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Original Paper

Oncofertility Decision Support Resources for Women of Reproductive Age: Systematic Review

Brittany Speller^{1,2*}, MSc; Selena Micic^{1,2*}, MHI; Corinne Daly^{1,2*}, MSc; Lebei Pi^{1,2*}, BHSc, MD; Tari Little^{1,2*}, BSc; Nancy N Baxter^{1,2,3*}, MD, PhD

¹Department of Surgery, St. Michael's Hospital, Toronto, ON, Canada

²Li Ka Shing Knowledge Institute, St. Michael's Hospital, Toronto, ON, Canada

³Institute of Health Policy, Management, and Evaluation, Dalla Lana School of Public Health, University of Toronto, Toronto, ON, Canada

* all authors contributed equally

Corresponding Author:

Nancy N Baxter, MD, PhD

Department of Surgery

St. Michael's Hospital

16-040 Cardinal Carter Wing

30 Bond Street

Toronto, ON, M5B 1W8

Canada

Phone: 1 416 864 5168

Email: baxtern@smh.ca

Abstract

Background: Cancer treatments have the potential to cause infertility among women of reproductive age. Many cancer patients do not receive sufficient oncofertility information or referrals to reproductive specialists prior to starting cancer treatment. While health care providers cite lack of awareness on the available oncofertility resources, the majority of cancer patients use the internet as a resource to find additional information to supplement discussions with their providers.

Objective: Our aim was to identify and characterize Web-based oncofertility decision aids and health education materials accessible for women of reproductive age with a diagnosis of any cancer.

Methods: We searched five databases and the gray literature for the years 1994-2018. The developer and content information for identified resources was extracted. Each resource underwent a quality assessment.

Results: We identified 31 open access resources including 4 decision aids and 27 health educational materials. The most common fertility preservation options listed in the resources included embryo (31/31, 100%), egg (31, 100%), and ovarian tissue freezing (30, 97%). Notably, approximately one-third (11, 35%) contained references and 5 (16%) had a reading level of grade 8 or below. Resources were of varying quality; two decision aids from Australia and the Netherlands, two booklets from Australia and the United Kingdom, and three websites from Canada and the United States rated as the highest quality.

Conclusions: This comprehensive review characterizes numerous resources available to support patients and providers with oncofertility information, counseling, and decision making. More focus is required to improve the awareness and the access of existing resources among patients and providers. Providers can address patient information needs by leveraging or adapting existing resources to support clinical discussions and their specific patient population.

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KEYWORDS

decision aids; health education materials; fertility; cancer; young women; decision-making; patient education

Introduction

Many life-saving cancer treatments, including chemotherapy, radiation, and surgery, have the potential to impair reproductive function in women [1-3]. Even if treatment does not directly

impact fertility, some cancer treatments are recommended for up to 10 years after diagnosis, delaying pregnancy attempts and resulting in natural fertility declines as patients age [4,5]. As such, women of reproductive age who are diagnosed with cancer

have to make a fertility preservation (FP) decision before they begin treatment [3].

The decision to pursue FP is preference-sensitive. There is no “best” option for everyone; rather, the weighting of the risks and benefits of each FP option depend on personal values [6,7]. For optimal decision making, patients need to work in partnership with their health care team to receive fertility information and (when necessary) referrals to reproductive specialists or psychosocial support in a timely manner that promotes understanding of the possible outcomes for different options with consideration of the personal value placed on risks and benefits [8]. This process of shared decision making [9] is particularly important for preference-sensitive decisions, including FP decisions, as it helps ensure that clinical care aligns with patients’ values and preferences [10]. While women of reproductive age want fertility-related information prior to treatment [11,12], in reality many women start cancer treatment without adequate information on treatment-related risks to fertility, potential FP options, or referrals to reproductive specialists [13-15]. The implementation of oncofertility decision aids and health education material early in the clinical pathway is therefore recommended to supplement fertility discussions and assist patients and health care providers in collaborative decision making [8,11,13,16-20].

Decision aids and health education materials could be of great use to women diagnosed with cancer and a valuable tool for providers. However, many providers cite lack of awareness on the available resources as a barrier to information provision and fertility discussions with patients [21-23]. Recently published studies by de Man et al [24] and Mahmoodi et al [25] cataloged and assessed the quality of Web-based fertility health information for women. However, gaps remain in the categorization of available decision aids and health education material and the creation of an inventory of high-quality resources accessible online for providers to use and refer to their patients. Other studies have listed a selection of decision aids and health education materials but were limited to materials in the United States [19,26] and aids with a published evaluation [19,27]. As many patients access Web-based health information as an alternative source of medical information [28], and up to 96% of patients use the internet as a resource for more information [29], there is a need to systematically identify and evaluate existing decision aids and health education materials that are accessible to women and providers. Accordingly, the aim of this systematic review was to identify and characterize Web-based oncofertility decision aids and health education materials accessible for women of reproductive age with a diagnosis of any cancer.

Methods

Search Strategy

No protocol was registered for this study. Information specialists conducted a search of MEDLINE, PsycINFO, CINAHL, Cochrane Central and Database of Systematic Reviews, and EMBASE from January 1, 1994, to April 4, 2018, to capture open access decision aids and health education materials available on the Web. Key words and their synonyms were used

in the search strategy: [“Fertility” (“Reproductive Techniques,” “Infertility,” “Fertility Preservation,” “Cryopreservation,” “Cryofixation,” “Cryonic Suspension,” “Oocyte Retrieval,” “Oophoropexy”) AND “Cancer” (“Neoplasm,” “Tumor,” “Malignant,” “Oncology,” “Carcinoma,” “Chemotherapy”); OR “Oncofertility”] AND [“Decision Making;” OR “Patient Education.”] (Multimedia Appendix 1). The included articles’ reference lists were manually screened to further identify any relevant publications. The database search was limited to studies on human subjects and publications in English. Consultation with experts in the field of oncology and a Web-based search (Multimedia Appendix 2) allowed for the identification of additional relevant decision aids and health education material not captured in our database search. We searched the Web using the search engine Google [30], as it is the most popular search engine accounting for approximately 75% of Web-based searches [31], and the ClinicalTrials.gov [32] database entering the key phrase “resources for cancer patient’s fertility.” The Google search was run in Canada (Toronto, Ontario) on July 15, 2014, August 17, 2016, and March 13, 2018. We recorded the total number of results and screened the first five pages (approximately 50 website links) as evidence shows most users will not continue their search past the first few pages of search results [33].

Eligibility and Selection

We included decision aids and health education materials. Decision aids are defined as “evidence-based tools designed to help patients make specific and deliberate choices among healthcare options” [34]. They provide evidence-based information and a personalized focus on treatment options and outcomes to help people clarify their values on the benefits and risks of the available health options to allow for a more informed decision [34,35]. Health education materials “help people understand their diagnosis, treatment and management in general terms, but given their broader perspective, these materials are not focused on decision points” [34]. Inclusion of decision aids and health education materials in this review ensured identification of the diverse resources available through a patient-initiated Web search and those that providers can recommend to patients for supplementary information.

Two reviewers independently screened the websites, publication abstracts, and full texts. Criteria for inclusion included the following: (1) publication/website is in English and describes or is a decision aid or health education material on oncofertility or describes the development and/or evaluation of such a resource, (2) full decision aid or health education material is openly accessible at the time of the search, (3) website contains printable oncofertility information defined by the Patient Education Materials Assessment Tool (PEMAT) as “printed booklets, brochures, and materials that can be printed from websites (eg, PDFs or html text)” [36] or are non-printable websites dedicated to oncofertility, and (4) target audience includes women of reproductive age with a diagnosis of cancer facing an FP decision. We excluded articles that detailed only the development of decision aid components (eg, values clarification methods), survey articles, decision aids or health education materials intended solely for male patients, decision aids or health education materials without open access at the

time of the searches, as well as blogs, YouTube videos, forums, and websites from fertility programs/clinics as our search strategy was not designed to capture all clinics globally.

Data Extraction and Analysis

Two reviewers independently extracted descriptive information into a data extraction table created in Microsoft Excel 2010. Information included author, publication date and date of last update, target population, classification of decision aid or health education material and sections included, number of pages, development country, fertility options before treatment and parenthood options after treatment, and specific content pertaining to fertility (eg, cancer treatments impact on fertility). Analysis of the decision aids and health education materials involved synthesizing descriptive characteristics and tabulating the results.

Quality Assessment

Since no single quality assessment tool was appropriate for the evaluation of the different decision aids and health education materials identified, we used three separate quality assessment tools based on the type of resource. The International Patient Decision Aid Standards Collaboration (IPDAS) checklist (V.4.0) is internationally approved and recognized as the most credible measure to evaluate the quality of decision aids [37,38]. The modified version used for this review includes 44 items separated into three categories: (1) qualifying as decision aid criteria (6 items), (2) certification criteria (10 items), and (3) quality criteria (28 items), each rated as present or absent [39]. The PEMAT is the main tool used to assess any printable health educational material (eg, brochures, booklets, printable sections of websites) [36]. The PEMAT uses a systematic method to evaluate and compare the understandability and actionability of educational materials. An inventory of 17 characteristics produced an understandability score, and an inventory of 7 items produced an actionability score. Eysenbach et al [40] created the “Seven Quality Domains” for websites that includes 58 quality items most relevant for Web-based health information rated as present or absent, of which 49 items from six domains were applicable to the non-printable websites dedicated to oncofertility identified in this review. Finally, the Flesch-Kincaid readability test was used to determine the grade level of each decision aid and health education material using a readability calculator [41]. For the non-printable websites dedicated to oncofertility, an overall grade level was calculated based on the average readability level of each webpage.

Two reviewers (SM and CD) independently assessed the quality of each decision aid, and two reviewers (BS and TL) independently assessed the quality of each health educational material. The Cohen kappa score was obtained to determine the level of interreviewer agreement [42].

Results

Description of Decision Aids and Health Education Materials Identified

Figure 1 describes the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) [43] flow chart of systematic database and Web-based study selection resulting in a total of 31 decision aids and health education materials included in this review (Table 1). The database search yielded 2620 unique articles following removal of duplicates. After title and abstract review, 46 articles underwent a full-text review. Two studies describing decision aids met the selection criteria and were included; no additional articles were identified from the reference list review.

The Web-based search in 2014 yielded approximately 11,000,000 results and this increased over twofold in 4 years to approximately 26,600,000 results in the 2018 search. From the Web-based search and consultation with experts in the field of oncology, an additional two decision aids and 27 health education materials were identified. We also identified four decision aids in development, including one in Switzerland by Tschudin et al [44], one in the United Kingdom by the Cancer, Fertility and Me study group and Jones et al [45], one in the United States by Woodard et al [46,47], and one in Germany by Ehrbar et al [48]. These decision aids were not accessible on the Web at the time of the searches and therefore are not included in this review.

This review identified four decision aids categorized as two traditional decision aids (6.5%) and two option grids (6.5%). In 2011, Peate et al developed a decision aid in the form of a booklet for women with early-stage breast cancer in Australia [49]. The Australian decision aid was updated in 2016 and is also being developed into an easily accessible website [50]. In 2013, Garvelink et al developed a Web-based decision aid for women with breast cancer in the Netherlands [51]. In Canada, a shared decision-making fertility option grid was created in 2015 as part of a pan-Canadian study focusing on young breast cancer patients [52]. Finally, a personalizable tool from LIVESTRONG [53] was created that allows patients to input their age, treatment, and cancer type to identify and compare the available options in an option grid format.

An additional 27 health educational materials were identified and categorized as 10 printable handouts (eg, brochures and booklets), 15 printable website sections dedicated to oncofertility (eg, the Canadian Cancer Society contains a section of oncofertility information on their website that is printable), and 2 non-printable interactive websites dedicated to oncofertility. Table 2 outlines the characteristics of all decision aids and health education materials.

Figure 1. Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) flow chart of decision aid and health education material selection.

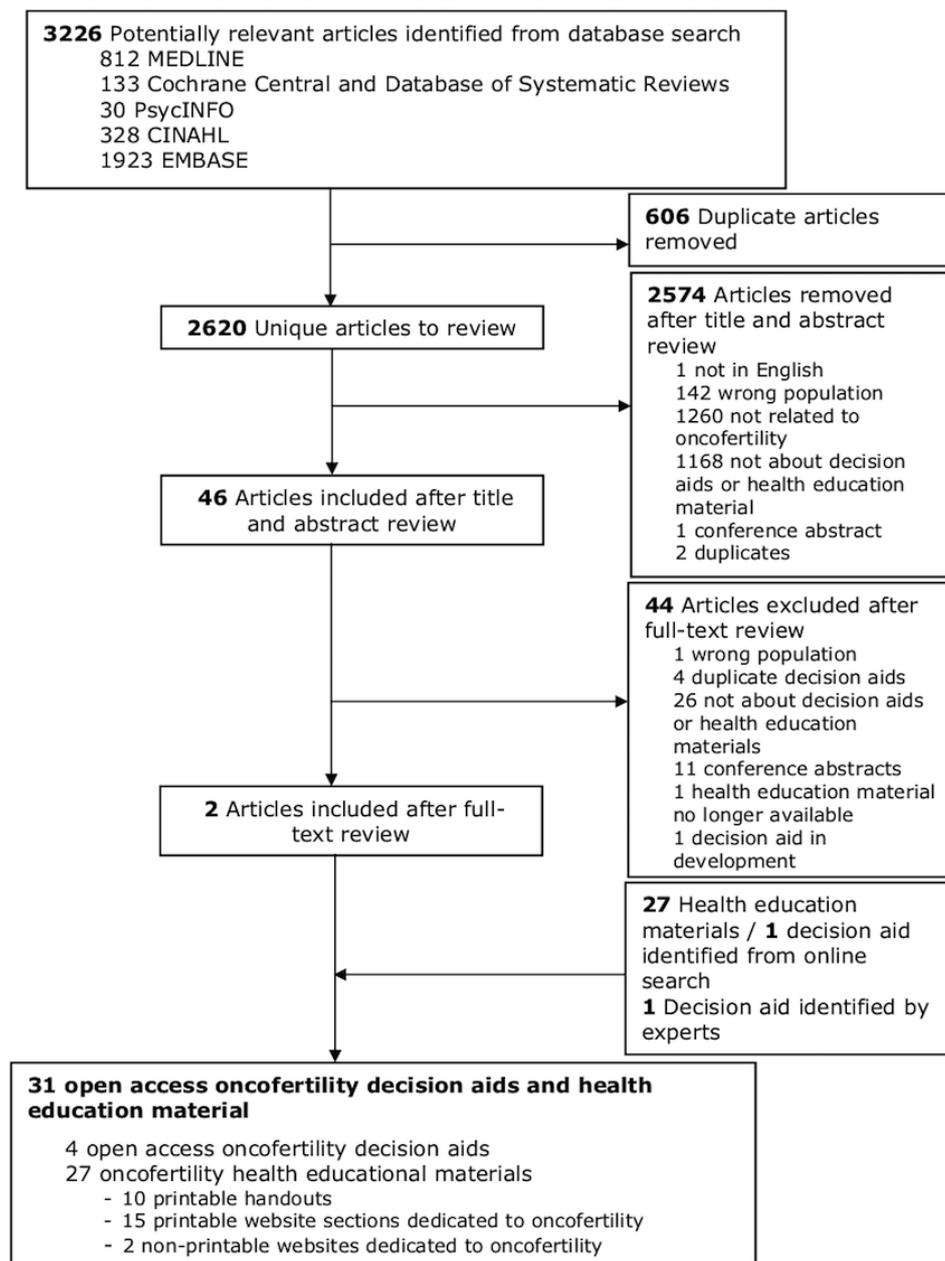


Table 1. Oncofertility decision aids and health education materials identified (N=31).

Resources identified	n (%)
Decision aids	4 (13)
Health education materials (printable handouts)	10 (32)
Health education materials (printable website sections dedicated to oncofertility)	15 (48)
Health education materials (non-printable website sections dedicated to oncofertility)	2 (7)

Table 2. Oncofertility decision aid and health education material description.

Resource	Author	Development group	Year	Type	Number of pages	Language	Sex	Cancer type	Country
Decision aids									
Australian Decision Aid	Peate et al	Academic teaching institution	2011 / 2016	Decision aid booklet	37	English	F ^a	Breast	AUS ^b
Dutch Decision Aid	Garvelink et al	Academic teaching institution	2013	Decision aid website	26 Web	Dutch	F	Breast	NLD ^c
SPOKE ^d Option Grid	Warner et al	Academic hospital	2015	Web-based PDF grid	1	English	F	Breast	CAN ^e
LIVESTRONG Family Building Option Tool	LIVE-STRONG	Non-profit organization	— ^f	Web-based tool	2 Web	English	All	All	USA ^g
Health educational materials (printable handouts)									
ASRM ^h Fact Sheet	ASRM	Non-profit organization	Revised 2014	Fact sheet	1	English	F	“Female cancers”	USA
Breast Cancer Care Booklet	Breast Cancer Care	Breast cancer charity	2017	Booklet	36	English	F	Breast	GBR ⁱ
Cancer Council Australia Booklet	Cancer Council Australia	Non-government organization	2014/2016	Booklet	84	English	All	All	AUS
Cancer.net	American Society of Clinical Oncology	Non-profit organization	2013	Fact sheet	1	English	All	All	USA
Cancer Care Fact Sheet	Editor: Lewis, S	National organization	Updated 2017	Fact sheet	2	English	All	All	USA
Fertile Future Brochure	Fertile Future	Non-profit organization	—	Brochure	6	English / French	All	All	CAN
LIVESTRONG Booklet	LIVE-STRONG	Non-profit organization	2013	Booklet	11	English	All	All	USA
LLSC ^j Fertility Facts	LLSC	Voluntary health agency	Revised 2014	Fact sheet	7	English	All	Leukemia / lymphoma	CAN / USA
Save My Fertility	Oncofertility Consortium	Private research university	2016	Pocket guide	2	English	All	All	USA
UHN ^k –PMH ^l Pamphlet	PMH	Teaching hospital	—	Booklet	2	English	F	All	CAN
Health educational materials (printable website sections dedicated to oncofertility)									
ACS ^m	ACS	Voluntary health organization	2017	Educational	2 Web, 16 print	English / Spanish	F	All	USA
BreastCancer.org	Breast Cancer.org	Non-profit organization	2018	Educational	21 Web	English / Spanish	F	Breast	USA
CancerPoints	Kantrowitz, M	Cancer information website	—	Educational	1 Web, 7 print	English	All	All	—
CCS ⁿ	CCS (ON ^o)	National organization	—	Educational	1 Web, 10 print	English / French	All	All	CAN
Cleveland Clinic	Cleveland Clinic	Academic hospital	2013	Educational	1 Web, 3 print	English	F	Breast	USA
Johns Hopkins Medicine	Kolp, L	Private research hospital	—	Educational	5 Web, 12 print	English	All	All	USA
Mayo Clinic	Mayo Clinic	Non-profit medical practice / research group	2016	Educational	2 Web, 10 print	English / Spanish / Portuguese / Chinese	All	All	USA

Resource	Author	Development group	Year	Type	Number of pages	Language	Sex	Cancer type	Country
MD Anderson Cancer Center	MD Anderson Cancer Center	Comprehensive cancer center	—	Educational	1 Web, 2 print	English / Spanish / Arabic / Chinese / Turkish	All	All	USA
MSKCC ^p	MSKCC	Private cancer center	2017	Educational	5 Web, 14 print	English	F	All	USA
NCCN ^q	NCCN	National organization	—	Educational	1 Web, 4 print	English	All	All	USA
NCI ^f	NCI	Government health agency	2017	Educational	1 Web, 5 print	English / Spanish	F	All	USA
NHS ^s	NHS UK	Government health agency	2015	Educational	1 Web, 5 print	English / Google Translate	All	All	GBR
OncoLink	Vachani, C	Cancer information website	2016	Educational	1 Web, 5 print	English / Spanish	F	All	USA
WebMD	WebMD	Web-based health publisher	2004	Educational	4 Web, 4 print	English	F	Breast	USA
YSC ^t	YSC	Non-profit global organization	—	Educational	5 Web, 12 print	English	F	Breast	USA
Health Educational Materials (non-printable websites dedicated to oncofertility)									
Alliance for Fertility Preservation	Alliance for Fertility Preservation	Charitable organization	2015	Educational	42 Web	English	All	All	USA
Fertile Action	Alice Crisci	Cancer charity	2008	Educational	54 Web	English	F	All	USA

^aF: female.

^bAUS: Australia.

^cNLD: Netherlands.

^dSPOKE: Surgeon and Patient Oncofertility Knowledge Enhancement.

^eCAN: Canada.

^f—: not available.

^gUSA: United States of America.

^hASRM: American Society for Reproductive Medicine.

ⁱGBR: United Kingdom of Great Britain and Northern Ireland.

^jLLSC: The Leukemia & Lymphoma Society of Canada.

^kUHN: University Health Network.

^lPMH: Princess Margaret Hospital.

^mACS: American Cancer Society.

ⁿCCS: Canadian Cancer Society.

^oON: Ontario.

^pMSKCC: Memorial Sloan Kettering Cancer Center.

^qNCCN: National Comprehension Cancer Network.

^rNCI: National Cancer Institute.

^sNHS: National Health Service.

^tYSC: Young Survival Coalition.

Fertility and Parenthood Options Presented in Decision Aids and Health Education Materials

All resources identified provided information on embryo and egg freezing. Most resources provided information on ovarian tissue freezing (30/31, 97%) and many provided information on ovarian suppression (23/31, 74%). Less than half of resources

provided information on other FP options including ovarian transposition (13/31, 42%), fertility-sparing surgery (12/31, 39%), ovarian shielding (6/31, 19%), and in vitro maturation (5/31, 16%). The Australian and Dutch decision aids as well as the PMH pamphlet, MSKCC website, Breast Cancer Care booklet, and Cancer Council Australia booklet (6/31, 19%) were the only resources to included information on the option of not

pursuing FP or “wait and see.” Nine resources (29%) provided no additional information on parenthood options after cancer treatment. The most commonly described parenthood options after treatment included egg donation (17/31, 55%), surrogacy (17/31, 55%), adoption (15/31, 48%), natural conception/having fertility testing completed (14/31, 45%), and embryo donation (13/31, 42%). Few resources listed no more children (6/31, 19%) or foster parenting (2/31, 6%) as parenthood options after cancer treatment. [Multimedia Appendix 3](#) presents all fertility options listed in each resource.

Content and Sections in Decision Aids and Health Education Materials

The Australian decision aid and Cancer Council Australia booklet were the most comprehensive resources covering a range of topics and included sections. These resources also contained the most pages, with 37 and 84 pages of content respectively. Only the decision aids from Australia and the Netherlands contained explicit values clarification methods. The values clarification method in the Australian decision aid is a personal worksheet with questions and a pros/cons list to identify the drawbacks and advantages for each fertility option [49]. The Dutch decision aid includes a 5-point scale where patients indicate their preference towards a fertility option by sliding the scale from very negative to very positive [51].

Few resources contained information on fertility in women (10/31, 32%), with more focusing on infertility in women (13/31, 42%). Most resources included information on cancer treatments (22/31, 71%), an explanation on how the treatment impacts fertility (25/31, 81%) and fertility outcomes after

treatment (eg, reduced fertility, early menopause or immediate menopause) (21/31, 68%). Many resources also listed sources for patients to access more information (23/31, 74%). Finally, 11 resources (35%) contained references detailing the sources of evidence and 7 resources (23%) had a glossary of medical terms. [Multimedia Appendix 4](#) lists the content for each decision support resource identified.

Quality Assessment of Decision Aids and Health Education Materials

Each resource underwent a quality assessment ([Multimedia Appendix 5](#)). The Cohen kappa score indicated substantial interrater agreement for all reviewers (0.75 kappa score) [42]. [Table 3](#) outlines the highest rated decision aids and health education materials (printable and non-printable) based on the specific quality assessment used.

The decision aid quality assessment revealed that the Australian and Dutch decision aids met all the qualifying criteria, while the two option grids met most qualifying criteria (5/6, 83%). The Dutch decision aid met all certification criteria, while the Australian decision aid and Canadian option grid met most applicable certification criteria, (5/6, 83% and 4/6, 67% respectively), and the LIVESTRONG option grid met only one certification criteria (1/6, 17%). All decision aids met at minimum three of the applicable quality criteria, including the ability to compare features of available options, inclusion of outcome probabilities, and the event rates for the outcome probabilities. The Australian and Dutch decision aids met the most quality criteria, (19/23, 83% and 20/23, 87%, respectively), when compared to the option grids.

Table 3. High-quality oncofertility decision aids and health education materials based on International Patient Decision Aid Standards Collaboration (IPDAS), Patient Education Materials Assessment Tool (PEMAT), and Seven Quality Domains.

Resource	Quality assessment tool	Quality assessment rating
Decision aid		
Australian Decision Aid	IPDAS	<ul style="list-style-type: none"> Qualifying criteria: 100% Certification criteria: 83% Quality criteria: 83%
Dutch Decision Aid	IPDAS	<ul style="list-style-type: none"> Qualifying criteria: 100% Certification criteria: 100% Quality criteria: 87%
Health educational materials (printable handouts)		
Breast Cancer Care Booklet	PEMAT	<ul style="list-style-type: none"> Understandability score: 87% Actionability score: 80%
Cancer Council Australia Booklet	PEMAT	<ul style="list-style-type: none"> Understandability score: 94% Actionability score: 80%
Health educational materials (printable website sections dedicated to oncofertility)		
Canadian Cancer Society	PEMAT	<ul style="list-style-type: none"> Understandability score: 83% Actionability score: 80%
Memorial Sloan Kettering Cancer Center (MSKCC)	PEMAT	<ul style="list-style-type: none"> Understandability score: 80% Actionability score: 80%
Health educational materials (non-printable websites dedicated to oncofertility)		
Alliance for Fertility Preservation	Seven Quality Domains	<ul style="list-style-type: none"> 38/49 quality characteristics (76%)

Using PEMAT, five of the printable handouts and printable website sections dedicated to oncofertility shared the greatest actionability score (4/5, 80%) (ie, material was the most actionable for patients), including the Cancer Council Australia booklet, the Leukemia and Lymphoma Society factsheet, the Breast Cancer Care booklet, and the Breastcancer.org, Canadian Cancer Society, MD Anderson Cancer Center, and MSKCC websites. Six materials rated 80% or above on understandability (ie, material was more understandable for patients), including the Cancer Council Australia booklet (16/17, 94%), American Cancer Society (13/15, 87%), Breast Cancer Care booklet (13/15, 87%), Canadian Cancer Society website (10/12, 83%), the MSKCC website (12/15, 80%), and the National Cancer Institute website (12/15, 80%). More than half (64%) of the printable handouts and printable website sections dedicated to oncofertility scored 50% or below on the actionability, and 52% of these resources scored below 70% on the understandability. However, all materials used the active voice for most sentences, did not expect users to complete any calculations, did not contain material that distracted from the resources purpose, and presented the information in a logical sequence.

The interactive oncofertility dedicated websites had variable quality, meeting between 23 (47%) and 38 (76%) of the 49 possible criteria. Both websites contained technical elements such as information on the ownership of the site, clear statement about their objectives and target audience, transparency on funding, compliance with advertising rules, and geographic location of the site. Additionally, each website contained design elements such as scroll bars, subheadings and grouping of information, a menu with listings, proper layout and typography, and correct presentation of content when viewed in a partial webpage window. For readability and usability, the websites had appropriate sentence construction, use of active voice for most sentences, and road signs to indicate next/previous topics, minimal downloading time, appropriate functionality to support content, and ease of navigation in finding the desired content. However, some aspects that neither website displayed included the date of creation/last update/technical maintenance, message alert when leaving the secure site, clear statement about the editorial review process, hierarchy of evidence clearly displayed, and interactive learning tools (eg, Web-based quiz).

Only five (16%) of the decision aids and health education materials were assessed at a reading level of grade 8 or below. All other resources ranged from a grade 8 to grade 12 and above readability level ([Multimedia Appendix 6](#)).

Discussion

Principal Considerations

This review identified and characterized 31 open access decision aids and health education materials of varying quality for use by women of reproductive age diagnosed with cancer and their providers. Of the identified resources, two decision aids from Australia [49] and the Netherlands [51], two printable handouts from the United Kingdom [54] and Australia [55], and two websites from Canada [56] and the United States [57,58] rated as the highest quality. This review adds multiple new decision aids and health education materials for women of reproductive

age with cancer to the three Web-based health education materials from the United States identified by Kelvin et al in 2012 [26], and the one decision aid for early stage breast cancer patients (Australian decision aid [49]) identified in a 2016 review by Zdenkowski et al [27]. Zdenkowski et al described a gap in oncofertility decision aids for young breast cancer patients, and this review revealed that decision aids are now available or under development for cancer patients in Canada, the Netherlands, Germany, Switzerland, the United States, and the United Kingdom. This review also expands on two recent reviews by de Man et al [24] and Mahmoodi et al [25] and further characterized the oncofertility decision aids and health education materials available for women of reproductive age diagnosed with cancer, extended the categorization and quality analysis by type of resource, and includes a quick reference list that practitioners can use to identify high-quality decision aids and health education materials to supplement fertility discussions and recommend to their patients. The creation and use of resources as an adjunct to fertility discussions with providers is strongly supported in the literature [8,19]. Additionally, this review highlighted the increased attention surrounding the topic of oncofertility in cancer patients as the search engine results more than doubled from 2014 to 2018.

