack of sufficient nationwide data on the categories of frequently asked questions (FAQs) asked by patients with lung cancer and their caregivers. We also decided to adopt an initial qualitative approach to generate hypotheses. We adopted the lens of health care providers to provide palliative care. This study was conducted at a tertiary care hospital in Japan.

Table 1. Study overview.

Phase #	Procedures	Product	Evaluation method
1	Conducted a questionnaire-based survey with physicians and paramedics	Categories of FAQs[a]	Qualitative
2	Formulated responses	FAQ-response pairs	N/A[b]
3	Developed the chatbot	Chatbot version 1	N/A
4	Conducted an α test with the physicians and paramedics involved in phase 1	Chatbot version 2	Quantitative
5	Conducted a β test with patients with lung cancer and their caregivers	Chatbot version 3	Quantitative

[a]FAQs: frequently asked questions.

[b]N/A: not applicable.

Phase 1: Qualitative Survey

We conducted a web-based anonymized qualitative survey from June to July 2019. We included physicians in the Department of Respiratory Medicine at our institution, along with paramedics including nurses, pharmacists, physical therapists, occupational therapists, and clerks working with patients with lung cancer in the clinic, emergency department, or ward. We asked these health care workers to respond to the FAQs obtained from patients with lung cancer or their caregivers in an open-ended manner. We also referred to a previous study [10] and website [11] that categorized data obtained from telephone-based consultations with patients with lung cancer in Japan or their caregivers.

Two board-certified respiratory physicians (TT and YK) conducted a content analysis on the questions from the perspective of improving self-management of symptoms. TT generated these categories, and YK confirmed them. Disagreements were resolved through discussion between TT and YK.

Phase 2: Generation of Responses

Based on the categories generated in phase 1, TT generated the appropriate responses, and YK proofread them. Wherever necessary, staff members from the relevant departments were asked to review the responses. We then edited the responses on the basis of their comments.

Phase 3: Development of the Chatbot

We decided to use Bot Designer (LINE Corp)—a bot designing service—owing to its ease of access, and the LINE social media platform to implement the chatbot. In Japan, LINE is the most popular social network service, being used by approximately 70% of the general population [12]. To generate automated responses, we used Google Cloud's Dialogflow [13]. The architecture of this design is illustrated in Figure 1.

We adopted two natural language processing systems to match the responses. The following workflow process was followed: after receiving a question in Japanese from a user, Dialogflow determined whether the keywords included in the question matched the predetermined keywords for each category. If a match was identified, an appropriate response developed in phase 2 was sent to the patients via LINE. Otherwise, the text was translated into English and parsed to identify an appropriate category; thereafter, a response was sent to the patients.

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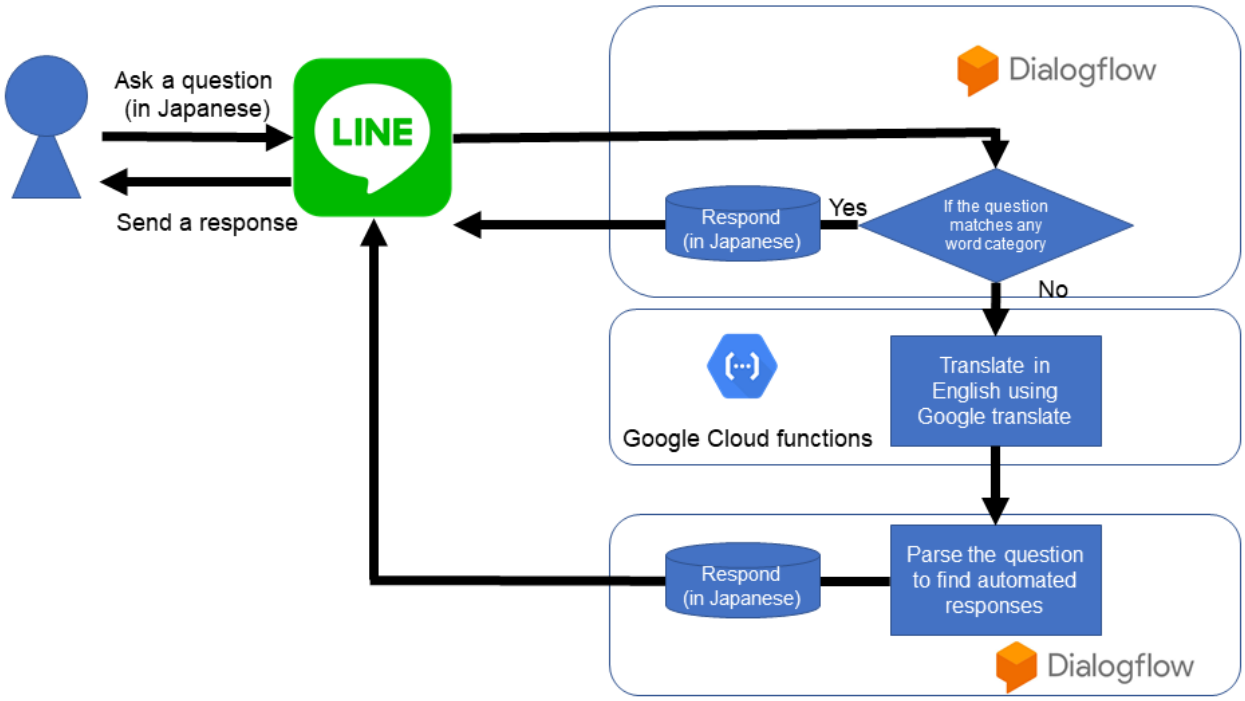
Figure 1. Chatbot architecture.



Phase 4: α Test (Quantitative)

From May to June 2020, we invited the participants in phase 1 to an α test that involved the addition of keywords corresponding to the categories specified on the basis of the errors.

Phase 5: β Test (Quantitative)

From July to December 2020, we invited patients with lung cancer and their caregivers to the β test through paper flyers. Individual consent was obtained before registering the chatbot. We asked the participants to indicate their satisfaction levels with a 5-point Likert scale after the experiments (0=highly dissatisfied, 5=highly satisfied).

Statistical Analysis

Descriptive statistics were used to summarize the results. We performed an unpaired *t* test for univariate analysis. We used Stata (version 16.1, Stata Corp) for statistical analysis.

Ethical Consideration

The study protocol was approved by the institutional review board of the Hyogo Prefectural Amagasaki General Medical Center (number 1-31). We obtained individual consent from the participants through a web form.

Results

Phase 1: Qualitative Survey

We obtained 246 questions from 15 health care providers. We identified 5 major categories (home care: n=50, 20%, changes in health condition: n=54, 22%, prognosis: n=20, 8%, lifestyle: n=82, 33%, and medications: n=39, 16%), and 75 supplementary categories (Multimedia Appendix 1). We identified 7 additional categories by screening resources (Multimedia Appendix 2).

Phase 2: Formulation of Responses

We formulated responses for 82 categories identified in phase 1. The responses contained brief information intended to teach patients and their caregivers to deal with symptoms and direct them to various weblinks to information resources that are maintained by the public budget.

Phase 3: Development of a Chatbot

Based on the FAQs identified in phase 2, we developed the first version of the chatbot and integrated it in the LINE social media network. Figure 2 shows a sample interaction shared with the chatbot.