While the number of resources has increased, this review found the quality of these resources could be enhanced. While more information is of benefit to patients and providers, developers should adhere to best practices, such as the IPDAS [35] when creating decision aids to ensure resources are high quality and usable by the target population and the Standards for Universal reporting of patient Decision Aid Evaluation (SUNDAE) checklist [59] when reporting on evaluations of decision aids. Additionally, only the IPDAS checklist evaluated if the decision aids underwent field testing with patients and providers. As the health educational materials were identified through the Web-based search, it was unclear if there had been any field testing of these materials with target users. Field testing is recommended by the IPDAS to ensure the information in the resource resonates with and is understood by the population of interest and does not cause any bias in decision making [60].

The Australian decision aid by Peate et al [49] and booklet by Cancer Council Australia [55] were the most comprehensive and detailed resources identified in our search. However, both resources were long, highlighting the tradeoff between comprehensiveness and ease of use in clinic for patients and providers. Longer resources may be more useful as a take-home resource since limited clinic time may result in the inability for patients and providers to fully review the resource and have in-depth fertility discussions. Yet, a challenge with comprehensive resources used by patients independently outside of clinic is the inability to guarantee that shared decision making occurs in follow-up consultations [61]. In comparison, resources such as the Canadian option grid were specifically designed to be used as a concise in-clinic shared decision-making tool with patients and providers. However, effective use of these in-clinic resources requires the active involvement and engagement of providers [62]. To ensure continued and proper use of in-clinic resources, providers must agree on need for the resource, use the resource in clinic regularly, and administer the resource

effectively to promote shared decision making with patients [62-64].

Women of reproductive age want fertility information and desire participation in discussions around FP prior to starting fertility-risking cancer treatment [65]. The risk of infertility from cancer treatment is of such importance to women that it can impact treatment decision making [66]. As such, patients' information needs are also important for providers to consider when deciding on the appropriate resource to provide as an adjunct to discussions. Some patients may benefit from shorter resources (eg, option grid or fact sheet) and more in-clinic shared decision making, whereas others may prefer more comprehensive resources that provide information on fertility, exposure to all available FP and parenthood options, and assistance in decision making. Additionally, some patients may benefit from both types of resources in clinic and to review independently or with their support person(s). This review identified a wide range of easily accessible resources, alleviating the barrier of lack of awareness on the available resources cited by providers [21-23]. Providers should promote the high quality and applicable resources to interested patients based on their identified information needs. Resource developers can also modify existing resources to improve their quality and meet the needs of their patient population. To enable use of the resources, developers should create a dissemination and education plan that is aligned with patients' needs and providers' practices to ensure accessibility and continued use [67].

Through the exploration of Web-based sources, the review was strengthened by the discovery of decision aids in development and resources not identified in previous reviews [19,27,68]. This review also included various resources created by academic centers, non-profit organizations, and charities for cancer patients accessible through a search engine query. While this review excluded resources designed solely for men, it is important to highlight that male-specific resources are also necessary to identify and evaluate. However, due to the differences in infertility risks and FP options between men and women [69], male resources should be characterized and evaluated in a separate review [70]. Only open access and English language resources were included. As such, resources not identified using the key search terms and phrases at the time of the search, resources in another language, or resources only accessible when logged on to an organization's network server may have been missed in this review. The characteristics of the resources including the content and the fertility options

presented in this review may change as developers update them to reflect advances in the field of oncofertility.

We also conducted the Web-based search using one search engine (Google) in one location (Toronto, Ontario). Although different results may have been obtained with other search engines and in other geographic locations, the search was conducted at three different time points capturing search engine index changes. Additionally, the review of approximately 50 websites during each search ensured a broad range of potentially eligible websites and aimed to replicate the searching strategy of a patient recently diagnosed with cancer. Our search did not include fertility clinic information as the search strategy was not designed to capture fertility clinics globally and a targeted search of fertility clinic information was out of scope for this review.

Practical Implications

This review allowed for the comparison and quality assessment of decision aids and health education materials potentially accessed by women of reproductive age with a diagnosis of cancer or used by providers as an adjunct to clinical discussions. Applicable resources that align with the clinical population, local context, and patient information needs can be identified from this review. As such, we need to focus on enhancing the awareness and the access of these resources to ensure use and promotion of high-quality resources to patients who desire more information before fertility decision making and cancer treatment. The identified decision aids and health education materials can also be modified to enhance their quality and to meet the local needs of a clinic and patient population.

Conclusion

Fertility preservation prior to cancer treatment is an important topic of discussion for women of reproductive age, and resources can help facilitate patient-provider discussions prior to fertility-risking treatment. This review identified 31 oncofertility decision aids and health education materials that are publicly available. The quality assessments revealed the resources are of varying quality, which indicates that there is room for improvement for many of these resources. As further resources are developed to fill an information gap, developers should adhere to patient education best practices during development to ensure a high-quality tool. Field testing should also be completed by stakeholders of the resource prior to publication of the content on the Web.

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Authors' Contributions

BS participated in the search for articles, selection of articles, data abstraction, quality assessment, and drafting of the manuscript. SM contributed to the design of the systematic review, search for articles, selection of articles, quality assessment, and drafting of the manuscript. CD participated in the design of the systematic review, quality assessment, and drafting of the manuscript. LP contributed to the systematic review data abstraction. TL assisted with selection of articles, quality assessment, and drafting of the manuscript. NB conducted the design of the study and assisted in drafting of the manuscript. All authors read and approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Search strategy (MEDLINE) used to retrieve records from January 1994 to April 2018 reporting oncofertility decision aids and health education materials.

[PDF File (Adobe PDF File), 39KB - [cancer_v5i1e12593_app1.pdf](#)]

Multimedia Appendix 2

Online sources searched.

[PDF File (Adobe PDF File), 43KB - [cancer_v5i1e12593_app2.pdf](#)]

Multimedia Appendix 3

Fertility and parenthood options in oncofertility decision aids and health education materials.

[PDF File (Adobe PDF File), 257KB - [cancer_v5i1e12593_app3.pdf](#)]

Multimedia Appendix 4

Content and sections in the oncofertility decision aids and health education materials.

[PDF File (Adobe PDF File), 273KB - [cancer_v5i1e12593_app4.pdf](#)]

Multimedia Appendix 5

Quality assessments of the oncofertility decision aids and health education materials.

[PDF File (Adobe PDF File), 520KB - [cancer_v5i1e12593_app5.pdf](#)]

Multimedia Appendix 6

Readability level of the oncofertility decision aids and health education materials using the Flesch-Kincaid Grade Level test.

[PDF File (Adobe PDF File), 34KB - [cancer_v5i1e12593_app6.pdf](#)]

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Abbreviations

FP: fertility preservation

IPDAS: International Patient Decision Aid Standards Collaboration

MSKCC: Memorial Sloan Kettering Cancer Center

PEMAT: Patient Education Materials Assessment Tool

PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analysis

SUNDAE: Standards for Universal reporting of patient Decision Aid Evaluation

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Viewpoint

Designing and Testing Apps to Support Patients With Cancer: Looking to Behavioral Science to Lead the Way

Lauren M Hamel¹, PhD; Hayley S Thompson¹, PhD; Terrance L Albrecht¹, PhD; Felicity WK Harper¹, PhD

Population Studies and Disparities Research Program, Department of Oncology, Wayne State University, Detroit, MI, United States

Corresponding Author:

Lauren M Hamel, PhD
Population Studies and Disparities Research Program
Department of Oncology
Wayne State University
4100 John R St
Detroit, MI, 48201
United States
Phone: 1 5868633884
Email: hamell@karmanos.org

Abstract

Background: Behavioral science has a long and strong tradition of rigorous experimental and applied methodologies, which have produced several influential and far-reaching theoretical frameworks and have guided countless inquiries of human behavior in various contexts. In cancer care, behavioral scientists have established a firm foundation of research focused on understanding the experience of cancer and using that understanding to design and implement theory- and evidenced-based interventions to help patients cope with the cancer experience. Given the rich behavioral research base in oncology, behavioral scientists are ideally positioned to lead the integration of evidence-based science on behavior and behavior change into the development of smartphone apps supporting patients with cancer. Smartphone apps are being disseminated to patients with cancer with claims of being able to help them negotiate areas of vulnerability in their cancer experience. However, the vast majority of these apps are developed without the rigor and expertise of behavioral scientists.

Objective: In this article, we have illustrated the importance of behavioral science leading the development and evaluation of apps to support patients with cancer by providing an illustrative scientific process that our team of behavioral scientists, patient stakeholders, medical oncologists, and software developers used to empirically design and evaluate 2 patient-focused apps: the Discussion of Cost App (DISCO App) and MyPatientPal.

Methods: Using a focused literature review and a descriptive roadmap of our team's process for designing and evaluating patient-focused behavioral apps for patients with cancer, we have demonstrated how behavioral scientists are integral to the development of empirically sound apps to help support patients with cancer. Specifically, we have illustrated the process by which our multidisciplinary team combined the established user-centered design principles and behavioral science theory and scientific rigor to design and evaluate 2 patient-focused apps.

Results: On the basis of initial acceptability and feasibility testing among patients and providers, our team has demonstrated how critical behavioral science is for designing and evaluating app-based interventions for patients with cancer.

Conclusions: Behavioral science can and should be coupled with user-centered design principles to provide theoretical guidance and the rigor of the scientific method, thereby adding the much-needed and critical evidence for these types of app-based interventions for patients with cancer.

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KEYWORDS

behavioral science; cancer; mobile apps; evidence-based practice; smartphone; mHealth

Introduction

Background

Behavioral scientists seek to understand the interpersonal and contextual motivations, and the limitations and parameters of those motivations, of human behavior. Guided by evidence-based theories and models, behavioral scientists apply the rigor of the scientific method to important areas of human behavior inquiry. For example, behavioral scientists have articulated, tested, and adapted several major theoretical frameworks (eg, Social Cognitive Theory [1], Theory of Planned Behavior [2], the Health Belief Model [3], and the Transtheoretical Model [4]) that have guided our systematic understanding of human behavior in myriad contexts, specifically in health contexts.

In cancer care, behavioral scientists have established a firm foundation of research focused on understanding the experience of cancer and using that understanding to design and implement theory- and evidence-based interventions for patients [5-9]. By integrating behavioral theories with the realities of patients' cancer experience, behavioral scientists have helped improve care and outcomes for numerous patients with cancer, including those most likely to experience disparities in the quality of their care and their health outcomes [10].

The Patient Experience

The National Comprehensive Cancer Network Distress Management Guidelines have identified areas of vulnerability that patients are likely to experience, including but not limited to the diagnostic workup, treatment planning, treatment for advanced disease, and when there is recurrence or disease progression [11,12]. Research by behavioral scientists has found that, for many patients, simply interacting with the health care system is a novel experience and may pose significant emotional and practical challenges for them and their families. For example, patients may struggle with effectively communicating with physicians and other providers [13-16], sharing in the decision making of their care plan [17,18], understanding complicated treatment regimens [19,20], and managing intrusive treatment side effects [21]. They may also have difficulty navigating a maze of appointments [22,23], frequently characterized by long wait times [24] and confusing physical surroundings, not to mention worrying about the financial burden of care [25]. Difficulties negotiating these areas of vulnerabilities can lead to poor patient satisfaction with care [15,17,18], increased psychological distress [12,21], missed or delayed appointments, and nonadherence to treatment [15].

Leveraging Technology to Support Patients

Advances in smartphone apps have provided patients with readily available and low-cost tools to help manage their health [26,27] and, more importantly, navigate these areas of vulnerability [28-30]. In fact, apps are already being used to provide patients with information and strategies for prevention, detection, and management of treatments and side effects of cancer [31]. A recent review of apps specifically for patients diagnosed with breast cancer identified 599 unique apps. Unfortunately, less than 20% (118/599) of those apps included

references to empirical studies or background source materials, highlighting the lack of an evidence base behind most patient-focused apps [32]. Another review of apps focusing on breast diseases, including breast cancer, evaluated whether apps were evidence-based, whether they had the involvement of a medical professional in the development, or had evaluated potential safety concerns. Of the 185 apps reviewed, only 11.4% (21/185) were evidence-based and only 10.3% (19/185) had the involvement of a medical professional in their development. Furthermore, 15.7% (29/185) of the apps had the potential to cause indirect harm to the consumer as they provided advice without documented evidence or medical professional input. Thus, although there is an abundance of apps available to support cancer patients, there is a remarkable lack of evidence underlying the content, underscoring the need for more scientific rigor in the development of apps for patients with cancer [33].

Review of the Evidence

Recent published reviews of the effectiveness of app-based behavior change interventions are useful in identifying what aspects of intervention content are most important for behavior change. One such review conducted by Zhao et al evaluated 23 papers reporting on the effectiveness tests of mobile phone apps designed to improve various health issues [34]. They noted that only 6 of the 23 reviewed apps included a theory or model of behavior change (eg, Theory of Planned Behavior and Social Cognitive Theory). Apps that were designed with the guidance of a theory of behavior change were, however, more effective at influencing outcomes than those that lacked a theoretical basis. Another review that assessed behavior change communication interventions was silent on whether any theories or models of behavior change were included with any of the reviewed apps [35]. In sum, evidence is indicating that apps designed with the benefit of a behavioral theory or model as a guide will be more effective at prompting behavior change.

The Role of Behavioral Science

As the findings from the review by Zhao et al demonstrate, behavioral scientists can play a unique and vital role in the design of app-based interventions and the evaluation of their effectiveness on key patient outcomes. An important exemplar is a report by Giunti et al on the design of an app to support patients with multiple sclerosis [36]. They described a user-centered design process guided by behavior change theories including the health belief model, goal setting theory, and self-determination theory. Similarly, Dicianno et al presented a roadmap of the design of a mobile health tool to promote goal achievement and self-management for patients with spina bifida and spinal cord injuries [37]. The intervention content, which focused on behavior change strategies, was informed by the self-determination theory, a theory of motivation to prompt behavior change. Although the effectiveness of these apps is yet to be published, they provided a promising genesis of the integration of behavioral science in app development.

Given the firm foundation of behavioral research in oncology, behavioral scientists are ideally positioned to lead the integration of evidence-based science on behavior and behavior change into the development of apps supporting patients with cancer. In this article, we have illustrated the contribution of behavioral

science by describing the scientific process that our team of behavioral scientists, patient stakeholders, medical oncologists, and software developers used to design and test 2 patient-focused apps. This team collectively and empirically designed, built, and conducted acceptability testing of 2 apps designed to help patients with cancer at certain points in the cancer care continuum.

Methods and Results

Examples of Behavioral Science–Driven App Development and Evaluation

The *Discussion of Cost App (DISCO App)*, built by CrossComm [38] is a patient-focused app designed to help patients proactively manage their treatment costs through enhanced efficacy by (1) educating patients with cancer about the different types of treatment costs (eg, copayments, transportation, and lodging) and (2) prompting patient-oncologist treatment cost discussions. The premise of the app is that educating patients about treatment cost and prompting treatment cost discussions earlier in the treatment will help evoke proactive responses to financial needs and help prevent financial toxicity [39-41]. The DISCO App design was based on similar paper-based interventions (question prompt lists [QPLs]), which have been shown to effectively prompt active participation of the patient in treatment discussions [5,42] and facilitate patient-centered communication [13,42]. The design of QPLs is rooted in communication and social psychological theories of behavior of change, and their effectiveness has been tested in randomized controlled trials in several care settings [5,42].

The DISCO App advances traditional QPLs in 3 ways. First, it provides patients with a short educational video about treatment costs, about ways to manage those costs, and showing that discussing costs with their oncologist is an important first step. Second, it focuses on specific cost concerns (an emerging problem for many patients with cancer) previously shown to be important to patients with cancer [41]. Third, it uses patient-reported demographic information to provide a tailored list of cost-related questions. Before meeting their oncologist, patients are shown a short educational video about treatment costs in the DISCO App using an iPad and then the app has patients complete a short financial and demographic survey (eg, What is your annual household income?; How much does your health insurance cover?). On the basis of the patient's responses, an individually-tailored list of cost-related questions is created. For example, patients may be prompted with the question "Is there someone I can talk to about my insurance and treatment cost questions?" Patients can then use these question prompts with their oncologist or other providers when discussing treatment cost.

MyPatientPal (built by CrossComm) is a patient app that is designed to help patients track and manage treatment side effects and medication adherence on a daily basis. The side effects of treatment (eg, pain, fatigue, diarrhea, and nausea) can be physically and emotionally debilitating and, when uncontrolled, can cause treatment complications, resulting in unscheduled care costs, patient's out-of-pocket costs, and delays or discontinuation of treatment. Research shows that

patient-reported outcomes (PROs), and in particular daily reporting of PROs, can help to identify significant changes in treatment-related side effects as well as quickly identify new and emerging side effects. On the basis of theories of self-management and self-efficacy [43-45], daily reporting of side effects and medications is theorized to increase patients' self-efficacy for managing their own care, which in turn may increase adherence to medication and increase communication with providers about side effects. The app allows personalization of the daily diaries such that patients can select the specific medications and dosage and side effects (using items from the National Cancer Institute Common Terminology Criteria for Adverse Events [46]) that they and their providers want to track. The app also has a charting feature, which provides an easy-to-read display of patients' daily reports, summarizing the intensity and frequency of side effects and medication use either by week or by month. Alongside allowing patients to see trends in their reports, these summaries can also be printed out and shared with providers to better inform their care.

In addition to being theoretically guided, both the DISCO App and MyPatientPal were developed using an iterative design-test-redesign process [47,48] in collaboration with a multidisciplinary team (eg, patients, providers, and software developers). First, the investigators discussed their app ideas with software experts in a university-based technology transfer department. Second, with guidance from the technology transfer department, the investigators conducted a series of customer discovery interviews (n=40 each) with key stakeholders (eg, on-treatment patients, survivors, caregivers, oncologists, and social workers) to determine (1) the relevance of the identified problem to stakeholders and (2) the extent to which the proposed app would help solve the problem. Responses from the discovery interviews were summarized and used to refine the content of the apps. Third, software designers in the technology transfer department developed wireframes. Wireframes provide a prototype of the structure and functions of a website or app and are often used at the initial phases of a build to allow redesign and refinement of the app. Wireframes also provide a roadmap for software developers by illustrating the various elements and screens of the app. Fourth, wireframes were reviewed with key stakeholders (eg, cancer survivors, clinicians, and social/behavioral scientists) for feedback on the design, content, and screen navigation. Finally, using that feedback, the investigators collaborated with a professional software development firm to revise the wireframes and use them to build the initial electronic prototype of the app, also known as a minimally viable product, to use in acceptability testing with key stakeholders. Using semistructured interviews, behavioral scientists then conducted qualitative interviews with stakeholders to review and provide feedback on the design and content of the app, its usefulness for patients, and suggestions for improvement. In the final stage, the investigators worked with the software development firm to create a final prototype (*build*) to use in feasibility and effectiveness testing in a clinic setting.

Discussion

In summary, smartphone apps are being disseminated to patients with cancer with claims of being able to help them negotiate areas of vulnerability in their cancer experience. However, the vast majority of these apps are developed without the rigor and expertise of behavioral scientists.

Principal Findings

To be sure, many apps benefit from user-centered design principles, which attend to how users interact with products and ensure they meet user needs. In contrast, behavioral scientists bring an important understanding of the psychological processes underlying the content and how the product can be used to effect behavior change, whether it is focused in health behaviors such as diet and exercise or self-management of diseases such as cancer. Thus, behavioral science has the potential to complement and even significantly augment user-centered design principles

by providing theoretical guidance and the rigor of the scientific method, thereby adding the currently lacking but much needed empirical support for these types of apps.

Conclusions

Thus, we argue that future apps designed to help patients with cancer should be built by a multidisciplinary team of experts including physicians, survivors, software developers, university technology transfer units, and behavioral scientists, who bring critical theoretical and evidence-based knowledge. This multidisciplinary approach means that app-based interventions will be user-friendly, evidence-based, and theoretically sound, and as such, more likely to be effective sources of support for patients with cancer through the myriad of issues and obstacles they will likely face. Furthermore, this type of team approach can lead to the development of patient-centered apps that meet the needs of stakeholders and improve the experience of cancer diagnosis, treatment, and survivorship for a diverse population of patients.

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Conflicts of Interest

None declared.

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Abbreviations

DISCO: Discussion of Cost

PRO: patient-reported outcome

QPL: question prompt list

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Original Paper

Investigation of Radiation Oncologists' Awareness of Online Reputation Management

Jonathan Fredric Waxer¹, MD; Sudesh Srivastav², PhD; Christian Steven DiBiase³; Steven Joseph DiBiase⁴, MD

¹Tulane University School of Medicine, New Orleans, LA, United States

²Department of Global Biostatistics and Data Science, Tulane University School of Public Health and Tropical Medicine, New Orleans, LA, United States

³Webb School of Knoxville, Knoxville, TN, United States

⁴Department of Radiation Oncology, New York-Presbyterian Queens, Weill Cornell Medicine, Flushing, NY, United States

Corresponding Author:

Steven Joseph DiBiase, MD

Department of Radiation Oncology

New York-Presbyterian Queens

Weill Cornell Medicine

56-45 Main Street

Flushing, NY, 11355

United States

Phone: 1 718 670 1501

Fax: 1 718 445 9846

Email: sdibiase@tulane.edu

Abstract

Background: Online reputation management (ORM) is an emerging practice strategy that emphasizes the systematic and proactive monitoring of online reviews relating to one's professional reputation.

Objective: We developed this survey project to assess whether radiation oncologists are aware of ORM and how it is utilized in their practices. We hypothesized that ORM is largely unknown by most practicing radiation oncologists and that little time is spent actively managing their reputations.

Methods: An online survey was submitted to 1222 radiation oncologists using the Qualtrics research platform. Physician emails were gathered from the American Society for Radiation Oncology member directory. A total of 85 physicians initiated the survey, whereas 76 physicians completed more than or equal to 94% (15/16) of the survey questions and were subsequently used in our analyses. The survey consisted of 15 questions querying practice demographics, patient satisfaction determination, ORM understanding, and activities to address ORM and 1 question for physicians to opt-in to a US \$50 Amazon gift card raffle. The survey data were summarized using a frequency table, and data were analyzed using the Chi-square test, Fisher exact test, and Spearman correlation coefficients.

Results: We calculated a 7% (85/1222) response rate for our survey, with a completion rate of 89% (76/85). A majority of respondents (97%, 74/76) endorsed being somewhat or strongly concerned about patient satisfaction ($P < .001$). However, 58% (44/76) of respondents reported spending 0 hours per week reviewing or managing their online reputation and 39% (30/76) reported spending less than 1 hour per week ($P < .001$). A majority of physicians (58%, 44/76) endorsed no familiarity with ORM ($P < .001$) and 70% (53/76) did not actively manage their online reputation ($P < .001$). Although 83% (63/76) of respondents strongly or somewhat believed that patients read online reviews ($P < .001$), 57% (43/76) of respondents did not check their online reviews ($P = .25$) and 80% (61/76) endorsed never responding to online reviews ($P < .001$). Moreover, 58% (44/76) of the respondents strongly or somewhat supported the idea of managing their online reputation going forward ($P = .001$). In addition, 11 out of the 28 pairs of questions asked in our correlation studies reached statistical significance. Degree of concern for patient satisfaction and the notion of managing one's ORM going forward were the 2 most frequently correlated topics of statistical significance in our analyses.

Conclusions: ORM is presently under-recognized in radiation oncology. Although most practitioners are concerned about patient satisfaction, little effort is directed toward the internet on this matter. ORM offers an area of practice improvement for many practicing radiation oncologists.

KEYWORDS

reputation; management; internet; patient satisfaction; surveys and questionnaires; radiation oncology

Introduction

Theory

The path to becoming a physician involves a decade-long investment in time and money, making a physician's professional reputation one of the most valuable parts of their practice. Online reputation management (ORM) has been a growing activity in the last decade. The idea of ORM is to systematically monitor, analyze, and filter online media sources and even interact with consumers via online reviews. In health care, ORM has been largely overlooked from a literature perspective, with limited articles dedicated to its presence, benefits, or practices. Despite the current paucity of literature regarding ORM in the health care setting, we believe the study of ORM is indicated, especially because of the numerous existing studies that discuss physician review websites (PRW) and how that form of data can guide future changes in practice. Furthermore, health maintenance organizations and other payers increasingly use patient satisfaction reports to profile individual physicians and guide physician compensation [1]. These examples highlight only a few examples of why physicians should be educated and up to date on this topic.

Prior Work

As patients increasingly turn to the internet to search for health information and health care providers [2], online forums have become increasingly popular, and popular large-scale websites such as Yelp, Facebook, and Google Reviews now publish reviews on nearly every aspect of life. Other online forums, known as PRWs, have surfaced that solely discuss health care providers. PRWs are online services that allow patients and other third-party reviewers to grade physicians and hospitals in an online forum. Some examples of PRWs include Healthgrades.com, WebMD.com, ZocDoc.com, Vitals.com, and RateMDs.com.

Research on this topic has suggested that the popularity of PRWs is steadily increasing, and, as an example, the number of reviews on RateMDs.com has grown from 2475 reviews in 2005 to 112,024 in 2010 [3]. In 2012, 36% of surveyed Americans reported having searched for a physician on the internet [4], and over the past decade, the percentage of individuals that utilized the internet to obtain health information increased from 20% to 60% [3]. A survey of health care consumers in 2011 found that 28% (1120/4000) of respondents searched online for information regarding the quality of care provided by a primary care physician or a medical specialist, which was an increase from 24% in 2010 (960/4000). In addition, this number was found to be as high as 34% among younger generations [5], and based on a survey in 2015, more than a quarter of young parents

selected a pediatrician for their child by using the internet [6]. This upward trend is expected to steadily increase as the ease of technological access improves and as the age demographics shift—resulting in a society of proportionally more tech-savvy individuals.

Hypotheses

We developed this survey project to assess whether radiation oncologists are aware of ORM and how it is utilized in their practices. We hypothesized that ORM is largely unknown by most practicing radiation oncologists and that little time is spent actively managing their reputations.

Methods

Recruitment

Under institutional review board (IRB) guidelines, our anonymous survey project qualified as an exempt review. Collaborative Institutional Training Initiative certificates were completed and uploaded in the submission for all research personnel, and our study was subsequently approved by the IRB. A closed, voluntary online survey pertaining to ORM was created (Table 1).

The survey consisted of 16 questionnaire items over 2 pages that queried practice demographics, patient satisfaction, ORM understanding, and activities to address ORM. The survey questions were largely a collection of multiple-choice responses with a few fill-in-the-blank responses. Many of the questions utilized a 5-point Likert scale and asked respondents to rate their level of agreement with questions related to ORM: 1=strongly agree, 2=somewhat agree, 3=undecided, 4=somewhat disagree, and 5=strongly disagree [7].

Our target population was practicing radiation oncologists. We gathered 1222 radiation oncologists' emails from the American Society for Radiation Oncology (ASTRO) membership database while excluding radiation physicists, nurses, and radiation oncology residents in training from our study. The electronic survey was created and subsequently delivered via email using the Qualtrics survey software. The electronic survey was tested for usability and technical functionality before being sent to our group of radiation oncologists. To ensure no duplicate entries were gathered, all respondents had a unique survey link, and users with the same internet protocol address were prevented from accessing the survey twice over the 3-month period in which the questionnaire was live. Electronic informed consent was delivered via email. Participants were told the purpose of the study, the investigator, the estimated length of time of the survey, and the IRB approval number. Informed consent was obtained by having the study participants begin the survey.

Table 1. Online reputation management physician survey and data. Overall, 16 questions were developed that assessed physician understanding of online reputation management, demographics, and opinions pertaining to patient satisfaction. For each multiple-choice response, frequency data, response percentages, and *P* values are included, where applicable.

Question	n (%)	<i>P</i> value
1. Which of the following best describes your Radiation Oncology practice?		
A. Freestanding Practice	20 (26)	.02
B. Hospital-Based Practice	26 (34)	.02
C. Academic or University Practice	22 (29)	.02
D. Other	8 (11)	.02
2. How many years have you been practicing (since completing residency)?		
A. 0-5 years	20 (26)	.01
B. 5-10 years	9 (12)	.01
C. 10-15 years	13 (17)	.01
D. 15-20 years	9 (12)	.01
E. 20+ years	25(33)	.01
3. What state is your practice located in?		
4. I am concerned about patient satisfaction.		
A. Strongly agree	58 (76)	<.001
B. Somewhat agree	16 (21)	<.001
C. Undecided	2 (3)	<.001
D. Somewhat disagree	0	<.001
E. Strongly disagree	0	<.001
5. Does your practice perform patient satisfaction surveys?		
A. Yes, on paper	49 (65)	<.001
B. Yes, online	20 (26)	<.001
C. No	7 (9)	<.001
6. I am familiar with the term Online Reputation Management (ORM).		
A. Yes	32 (42)	<.001
B. No	44 (58)	<.001
7. Which of the following best describes your level of management of your online reputation?		
A. I do not manage my online reputation	53 (70)	<.001
B. I read online reviews	15 (20)	<.001
C. I actively manage online reviews (ie, respond to negative/positive comments)	0	<.001
D. I proactively ask patients to write and post reviews about their care online	3 (4)	<.001
E. I pay someone to manage my online reputation	5 (6)	<.001
8. How much time per week do you spend reviewing/managing your online reputation?		
A. <1 hour	30 (39)	<.001
B. 1-2 hours	2 (3)	<.001
C. 2-3 hours	0	<.001
D. 3+ hours	0	<.001
E. None at all	44 (58)	<.001
9. I am concerned about my reputation.		
A. Strongly agree	47 (62)	<.001
B. Somewhat agree	21 (28)	<.001
C. Undecided	4 (5)	<.001

Question	n (%)	<i>P</i> value
D. Somewhat disagree	3 (4)	<.001
E. Strongly disagree	1 (1)	<.001
10. I am aware of third-party physician review sites.		
A. Strongly agree	33 (44)	<.001
B. Somewhat agree	26 (34)	<.001
C. Undecided	7 (9)	<.001
D. Somewhat disagree	7 (9)	<.001
E. Strongly disagree	3 (4)	<.001
11. I believe online reviews are more impactful than ‘word of mouth.’		
A. Strongly agree	8 (11)	<.001
B. Somewhat agree	22 (29)	<.001
C. Undecided	26 (34)	<.001
D. Somewhat disagree	13 (17)	<.001
E. Strongly disagree	7 (9)	<.001
12. I believe that patients read online reviews.		
A. Strongly agree	23 (30)	<.001
B. Somewhat agree	40 (53)	<.001
C. Undecided	8 (11)	<.001
D. Somewhat disagree	4 (5)	<.001
E. Strongly disagree	1 (1)	<.001
13. I check online reviews that discuss my practice.		
A. Yes	33 (43)	.25
B. No	43 (57)	.25
14. I respond to online reviews that discuss my practice.		
A. Always	3 (4)	<.001
B. Sometimes	12 (16)	<.001
C. Never	61 (80)	<.001
15. I welcome the idea of managing my online reputation.		
A. Strongly agree	20 (26)	.001
B. Somewhat agree	24 (32)	.001
C. Undecided	18 (24)	.001
D. Somewhat disagree	11 (14)	.001
E. Strongly disagree	3 (4)	.001
16. Please provide your email address below if you wish to be entered into the drawing to win one of five US \$50 Amazon gift cards.		

Participants were given 3 months to complete the survey, and 4 email announcements were sent as reminders from December 2016 to February 2017 to participants who had not previously completed the survey as the study deadline approached. Respondents were able to review and change their answers before survey submission, and a completeness check tool was not utilized. We used 5 \$50 Amazon gift card raffles as incentives to improve participation. The survey data were automatically captured in Qualtrics. At the completion of our data gathering stage, the Qualtrics survey data were imported into Microsoft Excel, deidentified, and summarized using a

frequency table listing frequency, percentages, and *P* values (Table 1).

Statistical Analysis

All data relating to study specific aims were summarized using descriptive statistics. Frequency tables were drawn up for nominal and ordinal data. The Chi-square and Fisher exact test methods were applied to compare association and proportions. The Chi-square test was used because of the varying degrees of freedom per question and would be able to indicate how likely our observed distribution was because of chance. *P* values

for statistical significance were then analyzed using a 2-sided 5% significance level throughout the analyses. Correlation studies were conducted using the Spearman correlation coefficient. Correlation coefficients were characterized as either weak ($r < .30$), moderate ($.30 \leq r \leq .70$), or strong ($r > .70$). We performed our analyses on our multiple-choice, demographic-defining questions (1 and 2) and our survey questions that contained a 5-point Likert scale: 4, 9, 10, 11, 12, and 15 (Table 2). All data analyses, summaries, and listing were performed using SAS software (version 9 or higher in a Windows environment).

Results

Of the 1222 invites, 85 surveys were initiated, 79 were submitted, and 76 had answered more than or equal to 94% (15/16) of the total survey questions and were subsequently included in our analyses. A completeness rate of 94% was utilized as no completeness check was enforced, and the final question indicated whether participants wished to be entered in our gift card raffle and was not to be included in our analysis. A completion rate of 89% (76/85) was calculated, and we calculated our response rate at 7% (85/1222). We received responses from 28 separate states, with the highest concentration of respondents in the Northeast and Southern United States. In addition, 1 survey participant engaged in locum tenens, and 2 did not specify their location (see Multimedia Appendix 1). Overall, 26% (20/76) of our respondents were involved in free-standing practices, totaling fewer percentages than either hospital-based (26/76, 34%), academic/university-based practices (22/76, 29%), or other (8/76, 11%). When queried about the importance of patient satisfaction, a majority of respondents (74/76, 97%) endorsed being somewhat or strongly concerned about patient satisfaction ($P < .001$), as evident by the 91% (69/76) of respondents that reported conducting either paper or online surveys in their respective practices ($P < .001$).

When describing ORM, a majority of physicians (43/76, 57%) endorsed no familiarity with this practice management activity

($P < .001$) and 70% (53/76) did not actively manage their online reputation ($P < .001$). Although 83% (63/76) of respondents strongly or somewhat believed that patients read online reviews ($P < .001$), 57% (43/76) of respondents did not check their online reviews ($P = .25$) and 80% (61/76) endorsed never responding to online reviews ($P < .001$). However, when it came to the amount of time spent per week reviewing or managing their online reputation, 58% (44/76) of respondents reported spending 0 hours per week and 39% (30/76) reported spending less than 1 hour per week ($P < .001$). In terms of an area of active practice improvement, 58% (44/76) of respondents strongly or somewhat supported the idea of managing their online reputation going forward ($P = .0012$).

Overall, 11 out of the 28 pairs of questions asked in our correlation studies reached statistical significance (Table 2). The degree of concern for patient satisfaction and the notion of managing one's ORM going forward were the 2 most frequently correlated topics of statistical significance in our analyses. Our strongest correlation was observed between a respondent's belief that online reviews are more impactful than word of mouth (Q11) and their belief that patients read online reviews (Q12; $r = .46$, $P < .001$). Other statistically significant positive correlations of moderate strength occurred between a radiation oncologist's type of practice (Q1) and their degree of concern for their reputation (Q9; $r = .30$, $P = .008$); their type of practice (Q1) and their degree of agreement that patients read online reviews (Q12; $r = .37$, $P = .001$); and their type of practice (Q1) and the notion of managing their online reputation going forward (Q15; $r = .33$, $P = .003$).

There were other statistically significant positive correlations of weak strength between a respondent's degree of concern for patient satisfaction (Q4) and their reported awareness of third-party PRWs (Q10; $r = .23$, $P = .04$); their degree of concern for patient satisfaction (Q4) and their belief that online reviews are more impactful than word of mouth (Q11; $r = .26$, $P = .28$); and their degree of concern for patient satisfaction (Q4) and the notion of managing their online reputation going forward (Q15); ($r = .28$, $P = .01$).

Table 2. Spearman correlation coefficients (N=76). Correlation studies of our multiple-choice, demographic-defining questions (1 and 2) and our multiple-choice questions utilizing Likert scales (4, 9, 10, 11, 12, and 15) were conducted using the Spearman correlation coefficient. Statistically significant correlations are shown in italics. For each pair of questions, correlation coefficients and *P* values are included.

Question (Q) number	Q 1	Q2	Q4	Q9	Q10	Q11	Q12	Q15
Q1	1	<i>$r = -.03$, $P = .78$</i>	<i>$r = .23$, $P = .04$</i>	<i>$r = .19$, $P = .10$</i>	<i>$r = .02$, $P = .86$</i>	<i>$r = .04$, $P = .76$</i>	<i>$r = -.05$, $P = .64$</i>	<i>$r = .30$, $P = .008$</i>
Q2	<i>$r = -.03$, $P = .78$</i>	1	<i>$r = -.07$, $P = .57$</i>	<i>$r = .12$, $P = .28$</i>	<i>$r = -.14$, $P = .21$</i>	<i>$r = .26$, $P = .03$</i>	<i>$r = .18$, $P = .12$</i>	<i>$r = -.14$, $P = .22$</i>
Q4	<i>$r = .23$, $P = .04$</i>	<i>$r = -.07$, $P = .57$</i>	1	<i>$r = .29$, $P = .01$</i>	<i>$r = .27$, $P = .02$</i>	<i>$r = .06$, $P = .62$</i>	<i>$r = .16$, $P = .18$</i>	<i>$r = .23$, $P = .04$</i>
Q9	<i>$r = .19$, $P = .10$</i>	<i>$r = .12$, $P = .28$</i>	<i>$r = .29$, $P = .01$</i>	1	<i>$r = .21$, $P = .07$</i>	<i>$r = .20$, $P = .08$</i>	<i>$r = .20$, $P = .08$</i>	<i>$r = .37$, $P = .001$</i>
Q10	<i>$r = .02$, $P = .86$</i>	<i>$r = -.14$, $P = .21$</i>	<i>$r = .27$, $P = .02$</i>	<i>$r = .21$, $P = .07$</i>	1	<i>$r = .02$, $P = .84$</i>	<i>$r = .13$, $P = .26$</i>	<i>$r = .26$, $P = .02$</i>
Q11	<i>$r = .04$, $P = .76$</i>	<i>$r = .26$, $P = .03$</i>	<i>$r = .06$, $P = .62$</i>	<i>$r = .20$, $P = .08$</i>	<i>$r = .02$, $P = .84$</i>	1	<i>$r = .46$, $P \leq .001$</i>	<i>$r = .28$, $P = .01$</i>
Q12	<i>$r = -.05$, $P = .64$</i>	<i>$r = .18$, $P = .12$</i>	<i>$r = .16$, $P = .18$</i>	<i>$r = .20$, $P = .08$</i>	<i>$r = .13$, $P = .26$</i>	<i>$r = .46$, $P \leq .001$</i>	1	<i>$r = .34$, $P = .003$</i>
Q15	<i>$r = .30$, $P = .008$</i>	<i>$r = -.14$, $P = .22$</i>	<i>$r = .23$, $P = .04$</i>	<i>$r = .37$, $P = .001$</i>	<i>$r = .26$, $P = .02$</i>	<i>$r = .28$, $P = .01$</i>	<i>$r = .34$, $P = .003$</i>	1

Additional statistically significant positive correlations of weak strength were observed between one's type of practice (Q1) and

their degree of concern for their reputation (Q9; $r = .23$, $P = .04$); one's type of practice (Q1) and their reported awareness of

third-party PRWs (Q10; $r=.29$, $P=.01$); and one's type of practice (Q1) and their degree of concern for patient satisfaction (Q4; $r=.27$, $P=.02$). Finally, a statistically significant positive correlation of weak strength was observed between a radiation oncologist's number of years since completing residency (Q2) and their belief that online reviews are more impactful than word of mouth (Q11; $r=.26$, $P=.03$).

Discussion

Principal Findings

To our knowledge, this is the first study assessing the ORM of practicing radiation oncologists in the scientific literature. Radiation oncology, as a specialty, is dependent upon referrals, and therefore, we hoped to educate practicing radiation oncologists on the importance of managing their online reputation and to provide future strategies to increase overall patient satisfaction, retention, and referral. Our results indicate that radiation oncologists are very concerned about their professional reputation and patient satisfaction regardless of their type of practice; however, very little time is spent actively managing their online reputation as a majority of respondents (69/76, 91%) already utilize paper or online surveys in their practice, but so few physicians reported spending any meaningful amount of time actively managing their online reputation. Furthermore, concern for patient satisfaction and the notion of managing one's ORM going forward were the 2 most frequently correlated topics of statistical significance in our survey. We also observed that a radiation oncologist's degree of concern for patient satisfaction and their degree of agreement in managing their ORM in the future were correlated with those who identified working within free-standing practices versus hospital or academic/university-based practices. In addition, the belief that online reviews are more impactful than *word of mouth* was correlated with radiation oncologists that had fewer years since completing residency. These findings support the notion that ORM is an emerging area of practice management that is presently under-recognized in radiation oncology but offers a meaningful avenue for practice improvement and is of increased interest among younger radiation oncologists or those that operate in free-standing practices.

Comparison With Prior Work

How might ORM be relevant to health care practitioners? In a study, Fox and Jones showed that 61% of American adults look toward the internet for health information, and that percentage is theorized to be growing as ease of access to technology increases and younger generations transition into adulthood [8]. A separate study performed by the *Journal of the American Medical Association* reported that 25% of US adults consulted online physician rating sites, and more than 33% of online viewers went to a physician or avoided one based on their ratings [9]. Furthermore, a recent study analyzed online Healthgrades reviews of 2679 radiation oncologists and found that their "likelihood to recommend to family and friends" score was significantly lower for physicians with fewer numbers of online reviews (<10) compared with colleagues with more than 10 reviews [10]. These are just a few examples that underscore the

use of online health information and how public information might influence prospective patients. As alluded to before, much literature has been written on patient satisfaction, but despite the increased accessibility of these data, Rider and Perrin showed that less than 25% of primary care physicians used these data for improving patient care and even fewer report using the information to change their practice [11].

Prabhu et al [12] looked at the top 10 Google search results for 4443 Medicare-practicing radiation oncologists in the United States and Puerto Rico. These search results were extracted, categorized, and reviewed. They found that physician-, hospital-, and health care-controlled websites (39.3%) and third-party websites (25.7%) were the 2 most observed domain types. However, social media and academic journal articles accounted for only 6.7% and 3.4% of the results, respectively. They identified that self-controlled online content, such as social media websites, was disproportionately lacking, and they went on to discuss potential proactive strategies [12].

Many proactive strategies that can improve a physician's online presence exist with a minimal or modest additional time investment. The overarching goal of these efforts is to have better awareness and control of the published online content as well as a physician's search engine rankings [12]. For example, as surveys are already implemented at most of our respondents' practices, a proactive approach includes asking all patients to consider completing an end-visit survey online. The surveys could also provide an opportunity for patients to write testimonials, and they could be given the option to have their testimonials published online. These testimonials can be easily published by creating a personal blog or Web page that can further share patient education materials as well as one's personal and clinical research interests. Other strategies suggested by Prabhu et al [12] include having each provider go to the many existing PRWs (Healthgrades, RateMDs.com, ZocDoc.com, etc) and edit their listed contact information for accuracy as well as utilizing professional social networking sites, such as LinkedIn.com or Doximity.com, that reflect their curriculum vitae. Furthermore, in a study from Saudi Arabia, Househ showed that 99% of doctors utilize social media for personal use, but only 65% of doctors utilize social media for professional use [13]. The various social media apps can serve as a more personable and flexible platform to interact directly with patients and for increasing a physician's online visibility and transparency. It can also provide the opportunity to fully control and customize one's public information, including biographical data, that may otherwise be limited by official hospital or health care system websites.

King et al [14] used a mixed-methods approach in the United Kingdom to investigate the most important factors patients considered when choosing to see a health provider. By analyzing the relevant literature and conducting survey questionnaires and focus groups, they found that information about hospital staff—mainly their competency level—was important to patients. Relevant information that was highlighted included the amount of experience, qualifications, place of education, and interpersonal skills. Furthermore, staff competence seemed to best be captured by past users' reviews, and patients were willing to travel for higher ratings in this category. Other

categories that were highlighted included information about medical facilities, such as the modernity of the facilities and their technological equipment, as well as hospital statistics. Information about how to get to the hospital was not found to be an important factor [14].

Unfavorable reviews are unavoidable in medical practices, especially because of the expansion and increased popularity of PRWs. Furthermore, physicians should understand the permanency of the internet. Even if certain posts are deleted, there are sites that keep records of deleted posts, pages, and message boards. By proactively surveying and publishing patient testimonials, monitoring and updating contact information for PRWs, and creating other social media platforms, a physician's online reputation can be better controlled and shielded to look more well-rounded and less polarized—interspersing the few inevitable negative comments with many other neutral or positive responses.

In some cases, physicians may seek professional assistance. There has been a steady increase in the market demand of consultant companies offering expertise for these reputation services. Some notable labors that these ORM consultants might implement include conventional public relation activities, search engine reputation management, and building blogs and other social media channels for positive reviews. Our hope was to pique interest and awareness into the realm of ORM and help educate fellow radiation oncologists about the benefits of proactively managing their online reputation.

Limitations

Due to the nature of being an electronic survey, selection bias is an important limitation of this study, wherein the participants who chose to respond may not be generalizable to the greater population of all practicing radiation oncologists. This lack of generalizability is further complicated by radiation oncology as a field. For example, Lewis et al showed that 48% of radiation oncologists practiced in nonacademic, radiation oncology-only private practices; 20% in academic practice; 14% in nonacademic, multispecialty practices; and 11% in solo practice [15]. However, the range of demographics recorded by our study participants suggests a more evenly distributed sample. Our diversity in physician demographics may suggest the applicability and relevance of this topic to a variety of professional settings in radiation oncology and provides some reassurance of the validity of our findings. Although an argument could be made that ORM most financially impacts physicians involved in free-standing practices, our survey respondents involved in free-standing practices (26%) totaled smaller percentages than either hospital-based (34%) or academic/university-based practices (29%). This finding suggests the overall interest and applicability of ORM was recognized by most radiation oncologists in varying types of practices.

Another limitation of our study is our low response rate of 7%. This was well below the average response rate of 16% for the ASTRO annual membership survey from 2017 [16], and that

study did not provide any form of compensation for survey completion. An explanation for our below-average response rate could be because of a phenomenon called nonresponse bias—where a distinct difference exists between those who respond to a given survey and those who do not. For example, radiation oncologists that have some familiarity with ORM may feel more comfortable and confident in completing our survey, even if the survey is anonymous. If nonresponse bias did, in fact, account for our significantly lower response rate, then that would help explain why 47% our respondents were already familiar with ORM before survey completion, as that was a much higher percentage than we were expecting to observe. Eliminating this bias would, therefore, further strengthen our hypothesis that most radiation oncologists are not familiar with ORM and do not engage in regular practices catered toward strengthening their online reputation.

A final limitation of our survey was that the study had no objective testing component. By implementing a self-assessment of personal knowledge and practices, physicians may overestimate their perceived awareness or level of involvement in ORM. Future research utilizing direct observation would provide more objective data and insight regarding ORM and daily practices. Despite these limitations, we believe that the study is clinically meaningful and helps highlight underlying knowledge gaps in ORM. This underscoring can help direct educational efforts in the future. We believe more time should be allocated toward patient satisfaction and managing one's online reputation as both the patient and the physician will benefit.

Conclusions

The internet continues to exert profound effects on professional reputations in medical practices; patient satisfaction is increasingly becoming a metric to which physicians are rated and has already influenced physician compensation. This study indicates that a large majority of radiation oncologists are somewhat or strongly concerned about patient satisfaction, yet most were not familiar with ORM nor did they actively manage their online reputation. Furthermore, the concern for patient satisfaction and the notion of managing one's ORM going forward were the 2 most frequently correlated topics in our survey. We also observed correlations between radiation oncologists with fewer years since completing residency and the belief that online reviews are more impactful than *word of mouth* as well as between those working within free-standing practices and the notion of managing their ORM in the future. It is important to understand the current attitudes surrounding one's online reputation as well as the evolving role that PRWs and social media websites can have on patient referral and satisfaction. Many posts on social media can remain on the internet indefinitely, and just a few negative reviews can significantly impact a physician's reputation and be enough to deter potential patients. Our goal was to help identify gaps in radiation oncologists' understanding of ORM in hopes to raise awareness and persuade radiation oncologists to consider having a more active role in their online presence.

Conflicts of Interest

SJB is an author for UpToDate on *External Beam Radiation Therapy for Prostate Cancer, Brachytherapy for Prostate Cancer, and Radiation Therapy for the Management of Painful Bone Metastases*. JFW, SKS, and CSD have nothing to disclose.

Multimedia Appendix 1

Geographic distribution map of the United States showing location of survey participants' state of practice.

[[PPTX File, 451KB - cancer_v5i1e10530_app1.PPTX](#)]

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Abbreviations

ASTRO: American Society for Radiation Oncology
IRB: institutional review board
ORM: online reputation management
PRW: physician review website

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Original Paper

Adaptation and Implementation of a Mobile Phone–Based Remote Symptom Monitoring System for People With Cancer in Europe

Eileen Furlong¹, HDipOnc, MSc, PhD; Andrew Darley¹, BA (Mod), MSc; Patricia Fox¹, BNS, MA, PhD; Alison Buick¹, BSc, PhD; Grigorios Kotronoulas², RN, BSN, MSc, PhD; Morven Miller², BA (Hons), MSc, PhD; Adrian Flowerday³, BSc, CEng; Christine Miaskowski⁴, RN, PhD, FAAN; Elisabeth Patiraki⁵, RN, BSc, PhD; Stylianos Katsaragakis⁵, RN, BSN, MSc, PhD; Emma Ream⁶, BSc, MSc, PhD; Jo Armes⁶, BSc, MSc, PhD; Alexander Gaiger⁷, MD; Geir Berg^{8,9}, RN, MNsc, PhD; Paul McCrone¹⁰, PhD; Peter Donnan¹¹, BA, BSc (Hons), MSc, PhD; Lisa McCann², BSc (Hons), MSc, PhD; Roma Maguire², BN, MSc (Med Sci), PhD

¹School of Nursing, Midwifery and Health Systems, University College Dublin, Dublin, Ireland

²School of Psychological Sciences and Health, University of Strathclyde, Glasgow, United Kingdom

³Docobo Ltd, Surrey, United Kingdom

⁴Institute for Global Health Sciences, University of California San Francisco, San Francisco, CA, United States

⁵National and Kapodistrian University of Athens, Athens, Greece

⁶School of Health Sciences, University of Surrey, Surrey, United Kingdom

⁷Division of Hematology and Hemaostaseology, Medical University of Vienna, Vienna, Austria

⁸Faculty of Medicine and Health Sciences, Norwegian University of Science and Technology, Gjøvik, Norway

⁹Innlandet Hospital Trust Division Lillehammer, Lillehammer, Norway

¹⁰Institute of Psychiatry, Psychology & Neuroscience, King's College London, London, United Kingdom

¹¹Dundee Epidemiology and Biostatistics Unit, University of Dundee, Dundee, United Kingdom

Corresponding Author:

Eileen Furlong, HDipOnc, MSc, PhD
School of Nursing, Midwifery and Health Systems
University College Dublin
Belfield
Dublin, D04 V1W8
Ireland
Phone: 353 7166478
Email: eileen.furlong@ucd.ie

Abstract

Background: There has been an international shift in health care, which has seen an increasing focus and development of technological and personalized at-home interventions that aim to improve health outcomes and patient-clinician communication. However, there is a notable lack of empirical evidence describing the preparatory steps of adapting and implementing technology of this kind across multiple countries and clinical settings.

Objective: This study aimed to describe the steps undertaken in the preparation of a multinational, multicenter randomized controlled trial (RCT) to test a mobile phone–based remote symptom monitoring system, that is, Advanced Symptom Management System (ASyMS), designed to enhance management of chemotherapy toxicities among people with cancer receiving adjuvant chemotherapy versus standard cancer center care.

Methods: There were 13 cancer centers across 5 European countries (Austria, Greece, Ireland, Norway, and the United Kingdom). Multiple steps were undertaken, including a scoping review of empirical literature and clinical guidelines, translation and linguistic validation of study materials, development of standardized international care procedures, and the integration and evaluation of the technology within each cancer center.

Results: The ASyMS was successfully implemented and deployed in clinical practices across 5 European countries. The rigorous and simultaneous steps undertaken by the research team highlighted the strengths of the system in clinical practice, as well as the clinical and technical changes required to meet the diverse needs of its intended users within each country, before the commencement of the RCT.

Conclusions: Adapting and implementing this multinational, multicenter system required close attention to diverse considerations and unique challenges primarily related to communication and clinical and technical issues. Success was dependent on collaborative and transparent communication among academics, the technology industry, translation partners, patients, and clinicians as well as a simultaneous and rigorous methodological approach within the 5 relevant countries.

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KEYWORDS

telemedicine; methods; patient care; cancer; symptom management

Introduction

Background

The expanding field of electronic health (eHealth) and the global deployment of technology within health care have become more apparent over 20 years of research [1-4]. The increase in technological capabilities has led to many promising eHealth advancements in the cancer setting. For instance, an increasing number of health care initiatives in cancer care have utilized patients' self-reports to facilitate remote symptom monitoring [5-11]. With regard to conducting empirical research on this scale in this field, there is an increasing awareness of the importance of preliminary work in preparation for large publicly funded randomized controlled trials (RCTs) [12]. This preliminary study allows a research team to make judgments about an eHealth system, and such preparation can facilitate researcher readiness for full-scale implementation [13]. While multinational research to evaluate the effectiveness of eHealth may present several opportunities and important findings, there are also a number of challenges and considerations when conducting research involving multiple countries, including differences in clinical settings such as resources and workflow, language and translation issues, as well as cultural and societal differences [14].

Moreover, conducting cross-cultural, multinational eHealth research requires collaboration and multiple considerations to ensure an eHealth system's validity, fidelity, and appropriateness within different cultural and clinical settings [15-17]. This paper seeks to address an important gap in knowledge regarding the steps involved in adapting an eHealth system within cancer care across multiple countries. This gap may be in part because of the fact that eHealth remains a relatively new area of research characterized by exploratory studies implementing novel technology in cancer care practice and assessing their feasibility in a single country [18-22].

In this paper, the steps employed to adapt and implement a mobile phone-based remote symptom monitoring system, the Advanced Symptom Management System (ASyMS), into European cancer care before its deployment in a multinational RCT involving 13 cancer centers across 5 countries (ie, Norway, Austria, Greece, Ireland, and the United Kingdom) are described. We detail the robust, structured, and systematic approach to the adaptation of the system and its controlled implementation at multiple cancer centers across Europe. The valuable points of learning arising from implementing this unique eHealth system on such a large multinational scale for future researchers will also be discussed.

Advanced Symptom Management System

The ASyMS is an eHealth system that has undergone several years of testing, development, and evaluation [23-29] to monitor and help patients with cancer manage their chemotherapy-related symptoms at home. Although previously tested and studied in the United Kingdom, the ASyMS is currently being studied at a multinational level for the first time as an RCT—study title: *Electronic Symptom Management using Advanced Symptom Management System (ASyMS) Remote Technology for Patients With Cancer (eSMART)*. The protocol for the study has been previously published [30]. The purpose of undertaking the steps described in this paper was to examine and ensure cancer centers' technological readiness before commencing the RCT.

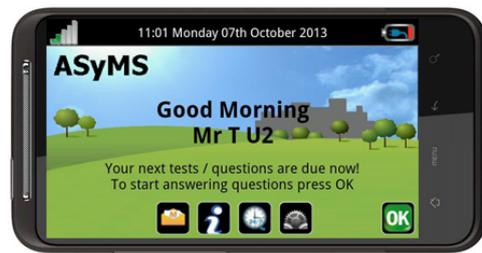
The ASyMS is a purpose-built, mobile phone-based remote symptom monitoring system to enable real-time, 24-hour monitoring and management of patients' self-reported chemotherapy-related toxicities. The ASyMS is hosted by the eSMART Consortium technological partner, Docobo. The core component of the ASyMS is the mobile phone device, that is, the ASyMS patient handset (Figure 1).

Patients are required to complete a symptom questionnaire—Chemotherapy Toxicity Self-Assessment Questionnaire—once a day, which is a patient-related outcome measure, developed by the ASyMS research team to facilitate rapid and accurate daily assessments of chemotherapy toxicity in clinical practice [31]. The questionnaire assesses 10 specific chemotherapy-related symptoms (ie, nausea, vomiting, diarrhea, constipation, hand-foot syndrome, mucositis, paresthesia, flu-like symptoms, fatigue, and pain). Additionally, if patients' existing symptoms escalate or new symptoms are experienced, they can be reported using the ASyMS patient handset. The ASyMS analyses the information using an integrated clinical risk algorithm, as shown in The ASyMS Care Pathway (Figure 2), which initiates an alert to the clinical team at the patient's cancer center. The ASyMS involves 3 types of alerts [30]:

1. A *green alert* is activated when a patient reports symptom that can be managed at home, without requiring current clinical intervention, using self-care advice by a clinician.
2. An *amber alert* is sent to a clinician if patients' symptoms are bordering on becoming problematic and are responsive to early preventative interventions. Amber alerts are to be addressed within 8 hours by a clinician.
3. A *red alert* is sent to a clinician if patients' symptoms are severe or life-threatening. Red alerts are to be addressed within 30 minutes.

Figure 1. The Advanced Symptom Management System patient handset.