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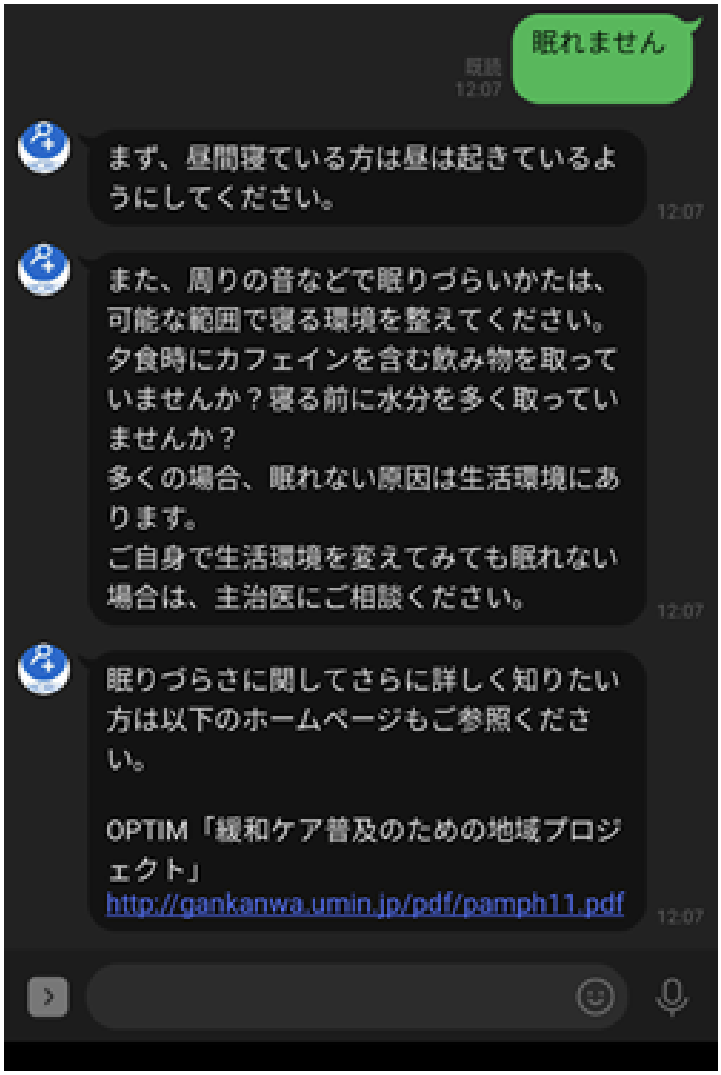
Figure 2. A sample conversation with the chatbot.



Phase 4: α Test (Quantitative)

A total of 14 medical staff participated in the α test. They asked 71 questions to the chatbot during this period. Of these, 11 (15%) questions did not match the appropriate categories. Therefore, we added 3 new categories. Some of the categories had corresponding responses because the questions included the names of products associated with drinking and smoking. Thus, we added keywords for the corresponding categories to match responses.

Phase 5: β Test (Quantitative)

From among 309 patients who received either oral or intravenous chemotherapy at our hospital, 11 patients and 1 caregiver participated in the β test. Of them, 9 patients were aged <60 years, 1 was aged between 60 and 70 years, and 2 were aged >70 years. All of them used computers or smartphones daily. The participants were asked 60 questions, of which 8 (13%) did not match with the appropriate categories. Furthermore, 2 (3%) questions had corresponding responses, and 6 (10%) questions did not. Additionally, 3 (5%) questions based on daily conversation did not have corresponding responses (eg, “I played golf today in the morning”).

After the test, 7 participants responded to the postexperimental questionnaire. The mean satisfaction score was 2.7 (SD 0.5) points out of 5. We used two free feedback comments: “those who have a connection with a patient group, the answers were not too much to hope for” and “there were many times when I did not get a proper answer.” We added 3 categories based on the unmatched questions. Finally, 91 categories and responses were curated [14].

Discussion

Principal Findings

This is the first study to develop a chatbot and evaluate its early feasibility to improve the knowledge of symptom management among patients with lung cancer and their caregivers. Based on the experience of medical professionals, we developed an autoresponsive chatbot, which could respond to most of the FAQs. However, it was not adequately used, and user satisfaction was low.

Comparison with Previous Studies

The categories identified in this study could be used as a reference for patient education in future. Currently, only one chatbot is available to empower patients with cancer and their

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caregivers. This chatbot was developed only for patients with breast cancer [6,15,16]. Given that patients with breast cancer and those with lung cancer differ in their age of onset, chemotherapy regimens, and cancer-related symptoms [17], it is important to increase the number of categories to improve their knowledge of symptom management based on the FAQs identified in this study.