For patients:



ASyMS: Advanced Symptom Management System

Figure 2. The Advanced Symptom Management System care pathway.

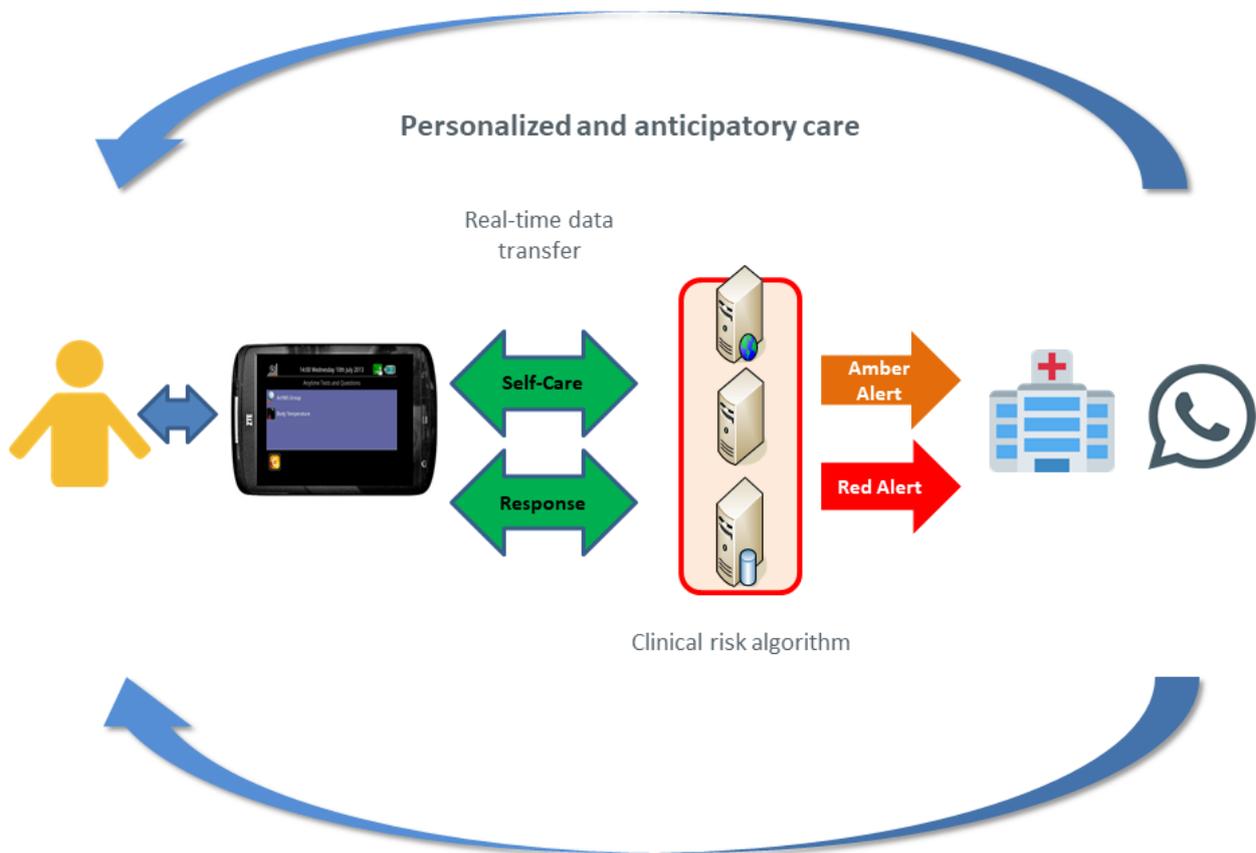


Figure 3. The Advanced Symptom Management System clinician handset.



The ASyMS patient handset contains an in-built library that generates self-care advice each time a patient completes the questionnaire, specific to the experienced symptoms. The self-care library and graphical depiction of their symptoms can be viewed by patients at any time.

For any symptom that requires clinical intervention (amber or red alerts), the algorithm generates *real-time* alerts to the cancer center via a dedicated ASyMS clinician handset (Figure 3). This specialized mobile phone-based clinician handset is carried by an alert handler (ie, clinician) at all times to receive alerts. Once an alert is received, the alert handler views the patient's *real-time* symptom reports on a secure stand-alone ASyMS clinician website before contacting the patient to initiate the appropriate care intervention.

Alert handlers can access patients' symptom reports, demographic and clinical information, contact telephone numbers, and addresses to facilitate an initial telephone assessment with the patient. Clinicians can store summaries of alert outcomes in the patients' local medical records. Clinical algorithms based on international, national, and local guidelines as well as feedback from clinicians and patients determine the appropriate standardized interventions for the type of alert generated. The alert handler documents the intervention in the patients' clinical case notes.

Methods

In preparation for the use of the ASyMS within a multinational, multicenter RCT, the following steps were undertaken.

Scoping Review

Although the ASyMS was rigorously developed and empirically studied previously in the United Kingdom [23-29], in order to upscale the system to various European countries, a scoping review was undertaken to ensure that it is consistent with international, national, and relevant local guidelines for assessing and managing the most common chemotherapy-related

symptoms. This review that included evidence on the management of chemotherapy toxicity within Europe (assessment, management, and self-care) was published [32]. Following the scoping review, the assessment, management interventions (including responses to alerts), and self-care for the ASyMS were agreed upon by the research team using a consultation exercise undertaken with clinicians (clinical advisory group) and patients (patient advisory group) at the participating cancer centers to ensure standardized practice across all cancer centers.

Translation and Linguistic Validation of the Advanced Symptom Management System Materials

Given that the ASyMS would be used simultaneously within 5 different European countries, it was paramount that all the study materials were translated and validated linguistically for use in non-English speaking countries. The ASyMS and all related study documents were to be available in German, Norwegian, and Greek. Although a majority of outcome measures were previously available in the language of the participating countries, some required translation for their use in the ASyMS. The International Society for Pharmacoeconomics and Outcomes Research (ISPOR) Patient-Reported Outcomes Translation and Linguistic Validation Task Force guidelines [33] were used to guide the translation and validation process. Included in the translation process were the following:

- The ASyMS clinician website
- The ASyMS patient handset
- The ASyMS clinician handset
- The ASyMS technical support website
- Patient-reported outcome measures
- Additional data collection forms and questionnaires
- Supporting documentation, including the study protocol, patient and clinician documents, and user manuals.
- eSMART research project website

The 2 key components of the translation process were (1) translation and linguistic validation of questionnaires into the required languages for the participating cancer centers and (2) translation of all additional study components and supporting documentation into the required languages (eg, patient information letters and consent forms). The employment of a translation company was necessary to complete this step. A total of 4 translation companies were evaluated to undertake this task based on the following criteria:

1. Compliance with ISPOR translation and validation guidelines
2. Experience in the translation and validation of patient-reported outcome measures as documented through previous collaborations and completed projects beforehand
3. Documented reliability and trustworthiness based on testimonials
4. Acceptable costs and turnaround times to ensure project cost-effectiveness

Following this evaluation process, Language Scientific was the chosen company that translated and linguistically validated the ASyMS questionnaires based on the robustness of their approach and costs.

Preparation and Evaluation of Cancer Centers for the Use of the Advanced Symptom Management System

The preparation and evaluation of the cancer centers for the use of the ASyMS required an assessment of their technology infrastructure and human and material resource requirements. As the ASyMS required simultaneous implementation within 13 cancer centers in 5 countries, monthly teleconferences were held with all study partners to provide an opportunity to inform, assess progress, update, and identify any issues in this step. The teleconferences were attended by representatives in all partner countries, which facilitated open discussions and necessary actions around issues including ethics and governance, data protection, study instruments, technology development, and language translation processes. Additionally, clinicians and researchers committed to and participated in monthly teleconference meetings which were well-attended at this stage of implementation to discuss practical, clinical, and technical issues of using the ASyMS at each cancer center.

Before the selection of each cancer center to participate in the RCT, the reliability of Wi-Fi and mobile data networks was assessed at each cancer center. This assessment was conducted by Docobo using a Connectivity Logger app, which was run on Motorola Moto g mobile handsets at each of the participating cancer centers. All the handsets were procured by Docobo, marked with an individual tracking number, uploaded with the ASyMS, and distributed to each cancer center. Each research nurse, clinician, and research assistant was provided with training on the ASyMS, this included education regarding how the ASyMS works, patient registration, and alert handling. They were then registered with individual log-ins on the ASyMS, with the appropriate functions of patient registration and alert handling. Subsequently, researchers at each cancer center managed the handsets and provided them to the patients when recruited to the feasibility study.

An assessment of the ASyMS technological readiness with cancer care practice was necessary before its use in the RCT. This was undertaken with a small sample (n=64) of the intended population for the RCT across the 13 cancer centers. Data captured (eg, patient completion of the daily questionnaire, clinician initial response times to alerts, and clinician handling times of alerts) were used to assess the readiness of each cancer center to begin the RCT. All feasibility data were extracted from the study's secure database hosted by Docobo. Technological readiness was assessed and confirmed using 2 Technological Feasibility Evaluation forms developed by the study investigators—1 for clinicians using the ASyMS ([Multimedia Appendix 1](#)) and 1 for Docobo ([Multimedia Appendix 2](#)) to complete. The 3 key parameters of technological readiness set out in the study protocol were examined:

1. *System set-up*: to assess whether clinicians and researchers had received sufficient training on the ASyMS, were able to register participants to use the ASyMS (using handset, tablet, and personal computer), and were confident to educate and register a new patient on a handset.
2. *Data transfer*: to assess whether data were successfully transferred between the ASyMS patient and clinician handsets, electronic clinical case note reviews, and the study server. It was essential that all handsets (ie, patient handsets and clinician handsets) had the required mobile or Wi-Fi connectivity for the intervention to be safe and effective.
3. *Usability issues*: to assess whether the patients could use the ASyMS patient handset, as well as the clinicians' ability to use the ASyMS clinician handset, log on to the ASyMS clinician website, handle patient alerts, and complete medical reviews at the end of the patients' chemotherapy cycle. The ASyMS technical support website, from both the clinician's and patient's perspective, was also evaluated.

On completion of the technological readiness assessment at each cancer center, a representative from the cancer center and the technological partner were required to complete their respective Technological Feasibility Evaluation forms, which were subsequently checked by the ASyMS research team for any discrepancies that needed to be addressed.

Results

The Findings

ASyMS was successfully adapted and implemented at 11 cancer centers across 5 European countries. The system was fully prepared for its deployment at each cancer center in providing care to their patients before commencing its large-scale RCT. The findings from each step of the adaptation and implementation process will now be outlined.

Scoping Review

The findings from the scoping review were used to update the self-care advice within the ASyMS and refine the clinical risk algorithms for the alerting system. Following the completion of the scoping review, a consultation exercise was undertaken with clinicians (clinical advisory group) and patients (patient advisory group) at the participating cancer centers [32]. The review found discrepancies among the published literature and

the clinical advisory groups regarding the treatment of febrile neutropenia (fever) and what temperature rating was considered to warrant medical attention. It was concluded to use the most conservative scenario for safety reasons (37.5 Celsius) [32].

Translation and Validation of Study Materials

The questionnaires and related documents involved in the ASyMS were successfully translated into the required languages. Minor queries were raised by the chosen translation company regarding specific items on the study questionnaires for Greek and Norwegian translation. The company sought confirmation from the research team to proceed with slight modifications of questionnaire items based on the feedback from the cognitive debriefing participants to ensure that they were culturally appropriate.

The translation involved 3 translation rounds and interviews with lay people in the respective countries (Austria, Greece, and Norway) in accordance with the current guidelines outlined by the ISPOR [33], which involved forward and back translation. For each component of the ASyMS, the information technology interface and documentation were adapted and translated for clinical use. Once the intervention content was translated and validated, ethical approval was obtained from the relevant ethics committees in all of the cancer centers across the 5 participating countries, as detailed in the protocol publication [30].

Assessment of the Cancer Centers' Technological Infrastructure

A crucial component of the implementation of the ASyMS at cancer centers was the assessment of technological readiness, which was undertaken by Docobo. The Connectivity Logger app, installed on the ASyMS clinician handset, measured and logged the quality of mobile and Wi-Fi networks at 1-min intervals while the handset was being carried by clinicians during their working hours. Areas in a cancer center where the clinician handset could not access Wi-Fi or a mobile data network were identified. The connectivity information was analyzed by Docobo. Clinicians were required to log at least 12 hours of mobile data and Wi-Fi.

The primary criterion for the connectivity assessment was the maximum sustained period for which no communication over

the mobile network (ie, neither mobile internet protocol or text communications) was possible, being no more than 15 minutes (target response time was 30 minutes). The secondary factors considered were the distribution of signal strength and the quality of the mobile data connection. Analysis showed that at most cancer centers, the connectivity environment was favorable in providing a reliable communication channel to the ASyMS clinician handset. However, 1 cancer center had a loss of connectivity for up to 20 minutes (based on 800 hours of testing) compared with other cancer centers that had between 5 and 12 min of lack of connectivity. The Docobo team visited the cancer center to investigate the cause and concluded that the lack of connectivity occurred in the corridors of the cancer center and not on the relevant oncology ward, where suboptimal connectivity forced the handset to connect to a weak mobile network. Given the potential impact on clinical care should an alert not be received on time because of lack of connectivity, all clinician handsets needed to monitor for and make clinicians aware of a loss of network connectivity. Changes were made to the ASyMS, which could monitor the clinician handset at all times and make clinicians aware, via automated short message service text messaging and email, when a handset lost connectivity. It was concluded that 2 active handsets were necessary at each cancer center, with one in use and the second on charge, to allow for efficient charging and thus ensuring clinicians could hold the handset with 24-hour coverage as required.

Feasibility Study of the Advanced Symptom Management System at European Cancer Centers

A total of 13 cancer centers across 5 European countries (ie, Austria, Greece, Ireland, Norway, and the United Kingdom) participated in the feasibility study. During this testing phase, 64 patients consented to use the ASyMS over 1 cycle of chemotherapy. At each cancer center, 2 patients per cancer type (not all cancer centers included all 3 patient populations) were recruited to test the system. Inclusion and exclusion criteria are detailed in [Textbox 1](#) and [Textbox 2](#), and patient numbers per diagnosis at the different European cancer centers are shown in [Table 1](#).

Textbox 1. Participant eligibility inclusion criteria.

- Adults (≥ 18 years)
- Diagnosed with breast cancer, colorectal cancer, Hodgkin's disease, or non-Hodgkin's lymphoma
- Currently receiving or about to start first-line chemotherapy
- Scheduled to receive 2, 3, or 4 weekly chemotherapy protocols (ie, chemotherapy administered every 14, 21, or 28 days, respectively)
- Scheduled to receive 1 cycle of chemotherapy
- Physically or psychologically fit to participate in the study
- Able to understand and communicate in the respective language

Textbox 2. Participant eligibility exclusion criteria.

- Diagnosed with a distant metastasis in the case of breast cancer or colorectal cancer
- Experiencing B symptoms in the context of a Hodgkin's disease or non-Hodgkin's lymphoma diagnosis
- Scheduled to receive concurrent radiotherapy
- Scheduled to receive weekly chemotherapy
- Diagnosed with recurrent cancer
- Patients who have had chemotherapy within the previous 5 years for any medical reason
- Unable to provide written informed consent

Table 1. Patients recruited to conduct the feasibility study at each cancer center.

Study Center	Breast, n	Colorectal, n	Hematological, n
Cancer Center 1: Austria	2	2	2
Cancer Center 2: United Kingdom	2	2	1
Cancer Center 3: United Kingdom	2	2	— ^a
Cancer Center 4: United Kingdom	2	2	2
Cancer Center 5: United Kingdom	2	2	2
Cancer Center 6: Greece	2	2	—
Cancer Center 7: Greece	2	2	—
Cancer Center 8: Greece	2	2	2
Cancer Center 9: Ireland	2	2	—
Cancer Center 10: Ireland	2	2	—
Cancer Center 11: Ireland	2	2	2
Cancer Center 12: Ireland	2	2	1
Cancer Center 13: Norway	2	2	—
Total	26	26	12

^aThese sites did not recruit participants with hematological cancer.

Participants

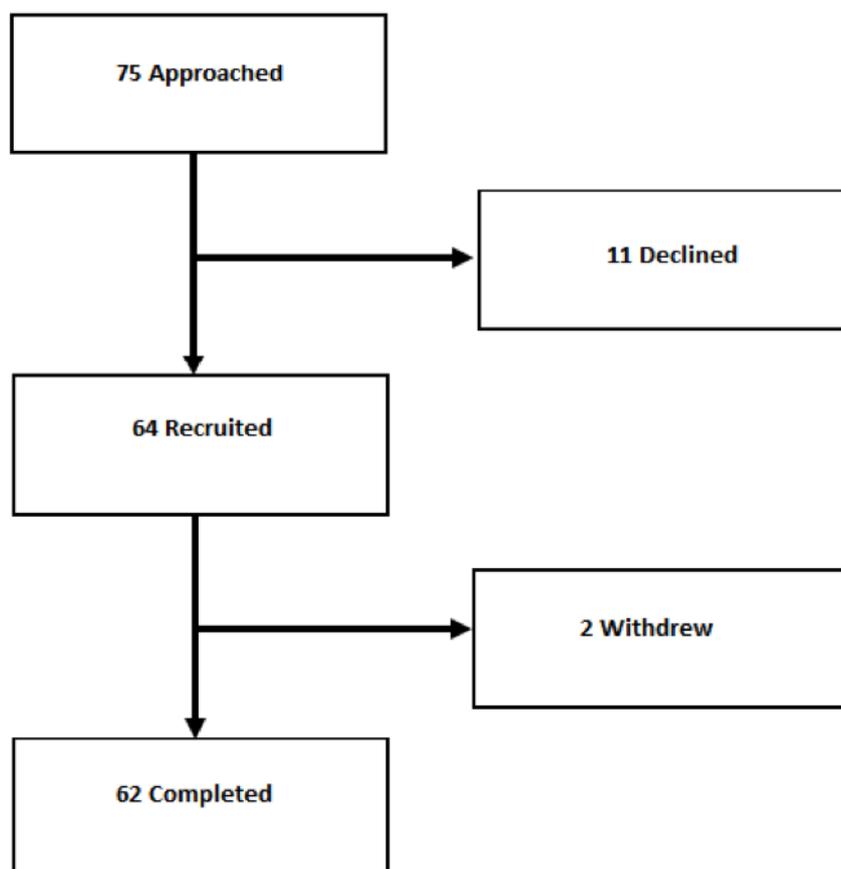
Data on the testing of the ASyMS at each cancer center were collated by Docobo and analyzed by the members of the author team. Across all cancer centers, 85% (64/75) of eligible patients agreed to participate (Figure 4). Those who declined to participate cited being too busy, feared the study would increase worry and stress about the diagnosis or had concerns about using technology, and they also added that using the handset may be a burden.

The analysis showed that 62 participants completed the feasibility study. Furthermore, 2 patients were withdrawn during the course of the feasibility study, 1 because of technical difficulties and the other because their chemotherapy treatment was discontinued. Completion of the daily symptom questionnaire on the ASyMS patient handset was high, with patients using it 87.36% (1064/1218) of the time. A 1-way between-groups analysis of variance showed no statistically significant differences in adherence rates ($P=.15$) across

countries (United Kingdom=83.1% [349/420], Ireland=90.2% [284/315], Norway=85.7% [60/70], Greece=86.8% [249/287], and Austria=96.8% [122/126]). Similarly, no differences were found in the adherence rates ($P=.47$) for completing the daily questionnaire by cancer type (breast cancer=87.9% [449/511], colorectal cancer=90.7% [400/441], and hematological cancers=80.8% [215/266]).

Alert Handling

Across all 13 European cancer centers, a total of 157 amber and 139 red alerts were generated by participants during the feasibility study. Patients with hematological cancers generated an average of 1.25 red alerts per person, those with colorectal cancer had an average of 2.3 red alerts, and those with breast cancer had 2.4 red alerts. Amber alerts followed a similar pattern: patients with hematological cancers generated an average of 2.6 amber alerts, those with colorectal cancer had an average of 2 amber alerts, and those with breast cancer had 2.8 amber alerts.

Figure 4. Patient recruitment.

On an average, it took 38.26 min (SD 138) to handle an amber alert and 15.7 min (SD 20) to handle a red alert. During the monthly trial management meetings, clinicians and researchers across all 5 countries agreed that the timeframe for handling amber alerts (ie, mild to moderate patient symptoms) should be changed from 4 to 8 hours. In addition, clinicians recommended modifications to the ASyMS algorithm regarding the symptom of mucositis (ie, painful inflammation and ulceration of the mouth and throat). It became apparent that clinicians were receiving numerous alerts from patients about mucositis. Even with prompt and appropriate interventions, mucositis takes time to improve. Consequently, patients reported this symptom over multiple days, which triggered an alert to the clinician based on the clinical algorithm. The alert remained active even after it had been handled and patients were given appropriate information and clinical interventions. The algorithm was modified, clinicians were alerted to a patient's initial report of mucositis, and depending on the severity, subsequent alerts were *silenced* for 1 or 2 days, allowing time for the intervention to relieve symptoms after the alert was initially handled. The modifications required technical changes in the ASyMS and subsequent simultaneous ethical amendments at all participating cancer centers in order to implement the changes.

Technical Issues

The ASyMS has a dedicated technical support website for clinicians and researchers to report technical problems and solve issues. This platform allowed users to log, solve, and track issues that arose during the feasibility study. A total of 112 issues were reported during this period. The ASyMS technical support

website facilitated rapid and tailored responses, as well as acted as a transparent record of correspondence on technological issues. The most common issues were in relation to using the ASyMS clinician website (31.3% [35/112]), which is the Web-based platform for clinicians and researchers to enroll patients, handle alerts, and monitor feasibility progress. Additionally, 25% (28/112) of the issues were related to the ASyMS clinician handset and 18.8% (21/112) were related to the ASyMS patient handset. All the issues were rectified at each cancer center by the technology partner, who provided additional training on using the system, before progression to the RCT.

Technological Readiness of the Advanced Symptom Management System at European Cancer Centers

The technological readiness of each cancer center was based on 3 key parameters: system setup, data transfer, and usability issues. Following the completion of the feasibility study, each cancer center was evaluated for readiness to move onto the RCT, using the Technological Feasibility Evaluation Checklists (Multimedia Appendices 1 and 2). Of the 13 cancer centers, 11 passed the technological feasibility evaluation successfully. It was notable that of the 13 cancer centers that completed the feasibility study, 2 reported the intervention was not feasible to integrate into clinical practice (ie, 1 cancer center in the United Kingdom and 1 in Ireland). Both cancer centers were unable to participate because of organizational issues, namely lack of staffing resources to facilitate 24-hour clinician alert handling and technology connectivity issues.

Of the 11 cancer centers that progressed to undertake the RCT, discrepancies existed between reports by the technology company and reports by the cancer centers. Discrepancies included issues involving Wi-Fi and mobile connectivity, local firewall regulations, clinicians' log-ins, patient enrollment, and completion of patient case note reviews. These issues were investigated and resolved by the researchers at University College Dublin (AB and AD). Following the feasibility study and the evaluation of each cancer center, the principal clinical investigator received a letter from the chief investigator with formal confirmation of permission to progress to the RCT for those 11 cancer centers.

Discussion

Principal Findings

This paper details the steps of adapting and implementing a mobile phone-based remote symptom monitoring system at multiple cancer centers across several European countries in preparation for an RCT. Our focus was to outline the complexities involved in preparing, adapting, and implementing an eHealth intervention for an RCT at a multinational scale. The ASyMS has now been adapted and implemented successfully at 11 cancer centers across 5 European countries (ie, Austria, Greece, Ireland, Norway, and the United Kingdom). It is currently being deployed and evaluated in clinical practice at these cancer centers as part of an RCT.

The undertaking of multinational and multicenter eHealth research requires several considerations to address the complexities involved in capturing electronic data [14,34], and researchers in this study faced diverse and unique challenges. While adopting the rigorous and simultaneous steps outlined across Europe, 4 key points of learning emerged, which may provide valuable information for future researchers implementing eHealth studies locally, across cultures and at multiple cancer centers.

Given the multifaceted nature of eHealth [35,36], it was necessary to ensure that the ASyMS was clinically safe and technologically secure at each cancer center before conducting the RCT. Significant time was needed to ensure the European integration of the ASyMS in preparation for its intended RCT. Although the ASyMS was based on preliminary work in the United Kingdom [23-29], the revision and adaptation of the system to make it applicable across multiple European cancer centers involved significant input. Implementation of the ASyMS was achieved through collaborative work with European study partners and a robust, iterative process to resolve problems in each cancer center. Technological Feasibility Evaluation Checklists (Multimedia Appendices 1 and 2) provided effective quality assurance across all cancer centers. The checklists provided a detailed and transparent method of ensuring that each cancer center was suitable to progress to conduct the RCT. The checklists established that the ASyMS was being independently evaluated by clinicians and the technology partner on the same key issues. These enabled the assurance that both clinical and technical issues were being assessed and the issues reported were effectively addressed by the research team. Although 112 issues were reported during the feasibility study,

we feel this number is low considering this was across 13 cancer centers and that the technology had not been used before in practice by the clinicians involved. The identification of issues, which could have only been identified through the use of the ASyMS in practice, were not foreseen during the adaptation of the system. We would encourage researchers in the field to use and modify the checklists to suit individual study needs, given that each study will have its own set of unique clinical and technical requirements.

As outlined, the questionnaires used in the ASyMS, risk algorithm, and alert management design were refined based on the consultation process, which occurred following the scoping review. This consultation approach aligns with the evidence that advocates the inclusion of clinician and patient consultation is more likely to lead to research that will translate into clinical practice [37,38]. In particular, patient involvement in clinical research is important to ensure that the correct research questions are being asked to address the patients' and public's needs [39]. Patient (n=15) and clinician advisory groups (n=21) informed the content of the symptom questionnaires, symptom protocols, clinical algorithms, and self-care advice to ensure consensus across the multiple European cancer centers. The scoping review combined with feedback from clinician and patient advisory groups provided valuable information, which enabled agreement among study partners on the format and content of the intervention, as well as making it current, evidence-based, and culturally sensitive.

Moreover, the content of the ASyMS had to reflect not only current international standards but also be delivered in the appropriate language. A substantial methodological challenge for cross-cultural research is the standardization of the research instruments, particularly the translation of instruments without losing the underlying context or cultural connotations of the wording [40-42]. This process is often time consuming, but it is a crucial investment in order to have confidence in the outcomes of the study. The goal of the translation procedure was to document that each translation adequately captures the concepts of the original English-language version and is readily understood by end users in the target population. We would encourage fellow researchers and developers of eHealth systems, who intend to implement in linguistically varied settings, to factor the time-consuming nature of this step when formulating study timelines and goals. Additionally, when choosing a translation company, we recommend that researchers conduct a scoping exercise of potential candidates to assess their services that will best suit their study's requirements including a number of criteria: compliance with ISPOR translation and validation guidelines [33]. It is important to consider the company's experience with translating similar questionnaires and documents with previous research collaborations and completed research projects, reliability and trustworthiness based on testimonials, service costings, and turnaround times to ensure project cost-effectiveness.

The feasibility study of the ASyMS at each cancer center was a crucial methodological step in the transition from its adaptation to implementation into clinical practice. Additional areas were identified where the technology needed to be modified in order to meet the diverse needs of both clinicians and patients.

Following the identification of a number of clinical and technical key issues and subsequent discussions at trial management group meetings, the ASyMS was refined and updated to reflect feedback provided by clinicians, researchers, and technological partners. This feedback highlighted that a 4-hour response timeframe was not feasible in busy cancer centers and that the algorithm for the symptom of mucositis warranted modification because of its persistent nature and the amount of alerts clinicians were receiving. Such considerations with the ASyMS algorithm and its related clinician alerts only became apparent during its deployment at multiple cancer centers. Thus, we encourage researchers who intend on conducting multicenter or multinational research using an eHealth intervention to conduct a feasibility study at each intended cancer center, as clinicians and researchers may experience the system differently at each cancer center or country and thus may identify areas of concern. One cannot assume a “one-size-fits-all” model regarding implementing eHealth systems within various clinical settings. In addition, the feasibility study allowed the research consortium to identify cancer centers that were unsuitable to progress to conducting the RCT because of existing heavy workloads and the perceived complexity of the intervention. This echoes the importance of testing an intervention in its intended and various contexts [43], as well as the establishment of communication pathways that clinicians and researchers can use to gain first-hand experience about the system [44].

Successfully implementing new clinical practices in real world settings can be challenging. A significant outcome of the feasibility study was the establishment of relationships and communication between the ASyMS research team and the clinicians at each cancer center. eHealth systems are often predeveloped by researchers to suit a clinical setting and clinicians are asked to assist in effectively implementing them [45]. This approach has been previously criticized as being ineffective in producing effective translation and sustained implementation of evidence-based practices [46]. In the case with the ASyMS, it was vital that strong working relationships and rapport were developed between the research team and the clinicians at the cancer centers. The establishment of relationships between the researchers and clinicians facilitated patient recruitment, since clinicians became aware of the participant criteria and notified the research team when a patient met the inclusion criteria. Additionally, the feasibility study allowed clinicians to become familiar with the study protocol and procedures. For example, when participants were recruited, it was done when they visited the cancer center for

chemotherapy treatment where relationships were already developed. On the basis of previous research that showed clinicians’ concern and apprehension about new eHealth technologies [47-49], the feasibility study of the ASyMS helped the research team identify clinicians’ concerns and provide additional training sessions that afforded clinicians the opportunity to learn about the study protocol [30], express their concerns, and ask questions about the technology.

Limitations

Although these findings may guide future research in multinational eHealth research in cancer care and other areas, the limitations of our approach must also be noted. The cancer centers approached to take part in the ASyMS research were deemed clinically and technologically ready to partake in the research, given that they were teaching hospitals and actively engaged in other research activity. Thus, the implementation and deployment of the ASyMS at these cancer centers may not be representative of other cancer centers that do not have such research and technological resources. The 2 cancer centers that did not proceed to the RCT had intended to implement the ASyMS but did not have the efficient resources (ie, time and staff). Cancer centers that were averse to technology may not be represented in this sample. Also, it must be noted that the feasibility study should be interpreted in the context of another limitation in that patients were not recruited before the initiation of chemotherapy. Therefore, some patients were chemotherapy naïve and others had received previous chemotherapy treatments, which may have affected the results. However, despite these limitations, our work provided significant data around feasibility, changes needed for future use, and the perceived benefits of such a system in cancer centers.

Conclusions

Patients with cancer who are receiving chemotherapy require prompt identification of symptoms and interventions to decrease the symptom burden and enhance their quality of life. Adapting and implementing a multicenter remote symptom monitoring eHealth system demands significant and substantial collaborative preparatory work across multinational settings before the deployment of an RCT. The findings discussed in this paper outline the importance of effective collaborative project management, diligent use of checklists, clear division of responsibilities with each partner, country, and associated cancer centers, along with addressing cultural and language requisites so that the scientific integrity and reproducibility of the study are assured.

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Conflicts of Interest

PD has received grants from Shire Pharmaceuticals and Gilead Sciences. PD is a member of the New Drugs Committee of the Scottish Medicines Consortium.

Multimedia Appendix 1

Feasibility evaluation checklist for clinicians.

[[PDF File \(Adobe PDF File\), 223KB - cancer_v5i1e10813_app1.pdf](#)]

Multimedia Appendix 2

Technological feasibility evaluation checklist.

[[PDF File \(Adobe PDF File\), 150KB - cancer_v5i1e10813_app2.pdf](#)]

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Abbreviations

ASyMS: Advanced Symptom Management System

eHealth: electronic health

eSMART: electronic Symptom Management using Advanced Symptom Management System Remote Technology

ISPOR: International Society for Pharmacoeconomics and Outcomes Research

RCT: randomized controlled trial

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Original Paper

A Thematic Analysis of Attitudes Toward Changes to Cervical Screening in Australia

Rachael H Dodd¹, BSc, MSc, PhD; Helena M Obermair¹, MD, MPH; Kirsten J McCaffery¹, BSc (Hons), PhD

School of Public Health, Faculty of Medicine and Health, The University of Sydney, Sydney, Australia

Corresponding Author:

Rachael H Dodd, BSc, MSc, PhD
School of Public Health
Faculty of Medicine and Health
The University of Sydney
Edward Ford Building
Sydney, 2006
Australia
Phone: 61 2 9351 5102
Email: rachael.dodd@sydney.edu.au

Abstract

Background: In December 2017, the Australian National Cervical Screening Program (NCSP) was changed to encompass a 5-yearly human papillomavirus (HPV) primary test for women aged 25 to 74 years. Public concerns about changes to screening programs has been demonstrated in other countries previously.

Objective: The aim of the study was to explore in depth women's understanding of and concerns about the specific changes to the Australian NCSP implemented in December 2017.

Methods: A Web-based petition (*Change.org*) opposing the changes received over 70,000 signatures and nearly 20,000 comments from February to March 2017. Of 19,633 comments, a random sample of 10% (2000/19,633) were analyzed using content analysis (reported elsewhere). Comments relating directly to the specific changes to the program were further analyzed using qualitative thematic analysis.

Results: Around one-third (34.55%; 691/2000) of the total comments were related to concerns about specific changes to the program. The greatest concern was that screening intervals would be too long and that cancer may not be detected in time for successful treatment. Missing cancer in younger women (aged <25 years) was also an important concern, perceiving younger women to remain at significant risk. Notably, concern was rarely expressed about the new test (the HPV test).

Conclusions: Gaps in knowledge and understanding about changes to the program and the rationale behind these have caused health concerns among women. Worry about the extended screening interval indicates little understanding of the slow progression of the HPV infection to cervical cancer or the high rates of regression. Identification of these knowledge gaps can inform both deintensification of other cancer screening programs and practitioners, so that they are able to address these concerns with their patients.

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KEYWORDS

screening; attitudes; cervical cancer; knowledge

Introduction

Background

Cervical cancer is mostly attributed to the human papillomavirus (HPV), which is a virus transmitted through sexual contact [1]. From the time cervical screening was introduced in Australia in 1991, the number of women aged 20 to 69 years diagnosed with cervical cancer has fallen from 17 per 100,000 women to

9 per 100,000 women, and mortality rates have halved from 4 per 100,000 to 2 per 100,000 [2]. Incidence and mortality rates of cervical cancer in Australia and New Zealand are comparable with Western Europe and North America [3]. Testing for HPV has been utilized in cervical screening programs for triage and test of cure for women with cervical abnormalities (eg, United Kingdom), but many countries are now moving toward HPV screening as the primary test in cervical screening.

Table 1. The changes implemented to the Australian National Cervical Screening Program (NCSP) on December 1, 2017.

Change	New program (2017 to present)	Old program (1991 to 2017)
Test technology	The Cervical Screening Test takes cells from the cervix to test for human papillomavirus infection	The Pap test took cells from the cervix and examined these cells for physical changes
Interval	The Cervical Screening Test is every 5 years	A Pap test every 2 years
Age	Women will be invited for a Cervical Screening Test from the age of 25 years Women will have their last Cervical Screening Test (<i>exit test</i>) between 70 and 74 years of age	Cervical screening began at 18 years of age Cervical screening ended at 69 years of age

Overdiagnosis and overtreatment are increasingly recognized as potential harms of screening, resulting in a need for screening programs to be reformed to ensure screening only occurs when benefits of early detection outweigh harms [4]. A renewed, deintensified National Cervical Screening Program (NCSP) was introduced in Australia in December 2017, which included a number of specific changes to the program (Table 1) [5]. The renewal based new recommendations on evidence of potential harms with the cytology (Pap test) program, in addition to data demonstrating success of the HPV vaccination and the development of new screening technology, which is more sensitive [6-8].

The deintensification of the NCSP has the potential to reduce overdiagnosis and overtreatment of cervical abnormalities and the additional harms associated with this. This is particularly relevant for women aged under 25 years, where incidence and mortality of cervical cancer is extremely low [2]; however, the transient nature of HPV in this age group results in women receiving potentially unnecessary and harmful treatment under the recommendations of the original program.

Although the changes were announced by the NCSP in April 2014, because there was no accompanying publicity, they went largely unnoticed by the public until February 2017 when a Web-based petition opposed to the changes was widely disseminated [9]. Similar hesitancy to changes in recommendations and deintensification of screening has been observed previously in the United States when the age of breast screening was increased from 40 to 50 years and the annual cervical screening interval was lengthened to every 3 or 5 years depending on the woman's age [10,11]. Public consultations on the review of evidence toward the age of first screening and frequency of screening conducted by the UK National Screening Committee in 2012 have also demonstrated examples of such public concern [12]. Concern has also been expressed previously in Australia and Canada over delaying the age of screening [13,14] and changing the primary test to HPV testing [15,16]. The deintensification of screening programs is continually met with concern and opposition from the public, which can result in the recommendations being retracted [17,18].

Objective

In our first study, we conducted a content analysis to identify and quantify the main themes and areas of concerns in women regarding the changes [19]. In this study, we explore in depth, women's understanding and concerns about the specific changes and elements of the deintensified program. This will provide insight into the main concerns that need to be addressed as these

changes are implemented and identify concerns that may be pre-empted for deintensifying other screening programs in the future in order to improve public communication strategies in screening.

Methods

Dataset

Comments posted on the *Change.org* petition, *Stop May 1st Changes to Pap Smears—Save Women's Lives* (Multimedia Appendix 1), between February 16, 2017, and March 19, 2017, inclusively provided the dataset for this study [9]. Further information on the dataset and procedure is given in our previous publication [19]. Information given by each commenter included their name, state, city, and postcode. Of 2000 comments coded, over one-third (34.55%; 691/2000) reflected concerns about the specific changes to the cervical screening program recommendations. These comments represent the dataset on which the qualitative analysis was performed. This study was reviewed and approved by the University of Sydney Human Research Ethics Committee (project number 2017/300). Participant consent was not required as they had consented to their comments being freely available when they commented at *Change.org*.

Analysis

A description of the content analysis from our first study is given in our previous publication [19]. The 2000 randomly selected comments were organized and coded in Microsoft Excel. Inter-rater reliability (Cohen kappa) between 2 coders (HO and RD) of the content analysis was 0.95, showing *nearly perfect* agreement [19]. Of 19 codes, 5 codes were related to specific changes to the screening program: opposition to the extended screening interval, concern about the increased age of the first invitation to screen, concern about missing cancer cases in older women, expressions of support for the current program, and disagreement with the HPV test itself. Comments relating directly to these 5 codes representing the specific changes to the cervical screening program were organized into worksheets in Microsoft Excel and then analyzed using qualitative thematic analysis [20]. This flexible approach gives theoretical freedom to analysis, enabling a rich and detailed account of the data. All the comments coded in each individual theme that related to the specific changes to the screening program were analyzed thematically. This analysis enabled the comments to be reviewed and defined in depth for further insight into the concerns expressed by commenters. Both coders of the data are women of screening-eligible age and acknowledge their

own theoretical positions and values from a public health (postdoctoral researcher) and medicine influence (medical doctor).

Results

Overview

Among the 691 comments expressing concern about specific changes to the program, there was overwhelming support for the current cytology (ie, the existing program at the time of the petition) cervical screening program. Concerns about the renewed HPV primary screening program included (1) worry about the increased screening interval (from 2- to 5-yearly interval); (2) opposition to an increased age of the first invitation to screen to the age of 25 years; (3) disagreement with the change in test technology; and (4) worry about missing cases of cervical cancer in older women because of the introduction of the exit test.

Support for the Current Cytology (Pap Test) Program

Keeping a Successful Program

Commenters viewed the current (cytology) cervical screening program as successful and therefore could not understand the reasons for changing a program that they know has been shown to be effective and save lives:

Vital to keep this system. It saves so many lives in Australia.

Some comments referred to the idea that the program was changing as a cost-saving measure, at the cost of saving lives:

The current system works very well, don't try and "fix" something that's not broken to save money instead of saving lives.

Same Access to Screening for Future Generations

Commenters also mentioned a desire for future generations to have the same access to cervical screening that they have experienced. Commenters displayed no awareness of the concept of overdiagnosis and overtreatment, with the consistent belief that more screening saves lives and that it is always best to detect changes early. Commenters' general understanding was that more screening equates to more lives saved:

I think it important that the current system remains as it is working. I have two daughters and would hope that the process was the same for them as it has been for me. More screening=early detection=lives saved.

Opposition to an Increased Screening Interval

Prefer More Frequent Screening

This was the most concerning change for women (334/2000; 16.70%), with the most comments indicating concern that the 5-yearly interval between tests was too long compared with the 2-yearly interval (Table 2). There was a general preference expressed for annual or biannual screening, which was in some cases related to women's own perception of increased risk owing to the experience of being diagnosed with abnormal cells:

I have a Pap smear every 2 years. I've needed to have abnormal cells removed. I changed to annual Pap smears for monitoring - nothing in 1 year to high risk in the next. This has happened to more women I know. It's extremely common. This change to 5 years makes no sense.

Perceived Risk

Commenters also believed that this change would be putting more lives at risk, with the common concern that if a woman developed abnormalities within the 5-yearly interval, then these would already be cancer, suggesting women see having an abnormal Pap smear as having a *near-miss* with cancer:

This is a step backwards...How far could a cancer progress in the five years between testing. This is so ridiculous, just leave things that are working well alone.

These comments reflect a lack of understanding that cervical cancer develops slowly over a long period of time. It also illustrates confusion between precancerous cells and cancer. Commenters expressed the opinion that cervical cancer is a fast-progressing cancer and that with the introduction of a 5-yearly screening interval, this would leave many women at risk:

5 years is far too long for something as quick progressing as cancer, and given that young people (well under 25) are sexually active, they have a right to the protection that Pap smears offer just like everyone else.

Adherence to Recommendations

There was also suggestion that some may not follow the recommendations and that inequalities would arise owing to *only the rich* being able to pay to continue to have more frequent tests:

This is such an important test for early detection. The rich are fine for paying tests in between but why should it be at the detriment of middle and low income earners. It shouldn't be the rich get treatment and those less fortunate die as they can't afford necessary tests when the government decides to increase the time between testing.

Worry About Missing Younger Women

Significant Risk to Young Women

Another concern expressed was the change to the age in which women would be invited, with the starting age increasing from 18 to 25 years. Commenters expressed that they believed this change would lead to more deaths in young women and that women in this age group remain at significant risk of cervical cancer:

I don't have much to say except this change is ridiculous. Chances are it will be responsible for the deaths of many young women.

Table 2. Concerns relating to the specific changes in recommendations.

Concerns ^a and coded most with...	Example comments
Want to keep current cytology (Pap Test) system	
Screening interval	There should be no change. Screening should be every two years.
Women's health	Pap smear testing is a vital health care service—so please leave it alone!! Women's lives depend on it!!
Prevention or early detection	I'm signing because early detection saves lives, why change something that has helped detect cervical cancer early.
Worry about screening interval	
Personal experience	I have had abnormal Pap smear result which changed 2 levels in 9 months. Leaving it for 3 years would have meant death.
Worry about missing young women	It should be decreased to once a year not increased to once every 5 years. The age should be decreased to 16 not increased to 25!!
Women's health	Women need their screening. 5 years is too long between screening. How many women have to end up with cancer before anything is done. Think about the women in your family.
Prevention or early detection	I don't agree with extending the time between tests. It should stay at every 2 years and that's it. This will hopefully lead to early detection. A test 5 years apart...I can't see how that can lead to early detection.
Worry about missing young women	
Screening interval	I want Pap smears to be available to everyone from 18 years old every two years.
Personal experience	A Pap smear detected pre-cancerous cells in my cervix when I was 20 years old. A delay of years could have compromised my survival.
Worry about missing older women	Any form of cancer does not discriminate against age young or old can still get it & if a Pap smear saves 1 life that means it's very worthwhile for all women of all ages.
Disagreement with HPV^b test	
Screening interval	5 years is too long between tests for 'early' detection and limiting the test to only screen for HPV induced cancers will put a greater number of lives at risk.
Women's health	This is not fair to women all over Australia they should test for everything when giving us Pap tests, because otherwise they are putting us in danger and it's not right.
Worry about missing young women	When I start to get Pap smears, I want to trust that I'm being tested for ANY abnormalities, not just the 80% and I want to be able to start now, not in 7 years when I may already have abnormalities or cancer that could have been prevented and detected.
Worry about missing older women	
Worry about missing young women	Screening should start as soon as girls are sexually active and certainly not finish at 70-75.

^a34.55% of total sample.

^bHPV: human papillomavirus.

Commenters believed if the age was to be changed, it should in fact be decreased because of this age group becoming more sexually active and that screening should start as soon as women become sexually active:

The 2 year Pap smear test should not change to 5 yearly, it's putting women's lives at risk. I think it should start early for younger women, especially if they are sexually active.

Personal Experience

Commenters had many examples of themselves, or someone else they knew having been diagnosed with cervical abnormalities under the age of 25 years, believing that had they or the woman they knew not been treated, cervical cancer would be inevitable. This reflects a gap in knowledge of the difference between cervical abnormalities and cervical cancer, with no awareness that cervical abnormalities can regress, particularly in younger women, often without requiring treatment:

A friend at age 19 during a regular Pap smear discovered cancerous cells—if she was meant to wait 'til 25 for her first one she would be dead.

Women also gave personal experiences as reasons for why the age of invitation should not be increased:

A Pap smear detected pre-cancerous cells in my cervix when I was 20 years old. A delay of years could have compromised my survival.

Comparison to Other Countries

A comparison was made to the age change to cervical screening in the United Kingdom, with the perception that many young women had died in the United Kingdom because the age of invitation was increased:

As for the age raising, this happened in the UK and there has been more and more young girls losing their battle because Paps are not even on their radar.

Symptomatic Screening

These comments reflected the notion that cervical cancer is always prevented through screening, with no commenters being seemingly aware that women still have the option of presenting to their doctors with symptoms, should these occur before women were invited for screening at the age of 25 years. As with the previous program, any woman presenting with symptoms can be screened outside of the screening program more frequently. These comments also reflect a gap in understanding that the vast majority of cervical abnormalities can regress without treatment.

Disagreement With the Introduction of Human Papillomavirus Testing

Misunderstanding the Pap Test

The change of the test itself, from a cytology-based test (Pap smear) to an HPV test (cervical screening test), was rarely commented on. However, among those who expressed concern, worry related to a desire to monitor *all abnormalities* and not just HPV. This was coupled with a belief that the Pap test currently tests for several types of infection:

When I start to get Pap smears, I want to trust that I'm being tested for ANY abnormalities, not just the 80% and I want to be able to start now, not in 7 years when I may already have abnormalities or cancer that could have been prevented and detected.

Commenters were strong advocates for the Pap smear, believing that it detects all abnormalities compared with HPV test that was viewed as less thorough and not as advanced:

So far testing for HPV isn't advanced enough. And doesn't cover all cancers...I ask you to do what's right and protect your women and keep the Pap smear testing unchanged.

Commenters continued to talk about screening in the context of Pap smears rather than HPV test:

Pap smears need to stay at two years...how dare a male run government make these decisions...it has been proven that age does not matter in these circumstances...

Commenters did not understand that HPV testing technology is a newer, more sensitive, and potentially sophisticated test than the Pap smear. They also believed that Pap smears detected other cancers as well as cervical cancer, when HPV testing will actually improve prevention of adenocarcinomas compared with the Pap smear:

It would be medically ignorant to make the changes you have suggested...Not all cervical cancer is caused by HPV and there are many types of cancers caught by the Pap smear testing.

Human Papillomavirus Vaccination

The HPV vaccine was also mentioned, with some recognition that the vaccine was already making a difference, but also with some understanding shown that the vaccine does not protect against all HPV types:

My understanding is that the HPV vaccination is only against 1 HPV & there are around 100 different HPVs.

There was recognition that a large proportion of the population (namely those older than the cohort offered the HPV vaccination) have not received the vaccine and commenters expressed the belief that the recommendations should be different for those who have not received the HPV vaccination:

I also understand MOST girls have now had the vaccination, perhaps those people who haven't, or don't know should at very least get a Pap early.

Worry About Missing Older Women

This theme mainly reflected comments from women that *all women of all ages are at risk* and "age is no barrier." This was the least coded concern from commenters.

Screening should start as soon as girls are sexually active and certainly not finish at 70-75.

Discussion

Principal Findings

This study presents an analysis of comments made to a Web-based petition opposing the changes to the Australian NCSP implemented in December 2017. This study focused on gaining an in-depth insight into comments opposed to the specific changes to the screening program, namely the extended screening interval, increased age of first screening, and the screening test itself. The greatest concern about the changes was reflected in comments opposing the extended interval between screening tests. Another important concern was the worry about missing cancer in young women owing to the later age of first screening, but the number of commenters showing concern about the new test (primary HPV testing) was minimal.

Strengths and Limitations

The study benefits from rich data generated from a large-scale petition, with a sample of almost 20,000 comments. Although the commenters responding to the petition could be described as the *vocal minority*, this was the second largest petition in 2016 and 2017 on *Change.org* in Australia. Despite this, the vocal minority can result in change and negative press can be very powerful, such as in the United States where screening recommendations were retracted as a consequence [17,18]. Additionally, no demographic data were available for the commenters, so we cannot draw conclusions on the representativeness of the sample or give any detail about the commenters. Although the analysis of qualitative data is viewed as subjective, measures were taken to recognize sources of bias in the analysis by 2 authors coding the data, and comments from participants have been included in the results to support the interpretive findings.

Comparison With Previous Work

The findings from this study build upon those from our previous content analysis [19] by adding a greater depth of analysis and providing more detail into women's concerns about the specific changes to the NCSP. Although our previous study descriptively

provides an overview of the opposition to the specific changes to the NCSP, this study discusses these further and reveals important concrete concerns.

Our findings support some prospective work conducted with a small cohort (n=149) of young Australian women (aged 16 to 28 years). This showed that although almost 79% were willing to screen with primary HPV testing, 65% were concerned about delaying cervical screening until the age of 25 years and 66% were unwilling to undertake screening with HPV testing from the age of 25 years, at 5-yearly intervals [13]. Extending the interval between cervical screens has also previously been found to be a concern for women in other countries [10,11,15] and was replicated in this study. Despite hesitancy from practitioners in Australia about the changes to the cervical screening program, encouragingly, if the changes were said to be recommended by the national guidelines, 60% have shown willingness to perform 5-yearly HPV testing from the age of 25 years [21]. The importance of practitioner support for a revised screening program is demonstrated by a US example, where despite a change in recommendations for cervical screening, health care providers still offer an annual Pap test [22,23].

Importantly, a number of misconceptions and gaps in knowledge about the progression of cervical cancer were apparent in the comments about the extended screening interval. Commenters expressed the belief that within the 5-yearly time frame between screening tests, it was likely that any cervical abnormalities could develop into cervical cancer, displaying a fundamental misunderstanding about both the natural history and progression of cervical cancer. This also demonstrates a failure to distinguish between precancerous abnormalities and cancer and no understanding about the high rates of regression of HPV and cervical abnormalities. Women therefore need to be educated about these issues, and primary practitioners are ideally placed to do this. Public awareness campaigns through social media may also be effective approaches given the increasing use of social media across the screening-eligible age. There were further gaps in knowledge about HPV testing technology, notably its sensitivity and its negative predictive value compared with the Pap smear, which is the rationale behind extending the screening interval. Previous research has shown that women with a better understanding of the rationale behind screening tests are more accepting of an extended screening interval [10,15]. In a sample of Canadian women, having a positive attitude toward the value of HPV testing was a significant predictor of willingness to participate in different screening regimens (HPV test, increased interval, and increased age of first screen) [14].

Missing younger women with cervical cancer owing to an increased age of the first screening invitation was a major concern. The common belief expressed by commenters in the petition was that women younger than 25 years of age were at increased risk of cervical cancer if they were no longer going to be screened. Not unsurprisingly, commenters showed no awareness of the concept of overdiagnosis and overtreatment in these younger women and did not have accurate knowledge

about the low incidence of cervical cancer in younger women and declining rates of high-grade abnormalities. There has been little public information on these topics, and these views may also be a consequence of the high rate of attention given to younger women diagnosed or those who have died from cervical cancer in the media, for example, *Jade Goody*. Understanding the concept of overdiagnosis and overtreatment is fundamental to understanding some of the reasons behind the deintensification of this and future screening programs.

The consequences of overtreatment should be communicated to women so that they may understand more about the rationale behind increasing the starting age of screening. Previous research has shown that women who believe the extended interval is changing owing to scientific evidence rather than being driven by cost are more likely to accept the change [11]. Although some commenters demonstrated a misunderstanding of the difference between the previous and renewed screening program by expressing concern about missing cases of cervical abnormalities in older women, these concerns were not commonplace. This misconception is possibly because of the use of the *exit test* terminology, which sounds more final than previously, where women would simply not be tested after the age of 69 years. Women in Australia will now receive a screen at an older age than previously included in the screening program, which will assess those women at low risk and invite them to exit the screening program.

Women often do not remember being informed or are not aware of any changes in recommendations that occur to screening programs [24,25]. Very few commenters disagreed with the introduction of the HPV test and continued to refer to the Pap smear, which may reflect a lack of awareness about the change in test or a lack of understanding about the purpose of the test. Commenters also expressed a belief that the Pap smear tests for multiple infections and multiple cancers and did not seem to understand the purpose of the Pap smear as screening asymptomatic women [10], perhaps confusing the combination of the Pap smear with their Well Women's Checks where other infections such as chlamydia are tested for but by using a different sample.

Health professionals have indicated their worry about the extended screening interval owing to women not attending regular health checks [22]. Previous research has indicated that between 56% and 75% of women would still attend regular Well Women's Checks if the Pap smear was no longer at the same interval [13,24,25]. The hesitancy of these health professionals needs to be addressed as this could undermine patient education efforts if they continue to screen more frequently regardless of guidelines, such as in the United States where clinical practice has been slow to change [10,22,23] and many women are unaware about changes to the recommendations. A total of 60% of health professionals in Australia and New Zealand reported being willing to screen by the new guidelines, but stated they would be likely to screen women who are unvaccinated, are sexually active, or have a past history of cervical abnormalities, more often [21].

Table 3. Recommendations for health care practitioners to address with patients concerned about deintensification of screening programs

Change in screening program	Recommended information
Changing screening intervals	Some cancers can be very slow growing, taking between 5 and 10 years before growing to a point of causing a problem for a person's health and so in some cases, might not cause any problems in a person's lifetime. For example, human papillomavirus (HPV) is the main cause of cervical cancer, which is a very common infection where most sexually active people will pick up HPV at some point in their lives. In cervical cancer, only a small number of people who get HPV go on to develop abnormal cells and an even smaller number go on to develop cancer. Persistent infection with a cancer-causing type of HPV can cause abnormal cell changes that may lead to cervical cancer. However, this usually takes a long time, often more than 10 years. As tests that we use for cancer screening are now more accurate and sensitive, we can trust the results from these for a longer period of time. This means that if you are found to be at low risk, you do not need to be tested as frequently and can be more confident in the test results.
Reducing age range for screening	Cancer does not affect every age group the same. We now have extensive data about the number of cases of different cancers across the population and so we know which age groups are most at risk and would benefit most from screening. In some cancers, there can be more harm than benefit to screening younger age groups, as some abnormalities may be detected which would otherwise go away by themselves, or not cause harm in that person's lifetime, but may lead to unnecessary treatment.
Changing screening technology	Owing to advancing technology, new tests are being developed which are more accurate and sensitive than previous tests. Some tests, such as the new cervical screening test, are also detecting changes at an earlier stage than the previous tests and will pick up any abnormal changes a stage earlier. The new cervical screening test is detecting HPV types which have the potential to cause cancer and the persistence of these HPV types, therefore detecting the virus that causes most cervical cancers.

Previous research has shown women are willing to be screened using the HPV test [13,16,24], particularly those who place more value on the national guideline recommendations [13], but that many do not understand what HPV testing is [26]. In response to the changing cervical screening program in Ireland, lacking knowledge about the test made it impossible for women to try to understand the reasons for any changes and make informed decisions about HPV testing [26]. It is conceivable that knowledge about how common HPV is, or an understanding that there is no treatment for the infection, could result in a hesitancy toward HPV testing and may cause women to question its reliability over cytology [26].

Successful messaging about early detection, plus an understanding of the success of the previous cervical screening program, has led to resistance to change. Women hold so much value to the Pap smear that some would continue to have it regardless of whether it is funded by the government. There was also a suggestion that those who could afford to, would still have more regular screening. However, in the United States, overscreening persists in the under- and uninsured [10].

Resistance to deintensifying screening programs has been demonstrated previously in the United States [10,11] with similar concerns demonstrated in these findings. Although differences exist among breast, cervical, and bowel cancer screening programs, there is likely to be considerable overlap in dealing with concerns for deintensification. For example, concerns women have about increasing the length of interval

between screens would likely be a common concern across all 3 screening programs owing to the message about early detection. Equally, with increasing the age of invitation for screening, there will be a focus on *missing* cancers in that age group that is no longer being screened, evident in this study by women concerned about both younger and older women. Introducing a change in test also requires explaining the difference between the old and the new test and the reason for change. Therefore, the recommendations given in this study could be applied to other screening programs, with subtle differences around the physical and psychological impact on individuals recognized.

Conclusions

Key features of the changes that elicited concern and may apply to other screening programs that undergo deintensification can provide lessons for the future. The most concerning change was regarding the increased screening interval, from 2 to 5 years, with further concern about the increased age of the first invitation to screen. The rationale behind these types of changes in the future needs to be communicated clearly to the public in an effort to increase understanding and alleviate concerns. In addition, communication of the benefits and harms of screening along with resultant overdiagnosis and overtreatment, is necessary to ensure the public are fully informed about screening decisions. We have outlined some recommendations (Table 3) for communicating about deintensifying screening programs, which would help improve the understanding and alleviate concerns.