However, since the generation of the chatbot alone did not yield adequate questions from participants, the low response rate potentially indicates that our chatbot may not be acceptable in its current form. Further studies are required to activate the interaction between patients and chatbots. A previous systematic review reported that web-based interactions between physicians and patients or those among patients may improve the patients' quality of life [18]. Thus, chatbots can be incorporated into web-based networks for increased interaction. Indeed, one of our patients involved in the β test (phase 5) preferred interactions with other patients rather than the chatbot. Therefore, further studies are required to generate a platform that initially forms a text messaging–based online support group involving medical professionals and patients and then gradually reduces the need for these professionals to respond to patient queries by involving chatbots instead.

Limitations

This study has two major limitations of note. First, 8 (13%) questions did not match suitably with responses in phase 5, and a patient complained of not receiving appropriate responses. Although the ability of the chatbot to match questions with categories was not a major problem, questions for nonexistent categories remained unmatched. Therefore, it is necessary to add educational categories and responses through further discussion. Furthermore, the integration of existing chatbots for daily conversations may improve the proportion of matches [19]. Second, this was a single-center study, and further studies are needed to evaluate the applicability of our findings in other hospitals.

Conclusions

Medical staff who provide care to patients with lung cancer may be able to educate them using a chatbot containing the categories of FAQs curated in this study. Nonetheless, further studies are required to improve this chatbot in terms of interaction, especially considering its low usage in this study.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Categories from the questionnaire.
[XLSX File (Microsoft Excel File), 30 KB - cancer_v7i1e26911_app1.xlsx]

Multimedia Appendix 2
Categories from the references.
[XLSX File (Microsoft Excel File), 10 KB - cancer_v7i1e26911_app2.xlsx]

References

1. Hui D, Hannon B, Zimmermann C, Bruera E. Improving patient and caregiver outcomes in oncology: Team-based, timely, and targeted palliative care. CA Cancer J Clin 2018 Sep;68(5):356-376 [FREE Full text] [doi: 10.3322/caac.21490] [Medline: 30277572]
2. Hannon B, Swami N, Rodin G, Pope A, Zimmermann C. Experiences of patients and caregivers with early palliative care: A qualitative study. Palliat Med 2017 Jan;31(1):72-81. [doi: 10.1177/0269216316649126] [Medline: 27495814]
3. Fisher R, Croxson C, Ashdown H, Hobbs F. GP views on strategies to cope with increasing workload: a qualitative interview study. Br J Gen Pract 2017 Feb;67(655):e148-e156 [FREE Full text] [doi: 10.3399/bjgp17X688861] [Medline: 28093421]
4. Parola V, Coelho A, Cardoso D, Sandgren A, Apóstolo J. Prevalence of burnout in health professionals working in palliative care: a systematic review. JBI Database System Rev Implement Rep 2017 Jul;15(7):1905-1933. [doi: 10.11124/JBISRIR-2016-003309] [Medline: 28708752]
5. Bibault J, Chaix B, Nectoux P, Pienkowsky A, Guillemasse A, Brouard B. Healthcare ex Machina: Are conversational agents ready for prime time in oncology? Clin Transl Radiat Oncol 2019 May;16:55-59 [FREE Full text] [doi: 10.1016/j.ctro.2019.04.002] [Medline: 31008379]