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Authors' Contributions

RHD was involved in the conception and design of the work, analyzed, and coded the original 2000 comments, further analyzed the sample in this study, and drafted the manuscript. HMO acquired the dataset, analyzed, and coded the original 2000 comments, and drafted the manuscript. KM was involved in the conception and design of the work and drafting the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Content of the petition.

[[PDF File \(Adobe PDF File\), 90KB - cancer_v5i1e12307_app1.pdf](#)]

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Abbreviations

HPV: human papillomavirus

NCSP: National Cervical Screening Program

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Original Paper

Benefit of Watching a Live Visual Inspection of the Cervix With Acetic Acid and Lugol Iodine on Women's Anxiety: Randomized Controlled Trial of an Educational Intervention Conducted in a Low-Resource Setting

Roxane Camail¹, MD; Bruno Kenfack², MD; Phuong Lien Tran¹, MD; Manuela Viviano¹, MD; Pierre-Marie Tebeu³, MD, MPH; Liliane Temogne², MD; Mohamed Akaaboune¹, MD; Eveline Tincho², MD; Joel Mbobda², MD; Rosa Catarino¹, MD; Pierre Vassilakos⁴, MD; Patrick Petignat¹, MD

¹University of Geneva, Geneva University Hospitals, Gynecology Division, Geneva, Switzerland

²University of Dschang, Department of Biomedical Sciences, Dschang, Cameroon

³Yaoundé University Hospital, Faculty of Medicine and Biomedical Sciences, Yaoundé, Cameroon

⁴Geneva Foundation for Medical Education and Research, Geneva, Switzerland

Corresponding Author:

Roxane Camail, MD
University of Geneva
Geneva University Hospitals
Gynecology Division
Boulevard de la Cluse 30
Geneva, 1205
Switzerland
Phone: 33 650175616
Email: roxanecamail@hotmail.fr

Abstract

Background: Women undergoing pelvic examination for cervical cancer screening can experience periprocedural anxiety.

Objective: The aim of this study was to assess the anxiety level experienced by women undergoing a visual inspection with acetic acid and Lugol iodine (VIA and VILI) examination, with or without watching the procedure on a digital screen.

Methods: This prospective randomized study took place in the district of Dschang, Cameroon. A previous cervical cancer screening campaign tested women aged between 30 and 49 years for human papillomavirus (HPV). HPV-positive women were invited for the 12-month follow-up control visit, including a VIA/VILI examination. During that visit, we recruited women to participate in this study. Before the examination, participants were randomized in a 1:1 ratio to a control group (CG) and an intervention group (IG). Women in both groups underwent a pelvic examination and were verbally informed about the steps undertaken during the gynecological examination. The IG could also watch it live on a tablet screen. Women's anxiety was assessed before and immediately after the examination, using the Spielberger State-Trait Anxiety Inventory (STAI). A paired *t* test was used to compare the mean STAI score for each question before and after VIA/VILI while a nonpaired, 2-sided *t* test was used to compare the mean differences of the STAI score between the 2 study groups.

Results: A total of 122 women were randomized in the study; 4 of them were excluded as they did not undergo the pelvic examination, did not answer to the second STAI questionnaire because of personal reasons, or the cervix could not be properly visualized. Thus, the final sample size consisted of 118 patients of whom 58 women were assigned to the CG and 60 to the IG. The mean age was 39.1 (SD 5.2) years. Before the examination, the mean (SD) STAI score was 33.6 (SD 10.9) in the CG and 36.4 (SD 11.8) in the IG ($P=.17$). The STAI score after pelvic examination was significantly reduced for both groups (CG: 29.3 [SD 11.2]; IG: 28.5 [SD 12.0]). Overall, the difference of the STAI scores before and after the pelvic examination was lower in the CG (4.2 [SD 9.0]) than in the IG (7.9 [SD 14.3]), although the difference was not significant ($P=.10$). However, the women's emotional state, such as *I feel secure* and *I feel strained*, was improved in the IG as compared with the CG (CG: $P=.01$; IG: $P=.007$).

Conclusions: Watching the VIA/VILI procedure in real time improved the women's emotional state but did not reduce the periprocedural anxiety measured by the STAI score. Furthermore, larger studies should assess women's satisfaction with watching their pelvic examination in real time to determine whether this tool could be included in VIA/VILI routine practice.

Trial Registration: ClinicalTrials.gov NCT02945111; <http://clinicaltrials.gov/ct2/show/NCT02945111>

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KEYWORDS

cervical cancer; papillomavirus infections; acetic acid; Lugol's iodine; anxiety

Introduction

Background

Persistent human papillomavirus (HPV) infection is a major factor of cervical cancer (CC), which is the leading cause of cancer-related death in women in South Africa [1]. The lack of policies and resources for CC prevention in low- and medium-income countries (LMICs) is responsible for a high number of CC cases [2]. The updated 2012 World Health Organization (WHO) guidelines recommend the use of visual inspection with acetic acid (VIA) as a primary CC screening tool in LMICs, a strategy that entails a pelvic examination performed by an experienced physician. The WHO also recommends HPV-based primary screening with or without VIA triage for HPV-positive women [3].

Evidence supports that women undergoing pelvic examination can experience anxiety. This distressful feeling can be experienced before the examination (especially when it follows a pathological screening test result), during the examination, and up to several weeks after it [4,5]. The negative emotional responses experienced by patients that accompany the pelvic examination derive mainly from a poor understanding of the anatomy and a lack of knowledge about CC prevention procedures, which lead women to think that the purpose of screening is to detect cancer rather than to prevent it. Several studies observed that the high levels of stress associated with pelvic examinations could result in an exacerbation of procedure-related discomfort, which could discourage women from undergoing the procedure and induce low patient compliance [6,7].

As low compliance is a major barrier limiting the screening programs' effectiveness, interventions were proposed to reduce the examination-related anxiety [8,9]. Among these, watching the examination in real time on a digital screen, giving women a better understanding of their anatomy, has shown to decrease women's anxiety in some cases [10].

Objectives

The aim of this study was to assess the anxiety level experienced by women undergoing a gynecological examination for VIA and visual inspection with Lugol iodine (VILI) while watching the procedure on a digital screen and to compare it with that of women who underwent the examination with no visual support.

Methods

Study Population and Setting

This prospective randomized study took place in September 2016 in the district of Dschang. Dschang is a city located in the West Province of Cameroon, with an estimated 200,000 inhabitants. A CC screening campaign was previously carried out in the Hospital of the District of Dschang in collaboration with the Geneva University Hospitals between July and October 2015, recruiting women aged between 30 and 49 years, living in Dschang and its surroundings. HPV-positive participants were invited for a 6- and 12-month follow-up visit to assess the disease status, and participants at the 12-month visit were invited to participate in this substudy. An inclusion protocol has already been previously reported [11]. The study was approved by the Central Ethics Committee on Human Research of the Geneva University Hospitals (approval number: CER 15-068) and the Ministry of Health of Cameroon [11], and the trial was registered on ClinicalTrials.gov with the identifier NCT02945111.

Study Design and Intervention

Participants were thoroughly informed about the study and gave their written informed consent before participation. Enrolled participants were randomized in a 1:1 ratio into 2 groups: control group (CG) and intervention group (IG).

Enrolled participants, as a part of the follow-up visit, underwent a VIA and VILI examination, during which the physician took a cervical sample for cytology and HPV testing. Women in the CG underwent routine pelvic examination as described above. They were verbally informed about the steps undertaken during the examination. Women in the IG were given verbal information about the gynecological examination while they underwent the pelvic examination and also while watching it live on a tablet screen. With the help of the local study investigators, all women filled out a validated questionnaire to determine their anxiety level both before and after the pelvic examination. To avoid potential bias before the examination and the participants' randomization, the tablet was placed on a table when it was not being used and picked up by the examiner only at the time of the pelvic examination for patients in the IG.

In the IG, the examiners took a picture of each step of the pelvic examination with a mobile phone camera (Samsung Galaxy S3, Samsung). This device, which was chosen for its high-quality camera (16 megapixels with autofocus and flash functions), allows highly precise and detailed visualization of the cervix after zooming and focusing in on the target. Photographs were obtained at a distance of 10 to 15 cm from the cervix, with 3.3

to 3.8x optical zoom in the flash mode. The smartphone was fixed on a tripod to improve the stability and quality of the images. The images were transmitted directly from the smartphone to the tablet, a Samsung Galaxy Tab (Samsung), using Bluetooth and a specifically designed app that enabled simultaneous communication between the 2 devices. Thus, women in this group could watch the pictures taken throughout the examination in real time. Image viewing was accompanied by the clinicians' explanations on the anatomy (ectropion, dysplasia, nulliparous cervix, and multiparous cervix) and the procedure (with an interpretation of the VIA/VILI assessment).

Spielberger State-Trait Anxiety Inventory Index

The anxiety was measured by asking participants in the two groups to complete the Spielberger State-Trait Anxiety Inventory (STAI) both before and immediately after the pelvic examination. The STAI is a standardized questionnaire created by Spielberger in 1983, broadly used and validated in psychology and in many medical fields [9]. It consists of 20 items describing various feelings and emotions that are present at that time. The following responses assess the intensity of current feelings *at this moment*: (1) not at all, (2) somewhat, (3) moderately so, and (4) very much so. Scoring should be reversed for anxiety-absent items. Once added up, the range of global scores is 20 to 80, the higher score indicating greater anxiety. This interview was usually self-completed, given the cultural differences and the heterogeneity of the educational backgrounds, although the STAI was filled out with the help of a local Cameroonian team consisting of 2 interviewers. The questionnaire was presented in French, which is one of the 2 national languages. When completing the STAI before the examination, neither the women nor the examiners knew in which group the patient was going to be randomly assigned. Randomization was done immediately before the pelvic examination, once the first STAI had been completed.

Sample Size and Randomization

A Web-based statistical software [12] was used to generate the randomization list, with randomly permuted participants' blocks of varying size (4, 6, and 8). This method made sure that the 122 participants were randomly attributed to either the CG or the IG while maintaining a balance across the 2 study groups. A further level of randomization consisted of using blocks of varying sizes. On the basis of this list, consecutively numbered, sealed opaque envelopes containing the group allocation were prepared. When a new participant gave her consent to participate in the study, and after having completed the first STAI questionnaire, the study investigator opened the next available envelope. We had assumed that 30% of patients in the CG would report an anxiety score ≥ 30 , and we estimated to observe an 85% reduction of the overall anxiety levels in the IG (about 4.5% of patients with a score ≥ 30 in the IG). We estimated that 61 women were needed in each group to have an 85% power

to detect a difference between groups with a 2-sided level of significance of .05 and while accounting for 30% of dropouts.

Medical Chart

A secured, electronic medical chart using the secuTrial database (interActive Systems GmbH) including the sociodemographic and medical information (HPV test, VIA/VILI results, and cervical images) was created to register and retrieve the participants' data.

Statistical Analyses

Data were analyzed with the use of a statistical software package (Stata statistical software, release 14, StataCorp). Analyses were conducted according to the per-protocol principle. The paired *t* tests and Wilcoxon signed rank tests were used to compare the mean STAI score for each question before and after VIA/VILI. A nonpaired, 2-sided *t* test was used to compare the mean differences of the STAI score between the 2 study groups, as these results concern 2 independent populations of the study. The 2-sided chi-square test, the Fisher exact probability test, and the *t* test were used, where appropriate, to test the relationship between the patients' sociodemographic and clinical characteristics and the STAI score both before and after the VIA/VILI examination.

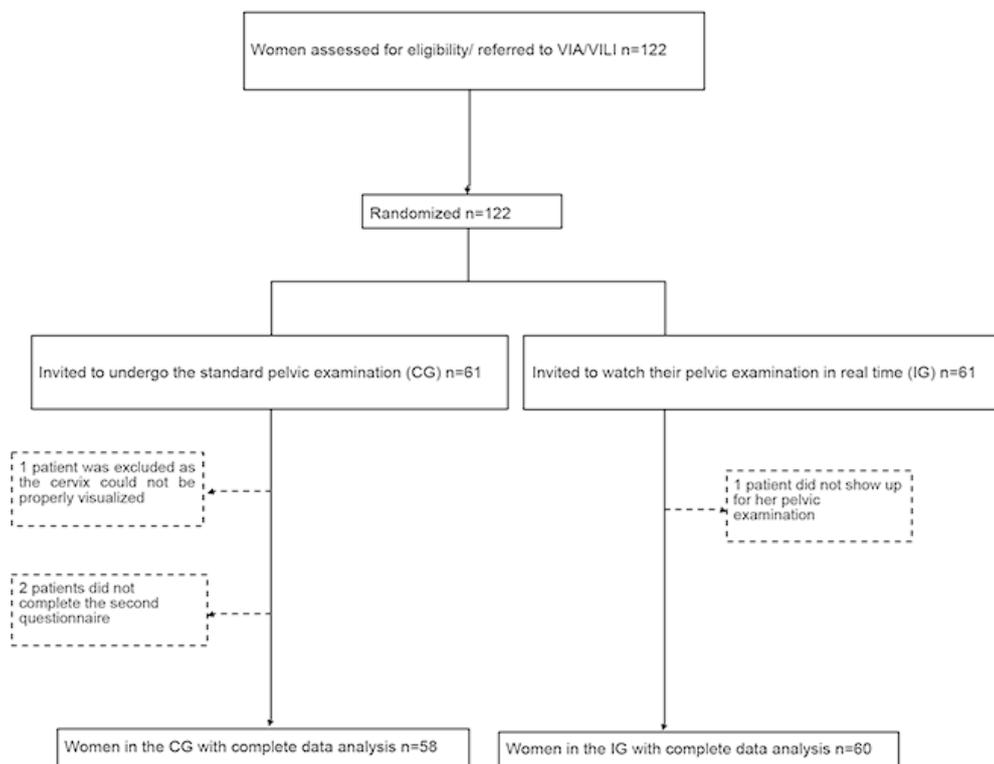
Results

Study Design

This study took place in September 2016. A total of 122 women were included in the study; of these, 4 were excluded after having been randomized. The reasons for exclusion were as follows: 3 women did not undergo the pelvic examination or did not answer to the second STAI questionnaire because of personal reasons and 1 woman was excluded because the cervix could not be properly visualized during the pelvic examination. The final sample size thus consisted of 118 patients, of which 58 women were assigned to the CG and 60 to the IG (the study design is reported in Figure 1).

Study Population and Setting

The mean (SD) age of the participants was 39.1 (SD 5.2) years. A total of 38 out of 58 (65%) women and 40 out of 60 (67%) women had part- or full-time employment in the CG and in the IG, respectively. As women were randomized, the 2 groups did not differ with regard to sociodemographic and clinical characteristics. Participants' characteristics are summarized in Table 1. The primary CC screening campaign took place between July and August 2015. Only women who were HPV positive at the primary screening campaign were called back in September 2016 and were, therefore, invited to take part in this study. The HPV status as reported in Table 1 refers to the HPV status obtained at the follow-up visit that took place in September 2016.

Figure 1. Flow chart. CG: control group; IG: intervention group; VIA: visual inspection with acetic acid; VILI: visual inspection with Lugol iodine.

Spielberger State-Trait Anxiety Inventory Index

Before the examination, the mean (SD) STAI score was 33.6 (SD 10.9) in the CG and 36.4 (SD 11.8) in the IG ($P=.17$). The mean STAI scores for each question before and after the pelvic examination are reported in Table 2. The total STAI score after the examination significantly decreased in both groups; in the CG, the mean score after examination was 29.3 (SD 11.2; $P=.001$) and in the IG, the STAI score dropped from 36.4 (SD 11.8) to 28.5 (SD 12.0; $P<.001$). The mean STAI scores before and after the pelvic examination in the CG and IG are illustrated in Figure 2. There was no particular reason to justify the presence of the 4 outlier cases in the IG having a higher STAI score than the rest of the participants in the same group after having undergone the pelvic examination. These 4 women were aged 38.9 (SD 5) years, they all had a full-time employment, and they had a mean of 4.1 (SD 1.1) children. These participants had a similar STAI score before and after the examination and did not increase their fear after the pelvic examination.

Overall, the difference of the STAI scores before and after the pelvic examination was higher in the IG (7.9 [SD 14.3]) than in the CG (4.2 [SD 9.0]), although the difference was not significant ($P=.10$). Questions such as *I feel secure* (number 2) and *I feel strained* (number 4) obtained a significantly higher score reduction among women in the IG when compared with those in the CG (0.1 [SD 1.1] in the CG and 0.7 [SD 1.2] in the IG, $P=.007$, for question 2 and 0.2 [SD 0.9] in the CG and 0.7 [SD 1.1] in the IG, $P=.01$, for question 4). Table 3 reports the comparison between the difference in STAI scores before and after the pelvic examination.

We found that women in both groups were less anxious if they had not been treated with thermocoagulation ($P<.001$) during the pelvic examination and if the VIA/VILI assessment had turned out to be nonpathological ($P=.04$). Results showed no other significant association.

Table 1. Sociodemographic and clinical characteristics of the study population

Variable	Control group (n=58)	Intervention group (n=60)
Sociodemographic characteristics, mean (SD)		
Age (years)	39.7 (5.2)	38.4 (5.2)
Parity ^a	3.8 (1.9)	4.3 (1.8)
Marital Status, n (%)		
Single	3 (5)	4 (7)
With a partner	55 (95)	56 (93)
Education level, n (%)		
None	11 (19)	1 (2)
Elementary school	1 (2)	11 (18)
Apprenticeship	33 (56)	3 (5)
High school	13 (22)	38 (63)
University	— ^b	7 (12)
Employment status, n (%)		
Employed	38 (65)	40 (67)
Farmer	2 (3)	4 (7)
Housewife	15 (26)	13 (22)
Other	3 (5)	3 (5)
Clinical characteristics		
HPV^c test result^d, n (%)		
Negative	41 (71)	36 (60)
HPV-16	—	2 (3)
HPV-18/45	4 (7)	3 (5)
Other hrHPV ^e	12 (21)	19 (32)

^a Parity: number of pregnancies ended at a viable gestational age.

^b Absence of corresponding data.

^c HPV: human papillomavirus.

^d There was one missing value in the control group's human papillomavirus test results.

^e hrHPV: high-risk human papillomavirus.

Table 2. Mean Spielberger State-Trait Anxiety Inventory scores in each study group.

Study question	Control group (n=58), mean (SD)			Intervention group (n=60), mean (SD)		
	Before pelvic examination	After pelvic examination	P value	Before pelvic examination	After pelvic examination	P value
1. I feel calm	1.7 (0.9)	1.7 (1.0)	.90	2.1 (1.0)	1.3 (0.8)	<.001
2. I feel secure	1.7 (0.9)	1.6 (1.0)	.62	2.1 (1.0)	1.5 (1.0)	<.001
3. I feel tense	1.5 (0.8)	1.3 (0.7)	.29	1.9 (1.0)	1.4 (0.9)	.002
4. I feel strained	1.4 (0.8)	1.2 (0.6)	.16	1.9 (1.0)	1.2 (0.7)	<.001
5. I feel at ease	1.7 (1.0)	1.4 (0.8)	.008	1.9 (1.0)	1.5 (1.0)	.03
6. I feel upset	1.7 (1.0)	1.3 (0.7)	.005	1.9 (1.0)	1.5 (1.0)	.02
7. I am presently worrying over possible misfortunes	1.6 (0.9)	1.3 (0.8)	.03	1.7 (1.0)	1.5 (1.1)	.23
8. I feel satisfied	1.8 (1.0)	1.6 (1.0)	.12	1.7 (1.0)	1.5 (1.0)	.15
9. I feel frightened	1.5 (0.9)	1.5 (0.9)	.74	1.7 (1.1)	1.6 (1.0)	.25
10. I feel uncomfortable	2.1 (1.3)	1.5 (1.0)	.002	1.9 (1.1)	1.4 (1.0)	.01
11. I feel self-confident	1.6 (0.9)	1.3 (0.8)	.08	1.7 (0.9)	1.4 (0.9)	.07
12. I feel nervous	1.4 (0.8)	1.2 (0.6)	.06	1.6 (0.9)	1.4 (1.0)	.27
13. I feel jittery	1.6 (0.9)	1.4 (0.9)	.09	1.7 (1.1)	1.4 (0.9)	.02
14. I feel indecisive	1.6 (0.9)	1.4 (0.8)	.12	1.7 (1.0)	1.3 (0.8)	.004
15. I am relaxed	1.8 (1.1)	1.6 (1.0)	.27	2.0 (1.0)	1.6 (1.1)	.03
16. I feel content	2.0 (1.1)	1.6 (1.0)	.002	1.7 (1.1)	1.4 (1.0)	.04
17. I am worried	1.9 (1.0)	1.5 (0.8)	.004	1.8 (1.0)	1.5 (1.0)	.10
18. I feel confused	1.6 (0.9)	1.3 (0.6)	.03	1.6 (0.9)	1.1 (0.5)	<.001
19. I feel steady	2.2 (1.0)	2.1 (1.1)	.46	2.1 (1.0)	1.6 (1.0)	.001
20. I feel pleasant	1.4 (0.8)	1.4 (0.9)	.47	1.8 (1.0)	1.6 (1.0)	.37
Total Spielberger State-Trait Anxiety Inventory score	33.6 (10.9)	29.3 (11.2)	.001	36.4 (11.8)	28.5 (12.0)	<.001

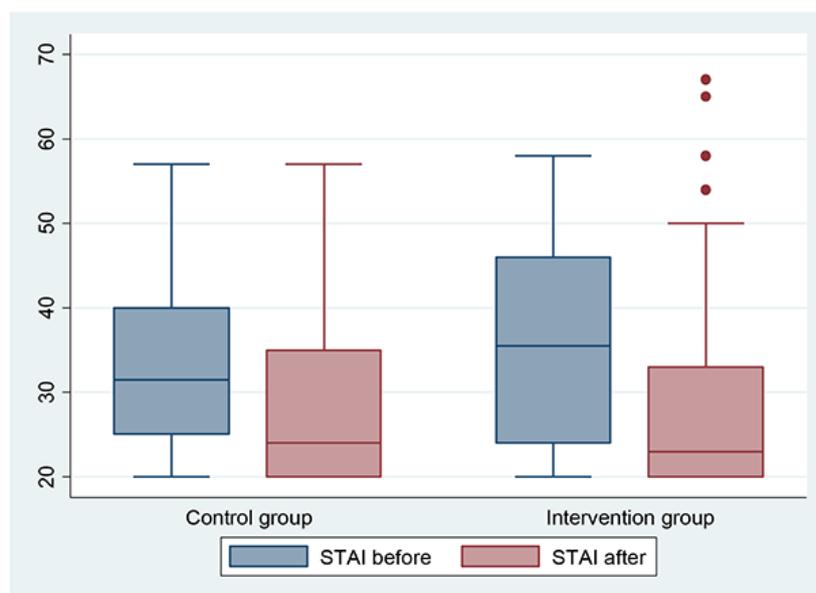
Figure 2. Box plot comparing anxiety between the control group and the intervention group. STAI: Spielberger State-Trait Anxiety Inventory.

Table 3. Difference in Spielberger State-Trait Anxiety Inventory scores before and after the pelvic examination in each study group.

Study question	Control group (n=58), mean (SD)	Intervention group (n=60), mean (SD)	P value
1. I feel calm	-0.02 (1.1)	-0.7 (1.2)	.002
2. I feel secure	-0.1 (1.1)	-0.7 (1.2)	.007
3. I feel tense	-0.1 (1.0)	-0.5 (1.2)	.06
4. I feel strained	-0.2 (0.9)	-0.7 (1.1)	.01
5. I feel at ease	-0.3 (0.9)	-0.4 (1.2)	.91
6. I feel upset	-0.3 (0.9)	-0.5 (1.5)	.58
7. I am presently worrying over possible misfortunes	-0.3 (1.0)	-0.2 (1.2)	.58
8. I feel satisfied	-0.2 (0.9)	-0.2 (1.2)	.83
9. I feel frightened	-0.03 (0.8)	-0.2 (1.1)	.46
10. I feel uncomfortable	-0.6 (1.3)	-0.5 (1.4)	.68
11. I feel self-confident	-0.2 (0.9)	-0.3 (1.1)	.75
12. I feel nervous	-0.2 (0.8)	-0.2 (1.2)	.83
13. I feel jittery	-0.2 (0.8)	-0.4 (1.1)	.38
14. I feel indecisive	-0.2 (0.8)	-0.5 (1.2)	.12
15. I am relaxed	-0.2 (1.3)	-0.4 (1.4)	.39
16. I feel content	-0.4 (1.0)	-0.4 (1.4)	.77
17. I am worried	-0.4 (1.1)	-0.3 (1.4)	.57
18. I feel confused	-0.3 (0.9)	-0.5 (1.0)	.19
19. I feel steady	-0.1 (1.2)	-0.6 (1.2)	.06
20. I feel pleasant	-0.1 (0.5)	-0.2 (1.4)	.27
Total Spielberger State-Trait Anxiety Inventory score	-4.2 (9.0)	-7.9 (14.3)	.10

Discussion

Principal Findings

This study conducted in Cameroon aimed to assess the effect of watching a live VIA/VILI examination on women's anxiety. The direct visualization of the pelvic examination was not associated with a reduction of anxiety as measured by the STAI score. When asked to report their emotional state through questions such as *I feel strained* and *I feel secure*, women who watched their examination on a digital screen were less anxious than women who underwent standard pelvic examination while receiving only a verbal explanation. Women in the 2 groups were similarly anxious before the pelvic examination, perhaps because of the limited knowledge of the visual support's use and its way of functioning. The overall anxiety score decreased after having undergone the gynecological exam for women in both groups, with no significant difference for women who underwent the examination with a visual support. This finding can be explained by the fact that women are generally nervous about the pelvic examination before it starts and that once the procedure has come to an end, their anxiety generally decreases, regardless of the presence of the visual support.

The findings in this study appear to be in contradiction with previous data obtained by Walsh et al [10], who reported a significant anxiety reduction in the group that watched their pelvic examinations in real time when compared with those

who did not watch the examination. However, it is difficult to compare our results with those obtained by Walsh et al as the study design was different: although they assessed the impact of watching live colposcopy on anxiety at a follow-up visit, we quantified anxiety with the STAI immediately after the procedure. On the contrary, our results are similar to those obtained by Hilal et al [13], who found no significant differences in anxiety ratings between the group of participants who viewed the procedure on a digital screen monitor and the CG.

Previous studies have found that pelvic examinations can significantly increase women's anxiety, thus discouraging them from attending screening and follow-up visits. As the anxiety of women participating in CC screening may be high, the negative emotional response associated with the pelvic examination can affect self-esteem, thus resulting in mood disorders such as depression and irritability [5]. An understanding of their anatomy and the natural history of CC is, therefore, an essential step in increasing women's trust in CC screening and follow-up.

Strengths and Limitations

The strengths of this study are the randomized and prospective design and the use of a measurement method that has previously been validated in the literature. Although the STAI is a standardized and validated questionnaire for Western countries, limited evidence has evaluated its use in settings such as in

sub-Saharan Africa. The use of an alternative tool to measure participants' anxiety may therefore have yielded different results.

One limitation of this study is that it took place at a 12-month follow-up visit, which means that all women had already undergone a gynecological examination with a VIA/VILI assessment. It is therefore possible that, as all women had already undergone the procedure, any intervention to reduce anxiety would be less influential. Another limitation is the cultural difference that may influence the perception of anxiety, which makes it difficult to generalize our study results to the rest of the worldwide population, in particular to that of industrialized countries. A limitation consists in the fact that there was no multiple comparison adjustment for statistically significant findings. Finally, the interviewer knew in which group the women had been randomized after the examination. This aspect may have introduced a potential bias, as knowing the participant's group allocation may have influenced the way in which the STAI questions were asked.

Similarly, the participants were aware of their group allocation during the pelvic examination, as well as when filling the STAI form after it. Such an unmasked allocation may have influenced the study's final results.

Conclusions

In conclusion, watching the VIA/VILI procedure in real time improved the women's emotional state but did not reduce the periprocedural anxiety measured by the STAI score. Furthermore, larger studies should assess women's satisfaction with watching their pelvic examination in real time to determine if this tool could be included in VIA/VILI routine practice. Moreover, further research should be focused on the effect on women's anxiety when showing their cervical images immediately after the procedure rather than during it.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1

CONSORT - EHEALTH checklist (V 1.6.1).

[\[PDF File \(Adobe PDF File\), 728KB - cancer_v5i1e9798_app1.pdf\]](#)

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Abbreviations

CC: cervical cancer
CG: control group
HPV: human papillomavirus
IG: intervention group
LMIC: low- and medium-income country
STAI: Spielberger State-Trait Anxiety Inventory
VIA: visual inspection with acetic acid
VILI: visual inspection with Lugol iodine
WHO: World Health Organization

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Original Paper

Analyzing Empowerment Processes Among Cancer Patients in an Online Community: A Text Mining Approach

Suzan Verberne¹, MA, PhD; Anika Batenburg², MA, PhD; Remco Sanders³, MA; Mies van Eenbergen⁴, MA; Enny Das², PhD; Mattijs S Lambooi⁵, PhD

¹Leiden Institute of Advanced Computer Science, Leiden University, Leiden, Netherlands

²Centre for Language Studies, Radboud University, Nijmegen, Netherlands

³Amsterdam School of Communication Research, University of Amsterdam, Amsterdam, Netherlands

⁴Department of Research, Netherlands Comprehensive Cancer Organization, Utrecht, Netherlands

⁵Department of Health Services Research and Health Economics, National Institute of Public Health and the Environment, Bilthoven, Netherlands

Corresponding Author:

Suzan Verberne, MA, PhD

Leiden Institute of Advanced Computer Science

Leiden University

Niels Bohrweg 1, Room 147

Leiden, 2333 CA

Netherlands

Phone: 31 715275772

Email: s.verberne@liacs.leidenuniv.nl

Abstract

Background: Peer-to-peer online support groups and the discussion forums in these groups can help patients by providing opportunities for increasing their empowerment. Most previous research on online empowerment and online social support uses qualitative methods or questionnaires to gain insight into the dynamics of online empowerment processes.

Objective: The overall goal of this study was to analyze the presence of the empowerment processes in the online peer-to-peer communication of people affected by cancer, using text mining techniques. Use of these relatively new methods enables us to study social processes such as empowerment on a large scale and with unsolicited data.

Methods: The sample consisted of 5534 messages in 1708 threads, written by 2071 users of a forum for cancer patients and their relatives. We labeled the posts in our sample with 2 types of labels: labels referring to empowerment processes and labels denoting psychological processes. The latter were identified using the Linguistic Inquiry and Word Count (LIWC) method. Both groups of labels were automatically assigned to posts. Automatic labeling of the empowerment processes was done by text classifiers trained on a manually labeled subsample. For the automatic labeling of the LIWC categories, we used the Dutch version of the LIWC consisting of a total of 66 word categories that are assigned to text based on occurrences of words in the text. After the automatic labeling with both types of labels, we investigated (1) the relationship between empowerment processes and the intensity of online participation, (2) the relationship between empowerment processes and the LIWC categories, and (3) the differences between patients with different types of cancer.

Results: The precision of the automatic labeling was 85.6%, which we considered to be sufficient for automatically labeling the complete corpus and doing further analyses on the labeled data. Overall, 62.94% (3482/5532) of the messages contained a narrative, 23.83% (1318/5532) a question, and 27.49% (1521/5532) informational support. Emotional support and references to external sources were less frequent. Users with more posts more often referred to an external source and more often provided informational support and emotional support (Kendall $\tau > 0.2$; $P < .001$) and less often shared narratives (Kendall $\tau = -0.297$; $P < .001$). A number of LIWC categories are significant predictors for the empowerment processes: words expressing assent (*ok* and *yes*) and emotional processes (expressions of feelings) are significant positive predictors for emotional support ($P = .002$). The differences between patients with different types of cancer are small.

Conclusions: Empowerment processes are associated with the intensity of online use. The relationship between linguistic analyses and empowerment processes indicates that empowerment processes can be identified from the occurrences of specific linguistic cues denoting psychological processes.

KEYWORDS

cancer; health communication; online social networking; empowerment; text mining; machine learning

Introduction

Background

Peer-to-peer online support groups and the discussion forums in these groups can help patients by providing opportunities for improving their empowerment [1-4]. We adopt our definition of empowerment from the work by Van Uden-Kraan et al [1,5]. Empowerment is a process by which patients gain mastery over their situation [1,5-7]. Previous studies found that peer-to-peer online platforms can be sources of information and emotional support, both being empowerment processes [8-13]. Online empowerment processes can facilitate empowerment outcomes outside the online environment such as being better informed, feeling more confident with the physician, and improved acceptance of the disease [1].

Most previous research on online empowerment and online social support uses qualitative methods or traditional questionnaires and interviews to gain insight into the complex dynamics of online empowerment processes [1,4,5,10,12,14]. These studies provide knowledge on empowerment processes, underlying mechanisms, and empowerment outcomes. In addition to these qualitative methods, it is valuable to systematically investigate the written communication between patients using automated text analysis methods. Automated analysis allows (1) more consistent and reproducible coding of user-generated content and (2) the scaling of the analysis to larger corpus sizes. This helps the research community to gain knowledge about general patterns and possible differences within and between patient communities. If this void is filled, it will generate knowledge about the presence of empowerment processes in online patient communities, the relation to online patient activities, and the differences between groups of patients. An important feature of this type of research is the use of unsolicited data, enabling to study natural use of language in patient communities. Within patient communities, we focus on the discussion forums (hereafter called *forums*) of people affected by cancer.

We use the qualitative work of Van Uden-Kraan et al [1,5] on the empowerment of users of online patient support groups as the basis of our study. According to these authors, there is an important difference between empowerment *processes* and empowerment *outcomes*. Empowerment processes are processes that occur on the online forum itself, manifesting as the online communication between patients (eg, as exchanging information and sharing experiences). Examples of *empowerment processes* occurring within the online environment are exchanging information, encountering emotional support, finding recognition, sharing experiences, helping others, and amusement. Empowerment outcomes occur mostly *outside the online environment*, that is, these processes help patients to feel better informed or feel more confident about their treatment (examples of empowerment outcomes). Examples of *empowerment outcomes* mentioned by patients are being better

informed; feeling confident with their physician (better shared decision making), their treatment, and their social environment; improved acceptance of the illness; increased optimism and control; and enhanced self-esteem, social well-being, and collective action. As our goal was to distill the concept of empowerment from the data that are available in online discussion forums, we focus on the *empowerment processes* in this study.

Prior Work

Defining Empowerment in Patient Support Groups

In this study, the messages posted in discussion forums were categorized based on empowerment processes defined in previous work [5,15-17]. The processes that we distinguish are listed and explained below:

1. Narrative: Patients share their disease and treatment history with their fellow users [15], often including emotions. Sometimes, they contain a reflection of one's life after the disease or have religious or spiritual references [16,17]. This empowerment process is included in this study as *narrative*.
2. Question asking: Users might ask questions (requests for information or support) to the community, to reach out for advice [5]. This empowerment process is included in our study as *question*.
3. Providing information: Informational support is provided if one shares *factual* information learned from their own experiences to help others (eg, information about cancer, the prognosis, or insurances [5]). This empowerment process is included in our study as *informational support*.
4. Providing emotional support (including esteem support, network support, affective support, and tangible support): Users can emotionally support each other, recognize and understand each other's feelings, and by doing that help one another [5,15,17]. This empowerment process is included in our study as *emotional support*.
5. Reference to external source of information: Due to the nature of the internet as an interlinked network, users can refer patients to external sources of information [16,17]. For instance, questions about how health care insurance works when receiving treatment can be answered by referring to information on an insurance company's website. This empowerment process is included in our study as *external source*.

Automated Text Analysis in Empowerment Studies

Previous text mining studies show that it is possible to identify (disease-related) topics that are discussed online. In particular, Wang et al [18] used text mining techniques to quantitatively analyze online activity related to empowerment. They found that people use online communities mainly to share their personal story and subsequently become less active in the community, in terms of posting messages. Chou et al found that

over time (2003, 2005, and 2008), the percentage of cancer survivors who were active in health-related peer-to-peer online communication remained stable [19].

Next to empowerment as an important indicator for how patients cope with their disease, the psychological processes of patients is also of importance. From expressive writing literature, it is known that when individuals go through a traumatic experience (such as being diagnosed with cancer), it is important to process this difficult experience in a *healthy* psychological manner [20]. A methodology for investigating these psychological processes through language use is the *Linguistic Inquiry and Word Count* (LIWC). The LIWC has been used in previous work to distill psychological processes from the content of online support communities, by Owen et al [21] and Lieberman [22]. Owen et al used the LIWC to analyze the content in an online coping skills training group for women with breast cancer and related the LIWC analysis to questionnaires about well-being. They found that the use of words related to cognitive processes (ie, uncertainty and logic) and affective processes (ie, anxiety, sadness, anger, and positive emotions) was significantly associated with improved emotional well-being. Lieberman analyzed the relation of 1 specific LIWC category, *insightful disclosure* (a subcategory of cognitive processes based on 116 words such as *aware*, *know*, and *realize*) to 4 outcome dimensions: depression, functional well-being, physical well-being, and breast cancer concerns. They found that for all the 4 outcome measures, insightful disclosure played a role.

In this study, we investigated the representation of LIWC categories in forum posts and the presence of empowerment processes to establish the relationship between empowerment and the psychological processes expressed. In other words, we investigated to which extent empowerment processes are co-occurring with textual indicators for psychological processes. We used the Dutch version of the LIWC, which was developed by Zijlstra et al [23].

Goals and Research Questions

The goal of this study was to quantify the presence of empowerment processes in the online forum discussions by people affected by cancer, using automated text analysis techniques.

We address the following research questions:

1. To what extent is the intensity of online participation correlated to indicators of empowerment processes in user-generated content on an online cancer patient discussion forum?
2. Are different aspects of empowerment related to different types of psychological processes, indicated by word use?
3. What are the differences in frequencies of empowerment patterns for patients with different forms of cancer?

Methods

Data Collection

We obtained a sample of the discussion forum of the Dutch online community Kanker.nl. Kanker.nl is an initiative of the Dutch Cancer Society, the Netherlands Comprehensive Cancer

Organisation, and the Dutch Federation of Cancer Patient Organizations. These 3 major cancer organizations have joined forces in 2012 to provide a single platform where people who have or have had cancer and their loved ones can find reliable medical and health information and exchange experiential knowledge about cancer. The discussion forum is 1 of the 3 main pillars of kanker.nl, together with a library and a collection of blogs. The forum sample consisted of all published posts at the kanker.nl discussion forum up until the start of this research project (November 23, 2016).

Data Coding and Annotation

We labeled the posts in our sample with 2 types of labels: labels referring to empowerment processes and labels denoting LIWC categories. Both groups of labels were automatically assigned to the posts. Automatic labeling of the empowerment processes was done by text classifiers trained on a manually labeled subsample. For the automatic labeling of the LIWC categories, we used the Dutch version of the LIWC consisting of a total of 66 word categories that are assigned to text based on occurrences of words in the text. Both forms of labeling are described below in more detail. After the automatic labeling with both types of labels, we investigated (1) the relationship between empowerment processes and the intensity of online participation, (2) the relationship between empowerment processes and the LIWC categories, and (3) the differences between patients with different types of cancer.

Labeling Forum Posts With Empowerment Processes

Selecting Empowerment Constructs for Manual Coding

To answer our research questions, we needed a forum sample with annotated empowerment processes. We developed a coding scheme consisting of the 5 previously listed empowerment processes derived from the literature that are relevant in the present context. We decided to define external source as a separate category besides informational support, because a reference to an external source can also be posted independent of a question, for example, when a user points to an interesting publication in the media. Posts containing these references often do not provide information in the post texts. Thus, we included in our study the following 5 empowerment constructs that occur in our forum sample: narrative, question, informational support, emotional support, and external source. In the remainder of this paper, we refer to these 5 categories as empowerment constructs. We first created a sample of manually labeled posts with this coding scheme. Using the labeled data, we then trained and evaluated classifiers with which we automatically labeled all posts in the corpus. This allowed us to quantitatively analyze empowerment constructs in the forum on a large scale.

This process is discussed step by step in the next 4 subsections.

Manual Annotation

We randomly selected 2051 forum posts from the Kanker.nl data to be manually annotated. From these 2051, 114 were coded by 2 raters to compute the reliability of the data in terms of interrater agreement. We used the Radboud Research participation system to recruit students as raters and additionally hired 5 paid student assistants. We created an online tool to

annotate the data [24]. In our annotation scheme, 1 post can have multiple empowerment constructs; thus, the posts are annotated with respect to each of the empowerment constructs as present in the post (*yes*) or not (*no*). The annotators were allowed to leave the answer to a question undecided (select neither *yes* nor *no*) if they were unsure about the presence of the empowerment construct.

Classifier Learning

As a post can be labeled with more than 1 empowerment construct, we trained 1 binary classifier per empowerment construct, with the labels being *yes* (construct is present in the post) and *no* (construct is not present in the post). As features, we used all words from the post, after we lowercased the text and removed punctuation. One exception is that we replaced the ? by the token `question_mark`. We did not remove stop words. Stop words are highly frequent words, typically function words (eg, *as*, *of*, *with*, and *the*), which are commonly removed for text categorization into topical categories because they bear little content. We do not remove stop words because we expect function words such as pronouns to play a role in the expression of empowerment constructs.

We ignored all the empty fields (the annotator chose neither *yes* nor *no*), which cause the number of example items to differ per construct. To avoid overfitting, we split the data into 2 partitions: 80% for training the classifiers and 20% for evaluating them. Thus, for each construct, we split the data in a training set (80% of the examples) and a held-out test set (the remaining 20%). From the 114 items that were labeled by 2 annotators, we included in the training set only the items where the raters agreed to avoid having conflicting training data. In the test set, we did include the items where the raters did not agree (value for 1 of the 2 raters), because the quality of the classifier would be overestimated if only the agreed (clear) instances were included.

We used scikit-learn in Python to train and validate the classifiers, 1 for every empowerment construct [25]. We experimented with 6 different classification methods and decided on the use of linear support vector classification (SVC) [26] because it gave the best classification results in terms of precision, recall, and F1, which is the harmonic mean of precision and recall.

Linear SVC has 1 hyperparameter (*c*). We used 25% of the training set for optimizing *c*, training on 75% of the train set, and evaluating different values of *c* on the remaining 25%. We experimented with a grid ranging from $c=10^{-3}$ to $c=10^3$ in steps of $\times 10$, as suggested in the documentation of scikit-learn [27]. We found $c=1.0$ to be the optimal value in terms of F1-score (averaged over the 5 binary classifiers for the empowerment constructs); thus, we used $c=1.0$ when training linear SVC on the full training set (80% of all labeled data), evaluating on the held-out test set (20% of all labeled data).

Automatically Labeling the Corpus With Empowerment Constructs

Provided that the precision of the classifiers was sufficient (>80%), we trained SVC classifiers on all manually labeled dataset and applied them to all unlabeled posts in the corpus.

SVC has a natural cutoff for assigning a label in binary classification: if the predicted value is larger than 0, the label *yes* is assigned, and if the predicted value is smaller than 0, the label *no* is assigned. This way, we automatically labeled the complete corpus with empowerment constructs. The 5 classifiers for the empowerment constructs operate independently of each other, meaning that each message is labeled with 0 or more empowerment constructs.

Labeling Forum Posts With Linguistic Inquiry and Word Count Categories

LIWC analyzes texts for indicators of psychological processes [28]. These indicators are occurrences of words. The LIWC dictionary defines which words are indicators for which linguistic or psychological category. The linguistic LIWC categories are categories such as first-person singular pronouns and past tense verbs. The psychological LIWC categories are categories such as positive emotions, negative emotions, and anxiety. Examples of indicator words are *me* for first-person singular pronouns and *pain* and *fear* for negative emotions. One limitation of this approach is that 1 word can have multiple meanings, depending on its context. For example, the word *well* could occur in positive (*feeling well*) and neutral contexts (*as well as*), and it could even be a noun (a source of water).

We used the Dutch version of the LIWC consisting of a total of 66 word categories that belong to 4 overarching groups of categories: (1) standard linguistic dimensions (eg, personal pronouns, first-person singular pronouns, and past tense verbs), (2) psychological processes (eg, positive emotions and anxiety), (3) relativity (time and space), and (4) personal concerns (eg, work, money, and religion). The categories are organized hierarchically. For example, the main category *cognitive processes* under *psychological processes* has several subcategories, among which *insightful disclosure*, *inclusive*, and *exclusive*. Due to this hierarchy, a word can belong to more than 1 category. For example, the word *ik* (*I*) occurs in the category *pronoun* as well as the category *1st-person singular*.

A forum post can have more than 1 LIWC category assigned to it, based on the words occurring in the post.

Data Analysis

Relating Empowerment Processes to the Intensity of Online Participation (Research Question 1)

We investigated the relationship between each of the empowerment constructs in the automatically labeled forum and the intensity of online participation. The most straightforward metric for intensity of participation is the number of messages that a member has posted. In addition, we also considered the average post length to be of relevance: a user who posted only short messages might be less involved in the community than a user who posts more lengthy messages. We also took into account 2 measures for a user's social relations in the community: the number of contacts and the number of *incoming* contacts (the number of users who follow this user). The latter is an indication of popularity. Thus, we related empowerment processes to 4 quantitative user activity characteristics: number of posts, average post length, number of contacts, and popularity.

To quantify the relations, we converted the label counts for the empowerment constructs per user to relative label counts, by dividing the number of occurrences of a label for the user by the total number of posts by the user. For example, a user might have 8 posts, with the following relative label counts of the 5 empowerment construct labels: narrative 0.5, question 0.125, informational support 0.0, emotional support 0.75, and external source 0.5.

We then computed the correlation in terms of Kendall τ between the user characteristic (eg, the number of posts) and the relative label count (eg, 0.125 for *question*).

Relating Empowerment Processes to Linguistic Inquiry and Word Count Categories (Research Question 2)

Once we completely annotated the corpus with empowerment constructs and with the LIWC categories, we investigated the correlations between the 2 types of variables. To that end, we created a table with for each post (N=5532) 5 columns. Each column denotes the presence (1 or 0) of each of the empowerment constructs (narrative, question, informational support, emotional support, and external source) according to the automatic classifiers and 20 columns for the relative frequencies of the 20 most frequent LIWC categories. The relative frequency of a LIWC category for a post is defined as the numbers of occurrences of all words from the category in the post divided by the total number of words in the post.

We then performed 5 separate logistic regression analyses (in *R*), 1 for each empowerment construct. Thus, in each analysis, the presence of an empowerment construct (true or false) is the dependent variable and the 20 LIWC categories are the independent variables. In this way, we can investigate which LIWC categories contribute to which empowerment variables. From the resulting regression models, we removed all variables with negative coefficients and all variables that are not significantly contributing to the model ($P > .01$).

Differences in Empowerment Patterns for Different Types of Cancer (Research Question 3)

Previous research has suggested that patients with different types of diseases have different online social support needs [29]. We investigated the differences in empowerment processes for patients with different cancer types by investigating the occurrences of empowerment processes for the 5 most occurring cancer types in our forum sample: breast cancer, lung cancer, colorectal cancer, gynecological cancer, and prostate cancer.

Results

Collected Sample

The collected sample comprises 5534 posts in 1708 threads by 2071 unique users, posted between April 17, 2013, and November 23, 2016. The threads are organized in 38 categories. The forum does not focus on 1 particular cancer type; over 15 cancer types are represented, the largest being breast cancer (760 posts), lung cancer (423 posts), and colorectal cancer (389 posts). In total, 1356 authors only posted 1 post and 33 posted

over 20 posts. In the sample, user names were replaced by unique keys. There was no identifying information of the forum users available to the researchers during the analyses.

Data Quality

Interrater Agreement

We report interrater agreement for the subsample that was annotated by 2 raters. The absolute agreement is defined as the number of items for which both raters agree divided by the number of items for which both raters selected a value (yes or no). Cohen kappa weighs the absolute agreement with the *chance agreement* based on the number of *yes* and *no* values for the empowerment constructs. For data that have a strong class imbalance, Cohen kappa is low, because the chance agreement is high (if both raters almost always select *no*, then there is a high chance that they both assigned *no* for a given item). A kappa value higher than 0.4 indicates moderate agreement; a kappa value higher than 0.6 indicates substantial agreement.

Table 1 shows the results for the empowerment constructs. The table shows that the interrater agreement is the lowest for informational support. This might be because this construct has the least explicit textual indicators. For the other 4 constructs, the agreement is substantial (Cohen kappa > 0.6).

Classifier Evaluation

We report precision and recall for the *yes* categories for each construct as evaluation measures:

- Given construct X, *precision* is the percentage of posts automatically labeled with X=yes that also have the label X=yes in the human-labeled data (true positives/[true positives+false positives]). Precision gives the proportion of the automatically assigned labels that are correct.
- Given construct X, *recall* is the percentage of posts with the label X=yes in the human-labeled data that were also automatically been labeled with X=yes (true positives/[true positives+false negatives]). Recall gives the proportion of true labels has been found automatically.

The results are provided in Table 2. The overall results are good. The average precision over constructs is 85.6%, which means that of the 100 assigned labels, 14 are incorrect (averaged over the constructs). The results also show that some constructs are easier to classify than others, but precision scores are all between 75% and 93%. The recall scores are lower (except for narrative); informational support and external source are missed quite often by the classifiers. Considering the goal of the automatic labeling (analysis of the labeled corpus), we consider precision to be more important than recall—it is more problematic to assign wrong labels than to miss labels because wrongly assigned labels might lead to unjustified conclusions. Moreover, the classifiers trained on all labeled data (instead of the 80% training set) are likely to be a bit better because they have more examples available. Therefore, we consider the quality of the classifiers sufficient for labeling the complete corpus.

Table 1. Interrater agreement results for the empowerment constructs

Empowerment construct	Number of items ^a	Measured agreement, %	Cohen kappa
Narrative	112	0.86	0.71
Question	58	0.90	0.79
Informational support	65	0.72	0.40
Emotional support	57	0.93	0.65
External source	65	0.86	0.68

^aRecall that the number of example items differs per construct because we ignore all the empty fields (the annotator chose neither yes nor no).

Table 2. Overall evaluation of the classifiers for the empowerment constructs, in terms of precision, recall, and F1 (the harmonic mean of precision and recall).

Empowerment construct	Precision, %	Recall, %	F1, %
Narrative	89.2	93.2	91.1
Question	87.2	62.4	72.7
Informational support	75.0	52.0	61.4
Emotional support	83.6	65.7	73.6
External source	93.0	55.9	69.8
Average over constructs	85.6	65.8	73.7

Statistics of the Automatically Labeled Corpus

On average, messages in the corpus were assigned 1.4 labels. [Table 3](#) shows the distribution of empowerment constructs in the automatically labeled corpus.

An example message text for each empowerment construct is listed below:

- Narrative: “My husband has invasive bladder cancer not operable. Now has a urine stoma that was OK to live with. But recently he got 2 kidney drains that constantly leak.”
- Question: “How are you feeling about your scar after the operation? Are you embarrassed or do not care? I’m curious about your comments.”
- Informational support: “After radiotherapy in the head and neck area there is a good chance that the salivary glands are also blasted, giving you a drier mouth and also a different chemical composition of the saliva.”
- Emotional support: “What a horribly scary time your mother (and all of you) is going through! Terrible to always be in

suspense whether or not the chemotherapy has done its work, very recognizable!”

- External source: “I saw this movie from SchoolTV via NLNet (patient association for people with lymphedema). It gives a clear explanation about lymphedema. Useful for patients themselves, or to show others if you find it difficult to explain (or do not feel like it ;-).”

Results for Research Question 1, Empowerment, and Intensity of Online Activity

[Table 4](#) shows the correlations in terms of Kendall τ between the user characteristics and the relative label count for each of the empowerment constructs. The correlations that are not significant ($P > .05$) are not shown.

The correlations indicate the number of posts is the strongest indicator of the empowerment constructs: users with more posts more often refer to an external source and provide informational support and emotional support (all correlations above 0.2) and less often share narratives (negative correlation). The relation with asking questions is weak (below 0.1).

Table 3. Distribution of assigned empowerment constructs in the automatically labeled corpus (N=5532). Note that the percentages do not sum to 100% because a post can have more than 1 label assigned to it.

Empowerment construct	Frequency of posts, n (%)
Narrative	3482 (62.94%)
Question	1318 (23.83%)
Informational support	1521 (27.49%)
Emotional support	855 (15.46%)
External source	753 (13.61%)

Table 4. The significant correlations (in terms of Kendall τ) between the frequency of an empowerment construct for a user and 4 user variables. In all cases, N=2071 (number of users who posted at least one message). Correlations with $P > .05$ are not shown. P values are shown for correlations with a significance of $.001 < P < .05$.

Empowerment construct	Correlation with user variables, Kendall τ			
	Number of posts	Average post length	Number of contacts	Popularity
Narrative	-0.297 ^a	0.232 ^a	-0.126 ^a	-0.117 ^a
Question	0.065 ^a	-0.105 ^a	— ^b	—
Informational support	0.204 ^a	0.072 ^a	0.086 ^a	0.090 ^a
Emotional support	0.232 ^a	0.037 ^c	0.168 ^a	0.168 ^a
External source	0.255 ^a	—	0.149 ^a	0.160 ^a

^a $P < .001$.

^bCorrelations with $P > .05$ are not shown.

^c $P = .03$

Results for Research Question 2, Empowerment, and Linguistic Patterns

Table 5 shows the results from the logistic regression analyses, predicting the presence of an empowerment construct from the relative frequencies of the 20 most frequent LIWC categories. The Dutch LIWC categories and the example words from Zijlstra et al [23] were translated here for the reader's convenience.

The table shows that a number of LIWC categories have significant correlations with the empowerment constructs. Not all correlations are interesting and easy to interpret. For example, questions contain many pronouns, and informational support is correlated with expression of leisure. Others are more interesting: narratives contain especially first-person singular and third-person pronouns and also correlate with the expression of religion. Emotional support contains more second-person

references and words expressing assent (eg, *ok* and *yes*) and emotional processes (expressions of feelings). External sources also contain more second-person references and correlate with cognitive processes (eg, knowing and thinking).

Results for Research Question 3: Differences Between Patients With Different Cancer Types

We investigated the differences between patients with different cancer types in our data by separately counting the occurrences of empowerment processes for the 5 most occurring cancer types in our forum sample: breast cancer, lung cancer, colorectal cancer, gynecological cancer, and prostate cancer. The resulting distributions are shown in Figure 1. The figure shows that although most relative frequencies are similar between the cancer types, patients with lung cancer ask more questions and provide less emotional support than patients with other common cancer types.

Table 5. Estimated regression coefficients for the Linguistic Inquiry and Word Count categories that are significant ($P < .01$) positive predictors for predicting the presence of an empowerment construct. P values are shown for predictors with a significance of .001; $P < .01$.

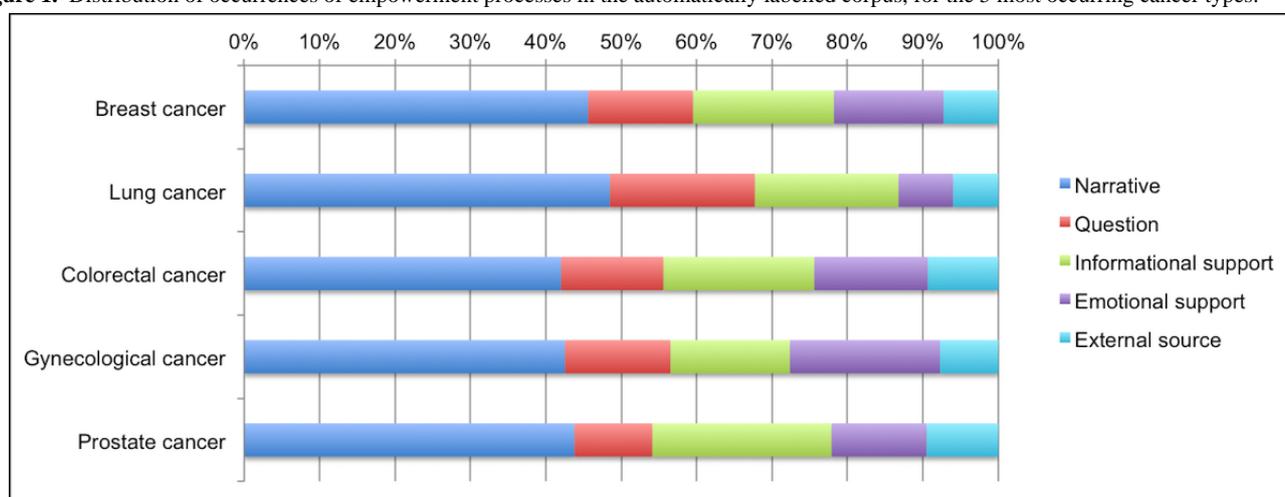
Linguistic Inquiry and Word Count category and subcategory (with 3 example words per subcategory)	Estimated regression coefficients				
	Narrative	Question	Informational support	Emotional support	External source
I Standard linguistic dimensions					
Total pronouns (I, you, our)	— ^a	3.11 ^b	—	—	—
1st person singular (I, me, my)	5.43 ^b	—	—	—	—
Total 2nd person (you, your)	—	—	3.16 ^b	4.15 ^b	4.67 ^b
Total 3rd person (she, he, them)	4.94 ^b	—	2.19 ^b	—	—
Negations (no, never, not)	1.93 ^b	—	1.13 ^c	—	—
Assent (yes, OK)	—	—	—	2.04 ^c	—
II Psychological processes					
Emotional processes (happy, sad, miserable)	—	—	—	1.35 ^b	—
Cognitive processes (know, cause, think)	—	—	—	—	1.27 ^b
Senses and perceptual processes (see, feel, hear)	—	0.85 ^b	—	—	—
Social processes (communicate, share, help)	1.69 ^b	0.45 ^c	—	—	—
Relativity					
Time (summer, previously, as soon as)	0.79 ^c	—	—	—	—
Space (close, place, north)	—	—	—	—	1.00 ^d
Personal affairs					
Leisure (cycling, fitness, training)	—	—	3.90 ^b	—	—
Religion (baptism, prayer, catholic)	2.77 ^b	1.09 ^b	—	—	—

^aNot applicable, as P values are only shown for predictors with a significance of $.001 < P < .01$.