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6. Milne-Ives M, de Cock C, Lim E, Shehadeh M, de Pennington N, Mole G, et al. The Effectiveness of Artificial Intelligence Conversational Agents in Health Care: Systematic Review. J Med Internet Res 2020 Oct 22;22(10):e20346 [FREE Full text] [doi: 10.2196/20346] [Medline: 33090118]
7. Chaix B, Bibault J, Pienkowski A, Delamon G, Guillemassé A, Nectoux P, et al. When Chatbots Meet Patients: One-Year Prospective Study of Conversations Between Patients With Breast Cancer and a Chatbot. JMIR Cancer 2019 May 02;5(1):e12856 [FREE Full text] [doi: 10.2196/12856] [Medline: 31045505]
8. Bibault J, Chaix B, Guillemassé A, Cousin S, Escande A, Perrin M, et al. A Chatbot Versus Physicians to Provide Information for Patients With Breast Cancer: Blind, Randomized Controlled Noninferiority Trial. J Med Internet Res 2019 Nov 27;21(11):e15787 [FREE Full text] [doi: 10.2196/15787] [Medline: 31774408]
9. Östlund U, Kidd L, Wengström Y, Rowa-Dewar N. Combining qualitative and quantitative research within mixed method research designs: a methodological review. Int J Nurs Stud 2011 Mar;48(3):369-383 [FREE Full text] [doi: 10.1016/j.ijnurstu.2010.10.005] [Medline: 21084086]
10. Miyazawa N, Kakizoe T. Anxiety Among Cancer Patients is Changing in Accordance with Advances in Cancer Treatment and the Development of Social Cancer Management: Ten Years' Experience as a Consultant for Cancer Patients and Their Families and Opinions Based on an Analysis of the Present Status. JJLC 2019;59(3):238-243. [doi: 10.2482/haigan.59.238]
11. Japan Cancer Society. URL: https://www.jcancer.jp/consultion_and_support/%E3%81%8C%E3%82%93%E7%9B%B8%E8%AB%87%E3%83%9B%E3%83%83%E3%83%88%E3%83%A9%E3%82%A4%E3%83%B3 [accessed 2020-11-27]
12. Supplementary financial information for the third quarter of the fiscal year ending December 31, 2020. LINE. URL: https://d.line-scdn.net/stf/linecorp/ja/ir/all/FY20Q3_earning_releases_JP.pdf [accessed 2020-11-30]
13. Dialogflow. Google Cloud. URL: https://cloud.google.com/dialogflow/docs [accessed 2020-11-29]
14. Kataoka Y. Development and early feasibility of a chatbot for educating patients with lung cancer in Japan: a mixed-method study. OSF. 2020 Dec 29. URL: https://osf.io/y72mv/ [accessed 2021-01-04]
15. Chaix B, Bibault J, Pienkowski A, Delamon G, Guillemassé A, Nectoux P, et al. When Chatbots Meet Patients: One-Year Prospective Study of Conversations Between Patients With Breast Cancer and a Chatbot. JMIR Cancer 2019 May 02;5(1):e12856 [FREE Full text] [doi: 10.2196/12856] [Medline: 31045505]
16. Bibault J, Chaix B, Guillemassé A, Cousin S, Escande A, Perrin M, et al. A Chatbot Versus Physicians to Provide Information for Patients With Breast Cancer: Blind, Randomized Controlled Noninferiority Trial. J Med Internet Res 2019 Nov 27;21(11):e15787 [FREE Full text] [doi: 10.2196/15787] [Medline: 31774408]
17. Guest JF, Ruiz FJ, Greener MJ, Trotman IF. Palliative care treatment patterns and associated costs of healthcare resource use for specific advanced cancer patients in the UK. Eur J Cancer Care (Engl) 2006 Mar;15(1):65-73. [doi: 10.1111/j.1365-2354.2005.00623.x] [Medline: 16441679]
18. McAlpine H, Joubert L, Martin-Sanchez F, Merolli M, Drummond KJ. A systematic review of types and efficacy of online interventions for cancer patients. Patient Educ Couns 2015 Mar;98(3):283-295. [doi: 10.1016/j.pec.2014.11.002] [Medline: 25535016]
19. Singh S, Thakur H. Survey of Various AI Chatbots Based on Technology Used. 2020 Presented at: 2020 8th International Conference on Reliability, Infocom Technologies and Optimization (Trends and Future Directions) (ICRITO); 4-5 June 2020; Noida, India p. 1074-1079. [doi: 10.1109/icrito48877.2020.9197943]

Abbreviations

AI: artificial intelligence
EPC: early palliative care
FAQ: frequently asked question

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