^b $P < .001$.

^c $P = .002$.

^d $P = .009$.

Figure 1. Distribution of occurrences of empowerment processes in the automatically labelled corpus, for the 5 most occurring cancer types.

Discussion

Principal Findings

In this paper, we presented methods to analyze empowerment processes in an online discussion forum in a structured, largely automatic way. We implemented and evaluated 2 automated methods for analyzing the content of an online cancer patient community: (1) word-based text classifiers for coding forum posts with empowerment constructs, using a manually coded subsample as training data, and (2) LIWC, an unsupervised (dictionary-based) analysis technique that was designed to distill psychological processes about user-generated content.

This paper shows that the theoretical construct patient empowerment can be operationalized and measured in online communication using automatic classifiers trained on a sample of manually labeled data. This implies that other theoretical constructs (in health care) on the patient level, such as health literacy or experienced quality of care, and care concepts related to governance, such as integrated care or access to health care, might be studied on online discussion forums if researchers are interested in the patients' perspective. When these types of analyses become further refined, they can be a cost-efficient way for policy makers to take account of the issues that are relevant in respective patient groups when setting the agenda for change or initiating improvements in health care.

In the remainder of this section, we answer our research questions.

Research Question 1. To What Extent Is the Intensity of Online Participation Correlated to Indicators of Empowerment From User-Generated Content on an Online Cancer Patient Discussion Forum?

We succeeded in distilling different types of empowerment processes from a peer-to-peer cancer patient forum. It was possible to automatically annotate a corpus of over 5500 messages on the message-level, by training a classifier on a smaller sample of manually created example data.

We observed empowerment constructs in the online conversations, and based on the linguistic associations, we conclude that online peer to peer contact fulfills the need for personal contact with others in a similar situation. Overall, sharing of personal stories with peers (narrative) was the most frequently observed process. Other empowerment processes we studied were providing peers with informational or emotional support, answering their questions, or referring them to external sources. Users that are more active online in terms of number of posts and number of contacts more often guide other users to external sources of information and provide more support than less active users.

Research Question 2. Are Different Aspects of Empowerment Related to Different Types of Psychological Processes, Indicated by Linguistic Patterns?

The combination of LIWC with the empowerment constructs has yielded a number of new insights. We found that the narrative is an important empowerment construct and that this

is a means for participants to relate to each other and the context. Being ill requires redefining of one's position to the rest of the world and finding a way to deal with this new situation [11]. In this study, this appears to take the form of talking about the relationships that the patients have with others around them. In terms of linguistic constructs, we observed that personal pronouns are related to empowerment constructs, indicating that online empowerment processes strongly fill a need to relate the personal situation to the context. The narrative is related to both the first-person and third-person pronoun, indicating that sharing a narrative is a means to share personal experience and to link this experience to others. It could be indicating that sharing a personal story is a means to reach out to others.

Research Question 3. What Are the Differences in Frequencies of Empowerment Patterns for Patients With Different Types of Cancer?

We found no striking differences between the frequencies of empowerment patterns for patients with different types of cancer: Most relative frequencies are similar between the cancer types; the only category that is slightly different from the others is the group of patients with lung cancer. They ask more questions and provide less emotional support than patients with other common cancer types. One aspect that might play a role here is that of these cancer types, lung cancer has the worst prognosis: 30% of the patients diagnosed with lung cancer are still alive 3 years after the diagnosis, as opposed to 70%-95% for the other cancer types.

Comparison With Prior Work

Most of the previous studies concerning online empowerment and online social support use qualitative methods to study online content [6,14-17] or established methods such as questionnaires [3,18,19]. These studies provide knowledge on empowerment processes, the underlying mechanisms, and the empowerment outcomes. The dominant role of narratives as empowerment process in patient support groups has been found in previous studies as well [30]. Previous text mining studies show that it is possible to identify (disease-related) topics that are discussed online. Birnbaum et al [28] identified self-report of schizophrenia from Twitter messages. Nzali et al [21] compared results from text mining techniques applied on social media with results from self-administered questionnaires and found good correspondence between detected topics on social media and topics in the questionnaires.

Our unique methodological contributions compared with previous studies are twofold: (1) we are the first to successfully apply text classification to the task of labeling forum posts with empowerment constructs and (2) we show the correlations between LIWC categories and empowerment processes in forum posts.

The combination of LIWC with the empowerment processes confirmed a number of findings from previous works. We found, for instance, that the narrative is an important empowerment process. Being ill requires redefining of one's position to the rest of the world and finding a way to deal with this new situation [12]. In this study, this process appears in the form of talking about the relationships that the patients have with others

around them, as the LIWC categories indicating relationships are prominently present in our analyses.

With respect to the development of user activity over time, Wang et al [18] showed that the participation rate in online communities dropped steeply in a short time span after a user's registration and that most participation was related to the narrative of the user's own situation. We found similar patterns in the relationship between empowerment processes and user activity, suggesting that new members of a community mainly share their own stories, whereas more experienced and active members provide social or informational support more frequently. This finding is in line with previous research. Coulson [17] found that older and more active users often take a more senior role in which they respond to questions of new users and thereby provide hope and encouragement (ie, emotional support). As Lasker et al [31] puts it: "posts from more 'senior' peer experts [long-active members] may provide role models for newer members". On the topic of narratives, Wang et al [32] showed the important role of narratives, the sharing of ones' status in online communities. They found that narratives can be used to both elicit (emotional) responses by using the narratives as a thread opening as well as a way to respond to questions from other users.

These findings suggest that persistent and active support group participation might contribute to experiential and informational empowerment, a conclusion that fits with the findings from a study on the relationship between online support group participation and emotional well-being over time [33]. Results from that study showed that being active online might especially benefit patients who do not actively approach their emotions naturally, suggesting that peer-to-peer forums might *teach* patients how to deal with illness.

Limitations

The findings presented in this paper are subject to some limitations. The forum posts that we included contained for obvious reasons only utterances from patients that are present online. The estimations of percentages of active and nonactive online group members differ from 1% to 10% [34], to a quarter active users [5], to about half of the group members [35,36]. It has been found that posters report higher levels of empowerment than lurkers, even though lurkers also benefit from reading the forum texts [5,35,36].

This study used data from a general cancer patient forum, and therefore, we involve a more diverse user group than previous studies addressing groups of patients having 1 type of cancer (eg, breast cancer [21]). On the other hand, our study was limited to patients who actively participate in an online discussion forum. These patients are usually younger and higher educated

than the average of the population [37]. This might imply that we studied the group of patients who are more empowered, more actively seeking online information, and more actively interacting with peers.

Empowerment is a much-used term, with many different definitions [38,39]. We limit our study to the analysis of empowerment *processes*, as they are likely to take place on the internet, whereas the empowerment *outcomes* will take place in interaction with physicians and insurers. Previous research found that patients experience both processes and outcomes, and this might indicate that both are related [12,40]. We found that most often forum users relate to their personal story, to exchange personal experiences and relate emotionally and socially to one another. References to external sources also occur frequently. This means that the information aspects of empowerment also take place in other parts of the internet apart from the forum itself.

In addition to that, this study focused on patients with cancer. Even though we assumed that the empowerment processes are similar between people who experience life-threatening diseases, more research needs to confirm whether the results in this study are generalizable to patients with other diseases.

We also acknowledge limitations of the methods that we applied for the analysis of the forum sample: the limitation of text classifiers is that they need training data (manual coding)—the more training data, the better the quality of the classifier. Hence, text classification is not a method that can be applied without any supervision. A known limitation of the LIWC is that it is based on word occurrences. This means that it does not take combinations and contexts of words into account, which are particularly relevant for negations (ie, *not*) and ambiguous words (ie, *well*).

Conclusions

In this paper, we studied empowerment processes in online peer-to-peer communication and showed that different empowerment processes are associated with intensity of online use. The combination of linguistic analyses with measurement of empowerment provided indications that online patient empowerment helps users to relate to peers and redefine their situation in addition to giving informational and emotional support.

We recommend the further use of text mining in future work addressing the online activities of patients, because it enables the analysis of large amounts of unsolicited data. Our study showed that quantitative content analysis can give interesting insights, with respect to empowerment, language use, and psychological processes.

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Authors' Contributions

AB and RS provided the conceptual framework of empowerment, coding scheme, and relation to prior work. SV conducted the text mining experiments and analyses. MvE provided expert knowledge on the content and use of patient communities. ED provided expertise on health communication and methodology in communication sciences. ML coordinated the project and the setup of the paper. Most text of the paper was written by SV and ML.

Conflicts of Interest

None declared.

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Abbreviations

LIWC: Linguistic Inquiry and Word Count

SVC: support vector classification

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Original Paper

When Chatbots Meet Patients: One-Year Prospective Study of Conversations Between Patients With Breast Cancer and a Chatbot

Benjamin Chaix^{1,2,3}, MSc; Jean-Emmanuel Bibault⁴, MD, PhD; Arthur Pienkowski³, PharmD; Guillaume Delamon³, PharmD; Arthur Guillemassé³, MSc; Pierre Nectoux³, MSc; Benoît Brouard³, PharmD

¹Department of Otolaryngology Head and Neck Surgery, University Hospital Gui de Chauliac, Montpellier, France

²Université Montpellier I, Montpellier, France

³Wefight, Brain & Spine Institute, Hospital Pitié-Salpêtrière, Paris, France

⁴Department of Radiation Oncology, European Hospital Georges Pompidou, Assistance Publique-Hôpitaux de Paris, Paris, France

Corresponding Author:

Benjamin Chaix, MSc

Department of Otolaryngology Head and Neck Surgery, University Hospital Gui de Chauliac

80 avenue Augustin Fliche

Montpellier, 34295

France

Phone: 33 684157321

Email: b-chaix@chu-montpellier.fr

Abstract

Background: A chatbot is a software that interacts with users by simulating a human conversation through text or voice via smartphones or computers. It could be a solution to follow up with patients during their disease while saving time for health care providers.

Objective: The aim of this study was to evaluate one year of conversations between patients with breast cancer and a chatbot.

Methods: Wefight Inc designed a chatbot (Vik) to empower patients with breast cancer and their relatives. Vik responds to the fears and concerns of patients with breast cancer using personalized insights through text messages. We conducted a prospective study by analyzing the users' and patients' data, their usage duration, their interest in the various educational contents proposed, and their level of interactivity. Patients were women with breast cancer or under remission.

Results: A total of 4737 patients were included. Results showed that an average of 132,970 messages exchanged per month was observed between patients and the chatbot, Vik. Thus, we calculated the average medication adherence rate over 4 weeks by using a prescription reminder function, and we showed that the more the patients used the chatbot, the more adherent they were. Patients regularly left positive comments and recommended Vik to their friends. The overall satisfaction was 93.95% (900/958). When asked what Vik meant to them and what Vik brought them, 88.00% (943/958) said that Vik provided them with support and helped them track their treatment effectively.

Conclusions: We demonstrated that it is possible to obtain support through a chatbot since Vik improved the medication adherence rate of patients with breast cancer.

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KEYWORDS

artificial intelligence; breast cancer; mobile phone; patient-reported outcomes; symptom management; chatbot; conversational agent

Introduction

Background

According to the World Health Organization, improved adherence would have more impact in terms of global health

than the development of new drugs [1]. In the field of cancer, noncompliance is a consequence of not only the toxicity of anticancer drugs but also the nature of new treatments: oral chemotherapies (50% of chemotherapies in 2020) [2,3] shift the responsibility for taking treatment from caregivers to

patients. Finally, the number of cancer patients is increasing exponentially (32.6 million and +17 million per year) [4], and this disease is becoming chronic (50% of patients are alive after 5 years) [5]. Most cancer patients are treated at home and have to manage their treatment alone.

On the other side, information technology is on the rise and is changing the way patients and physicians interact together [6,7]. Technology-based self-service channels [8] and digital health interventions [9] have the potential to support patients all day long and connect them to medical staff thanks to smartphone apps or wearable devices [10].

A chat is a software that interact with users by using a decision map, an algorithm, without human back-end intervention. Chatbots could be a solution to follow up with patients during their treatments and save time for health care providers. They create a dynamic interaction, are easy to use, and simulate a human conversation through text or voice via smartphones or computers.

Chatbots' conversational abilities quickly improve [11] and public interest grows [12]. Now, patients can interact to describe their symptoms, after which advice and information are given in return by chatbots. As an example, patients can use chatbots to check symptoms and monitor their mental health [13,14]. Ly et al [15] assessed the effectiveness and adherence of a smartphone app that delivers strategies used in positive psychology to improve happiness and reduce negative symptoms.

Objectives

In this study, we have aimed to determine what the interactions are when a human chats with a chat robot. Lucas et al [16] show that people may feel more comfortable disclosing personal information to a chatbot compared with a person as chatbots do not think or form judgments of their own. We suggest that health chatbots should be evaluated so that they can be an integral part of the doctor/patient relationship. Indeed, very few articles deal with chatbots in general and even fewer deal with health care chatbots and their interaction with humans. As such, we think that chatbots are an effective way to tackle the problems patients with breast cancer are facing. To accomplish this, Wefight Inc designed a chatbot named Vik to empower patients with breast cancer and their relatives via personalized text messages. Vik's answers are very diverse, and patients can find all the relevant, quality-checked medical information they need. Vik informs about breast cancer and its epidemiology, treatments and their side effects, and the quality of life, with information about sport, fertility, sexuality, and diet. More practical information, such as reimbursement and patients' rights, is also available. The goal is to improve the quality of life of the patients with breast cancer.

Methods

Study Design

In this study, we analyzed the conversations between patients with breast cancer and the chatbot, Vik, and the way they are using it. We also observed whether a chatbot like Vik could

reinforce medication adherence by using a prescription reminder through the conversation.

Vik is available for free on the Web or from any smartphone, iOS or Android, on Messenger [17]. Vik's platform is designed to address current and future patients' needs. Its architecture is composed of several technological parts, allowing a fine analysis of the questions posed by the patients and an adapted treatment of the answer. To understand the users' messages and send personalized answers, the conversation goes through 3 steps: the first step analyzes the sentence and identifies intents and entities, using machine learning. The second stage activates modules according to the intents and entities detected by the first stage, and the third stage aggregates the answers of all activated modules to build the answer sent to the user and saves the conversation on the user's profile.

The data collected are anonymized and then hosted by Wefight Inc. In accordance with the French and European laws on information technology and civil liberties (Commission Nationale Informatique et Libertés and Règlement Général pour la Protection des Données), users have a right of use at their disposal to verify its accuracy and, if necessary, to correct, complete, and update it. They also have a right to object to their use and a right to delete these data. General conditions of use are displayed and explained very clearly; they must be accepted before using Vik.

Intervention

To analyze the number of conversations between patients and Vik, we used the data collected since October 2017 to October 2018. We conducted a prospective study by analyzing the users' data, their usage time, their interest in the various themes proposed, and their level of interactivity.

To analyze the way patients are using Vik, users were asked questions from a survey on a weekly basis since May 2018. These questions concerned various fields (health, food, treatments, and life with the disease; Table 1). The *question of the day* is a subscription from the user who will receive from 1 to 2 times per week an open or a closed question. For open-ended questions, the user had the possibility to read the answers of other community members and to *like* these answers by clicking on *agree* or *disagree*. The sum of these *agree* and *disagree* was defined as the total of a user's interaction per question of the day.

Finally, we evaluated the general appreciation and level of confidence toward the chatbot with a survey (Table 1).

To evaluate the medication adherence rate of patients using Vik, we implemented a medication reminder function. The user can activate this feature at any time by asking the chatbot, for example, "remind me to take my tamoxifen every day at 4 pm." The chatbot will then send this person a reminder to take the medication with 3 possible choices for the user: say "yes I took it," "no I didn't take it," or "send me the message in 15 minutes." We then measured compliance by saving patient responses. The statistical analyses were done using the R software (R Foundation for Statistical Computing). The Student *t* test was used with a 95% CI.

Table 1. Examples of questions of the day and questions used for the satisfaction survey.

Thematics	Open-ended questions and closed questions
Diet	What has been the impact of cancer and your treatment on your diet?
Sexuality	Sexuality is often impacted by cancer, what about you? How did you handle it?
Announcement	How did you manage to tell your loved ones, especially your children, about cancer or metastases?
Information	Are you sufficiently informed about the treatments, their benefits, their side effects?
Screening	In your opinion, are breast cancer screening campaigns sufficient?
Clinical trial	Are you currently in a clinical trial?
Satisfaction survey	Do you trust my answers? What is your satisfaction when you chat with me? In your opinion, what could I do to improve myself and be even more useful to you (medical information, functionalities...)? Do you recommend me to your friends? What do I represent or bring to you?

Results

Number of Interactions Between Patients and Vik

A total sample of 4737 patients chatted with Vik, (mean age 48 years), 88.90% were female (4211/4737) and 11.10% were male (526/4737; [Table 2](#)). Finally, we included 958 patients who answered the various questions.

An average of 132,970 messages exchanged per month was observed between the patients and Vik. We defined the number of messages (a dialogue bubble corresponding to a message) exchanged as the total number of messages received and sent by Vik.

Both patients and relatives used the different features available. They used either direct questions or the answer buttons provided by Vik ([Table 3](#)).

We calculated the retention rate for cohorts of patients who started using Vik between February 2018 and October 2018 (n=958). Before that date, we did not have the technological means to measure it. The retention rate is computed for a cohort composed of users who started talking with Vik the same month. It is calculated for each month following the month of arrival of the cohort then. For a given month and a given cohort, the retention rate is the percentage of users in the cohort who were active during the month. A user is considered active from the moment he sent at least one message during over the period. The user retention rate is shown in [Table 4](#). This rate decreases over time, but we observed that some users still chatted with Vik after 8 months.

The Way Patients Used Vik

The total number of responses to the various questions of the day kept increasing. On average, 60 patients answered those

questions: 55.1 open-ended questions and 77.5 closed questions. The total number of interactions averaged 147 per question (for open-ended questions), which makes 2.7 interactions per person per question. User responses for open-ended questions averaged 21.5 words per response or 114.3 characters/response. There were significant differences in the average number of words for each question, according to the themes addressed. We observed a decreasing total number of interactions per question, whereas the average number of words per question increased. The total number of interactions as a function of the average number of words per response does not show a correlation between the 2 factors.

Both total answers and the average number of words per response seemed to increase similarly. Overall, satisfaction with the use of Vik was 93.95% (900/958). Patients regularly left positive comments and recommended Vik to their friends. When we asked them what Vik meant to them and what Vik brought them, 88.00% (843/958) said that Vik provided them with support and helped them follow their treatment effectively ([Table 5](#)).

The Medication Adherence Rate of Patients Using Vik

The number of people using the treatment reminder function was 61. We calculated the average compliance for over 5 weeks (n=33). During week 1, 51% (17/33) of the patients using the feature clicked on the reminder button. We measured this metric over the next 4 weeks.

[Table 6](#) shows that the more the patients chatted with Vik, the more observant they were when they used the feature. The average compliance of patients using the medication reminder feature improved by more than 20% ($P=.04$).

Table 2. Demographic data.

Characteristics	Bracket 1	Bracket 2	Bracket 3	Bracket 4	Bracket 5	Bracket 6	Bracket 7
Age groups (years)	13-17	18-24	25-34	35-44	45-54	55-64	65+
Female (n)	55	195	616	768	1427	920	229
Male (n)	0	118	250	95	63	0	0
Proportion (%)	1	7	18	18	32	19	5

Table 3. Excerpt from a discussion between a patient and Vik.

Interlocutor	Chat response ^a
Vik	Hello, I'm Vik  the little robot  . Are you affected by breast cancer? I'm here to accompany you, answer your questions and more. But before we talk, I wanted to tell you that I respect the European Regulation  regarding the protection of your data  . They are used only to:  Provide answers adapted to your questions;  Improve on your use;  Conduct anonymous statistical studies.  All our conversations are and will remain anonymous.  I will never sell your data. You can read here my Terms for more information.
User	I accept
Vik	To chat with me, click on the buttons below and tell me if you are a Patient  or a Relative  ?
User	Patient 
Vik	Alright  ! Now ask me a question or ask me for example, “what are the questions most frequently asked by other users?”
User	How can you help me Vik?
Vik	Here you can see everything I can do:  <i>All topics I can talk about</i>  <i>My features</i>  <i>Manage your subscriptions</i>
User	Create a reminder
Vik	To create a daily treatment reminder, send me for example: “Remember to take my Nolvadex at 2pm”  . To create an appointment reminder, send me instead: “Call back my appointment from June 18 at 3pm” 
User	How to get psychological help?
Vik	Several people can help you:  Social worker  Psycho-oncologists  Patient Association
User	 Psycho-oncologists
Vik	The psycho-oncologist  is a psychiatrist or a psychologist specialized in listening and situations of malaise. He is able to identify the distress related to the disease and its treatments. He intervenes on your request or on that of the medical team.

^aItalicization shows the available options to access other content.

Table 4. User retention rate over 8 months (N=956).

Month	Users, n (%)
February	956 (100)
March	691 (72)
April	603 (63)
June	518 (54)
July	427 (45)
August	387 (40)
September	321 (34)
October	296 (31)

Table 5. Patient testimonies to the survey: “What does Vik mean to you? What does it bring you?”

Patients	Testimonies
User 1	“Vik brings me information that I didn't know and that the doctor doesn't say.”
User 2	“He supports me. Answers to my questions and not to be alone in my fight. Thanks to vik.”
User 3	“Vik helps me to take my treatments and I really like all the tips and tricks.”
User 4	“Being in a rural area, he allows me to have a contact, like in a group of word, a sharing, and it shows that you are not alone.”
User 5	“Vik represents my reminder every day for my treatment and also offers to great tips.”
User 6	“It allows me to tell my story, to have additional information, to not have not been alone with my questions and just support: when I see Vik it makes me happy, it's a support.”
User 7	“It's a virtual help... A quick and succinct source of information...it's up to us to do research if you need more information. It's comforting to know that someone can answer us day and night...thank you it's very well done!”
User 8	“It's like a personal space where I can ask for what I want and have quick answers to the slightest question I have!”

Table 6. Observance rate over time (N=33).

Week	Mean observance, n (%)
1	17 (51)
2	20 (61)
3	22 (67)
4	23 (70)
5	25 (76)

Discussion

Principal Findings

We aimed to analyze one year of conversations between patients with breast cancer and the chatbot, Vik, and the way they were using it. We observed that some users still chatted with Vik after one year.

Sending a question of the day allowed us to notice that users are more likely to answer multiple choice questions. This is probably due to the fact that it is easier to just click on a button. Answering an open-ended question requires time and reflection. The specific relationship between the response rate to a question and the number of interactions is not apparent. Indeed, there is no *snowball effect* that would show a certain increase in the number of interactions when a question brings many answers.

The questions for which the patients interacted the most (number of likes) and with the most words were the questions dealing with their experiences, such as the announcement to the children or the role of the relatives. The turn of these questions encourages testimony and delivery of their opinion .

On a qualitative level, the question of the day functionality of the chatbot revealed that patients surprisingly shared much with Vik, especially when it came to personal and intimate topics such as sexuality and hair loss. Vik increased patients' compliance with their treatment thanks to the treatment reminder function. Morawski K et al [18] had already shown that this type of solution improved patient compliance.

Vik is a chatbot, a machine, but patients appreciated discussing with Vik. The results show that it is easy to find support in Vik. Therefore, we believe that a chatbot could allow an effective

collection of sensitive, intimate information before the conversation with a doctor in the office. This would probably increase the accuracy of an anamnesis, for example, before a consultation. We can indeed consider that a chatbot can perform this type of method in a way to engage the patients in the treatment of their illness by giving them the opportunity to express themselves about how it impacts their life.

The attention paid to it at that time and the ensuing dialogue can be reassuring and comforting for patients. We think that using a chatbot as an intermediary with physicians facilitates the collection of information. For health care professionals, real-life data feedback is a major asset in the management of their patients. Regular feedback on the progression of the disease and reactions to its treatment provide the physician with a better understanding of patients and their condition. These data can be an aid in the decision-making process.

General Appreciation

The experience with the chatbot seems very positive to us: patients greatly appreciate the conversational interface and its simplicity. Being able to ask a question and to instantly access a valid answer scientifically and succinctly is a *plus* reported by many patients.

We conducted focus groups with a sample of patients. They reported that the fact that each of Vik's answer is followed by 2 actions' contextual information was very popular with users, as it allows them to access the information they would not have thought of. This combination of questions asked and contextual actions (conversation scripting) also pleases, as it makes the interaction more flexible: the user does not systematically have to enter a sentence to access information of interest. We were surprised to find that a real emotional attachment was built up

as Vik was used. Some patients confided in other topics than those initially planned when others regularly wished Vik a “good day,” a “good night,” or “thank you.”

Conclusions

A health care chatbot such as Vik allows patients with breast cancer to have a way to find support and answers to their concerns during their disease. Furthermore, the chatbot Vik

improves medication adherence through reminders and educational content, explaining to patients how to take their medication properly, why they have this side effect, and how they can avoid it. New functionalities are planned to confirm Vik as an intermediary between the patient and medical team to provide relevant information to the physicians and enable real-time monitoring.

Conflicts of Interest

AP, GD, AG, BB, and PN are employed by Wefight Inc. BC and JEB own shares of Wefight Inc.

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Original Paper

Evaluation and Implementation of ListeningTime: A Web-Based Preparatory Communication Tool for Elderly Patients With Cancer and Their Health Care Providers

Janneke Noordman^{1,2}, PhD; Jeanine A Drienaar¹, PhD; Inge R van Bruinessen¹, PhD; Johanneke EA Portielje^{3,4}, PhD; Sandra van Dulmen^{1,2,5}, PhD

¹Nivel: Netherlands Institute for Health Services Research, Utrecht, Netherlands

²Department of Primary and Community Care, Radboud University Medical Center, Radboud Institute for Health Sciences, Nijmegen, Netherlands

³Department of Medical Oncology, Leiden University Medical Center, Leiden, Netherlands

⁴Department of Oncology, Hagaziekenhuis, Den Haag, Netherlands

⁵Faculty of Health and Social Sciences, University of South-Eastern Norway, Drammen, Norway

Corresponding Author:

Janneke Noordman, PhD

Nivel: Netherlands Institute for Health Services Research

PO Box 1568

Utrecht, 3500 BN

Netherlands

Phone: 31 302729770

Fax: 31 302729700

Email: j.noordman@nivel.nl

Abstract

Background: Effective patient-provider communication is an important condition to deliver optimal care and it supports patients in coping with their disease. The complex and emotionally loaded setting of oncology care challenges both health care providers (HCPs) and patients in reaching effective communication. ListeningTime is developed for elderly patients with cancer and their oncological HCPs to help them (better) prepare the clinical encounter and overcome communication barriers. ListeningTime is a Web-based preparatory communication tool including modeling videos and has an audio-facility to listen back to recorded encounters.

Objective: This study aims to evaluate the usability, perceived usefulness, and actual use of ListeningTime, through the eyes of elderly patients with cancer and their oncological HCPs. If highly rated, the ultimate goal is to make ListeningTime publicly available.

Methods: First, members of a panel of elderly cancer survivors and patients (age ≥ 65 years) were approached to evaluate ListeningTime through a Web-based questionnaire. The usability and perceived usefulness were assessed. Second, ListeningTime was evaluated in real-life practice through a pilot study in 3 Dutch hospitals. In these hospitals, elderly patients with cancer and their oncological HCPs were approached to evaluate ListeningTime through a similar Web-based questionnaire, measuring the perceived usefulness. In addition, we examined log files and user statistics to get insight into how the program was used.

Results: A total of 30 cancer survivors or patients from the patient panel, and 17 patients and 8 HCPs from the hospitals, evaluated ListeningTime. Overall, both panel members and hospital patients were positive about the ListeningTime website, audio-facility, and video fragments. Some patients suggested improvements with respect to the actors' performances in the video fragments and believed that ListeningTime is mainly suitable for non experienced patients. HCPs were also positive about ListeningTime; they valued the video fragments for patients and the audio-facility for patients and themselves. However, providers did not relisten their own recorded encounters. Patients did use the audio-facility to relisten their encounters.

Conclusions: ListeningTime was highly rated, both by patients and their oncological HCPs. As a result, the video fragments of ListeningTime are now made publicly available for elderly patients with cancer through the Dutch website "kanker.nl."

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KEYWORDS

audio-facility; cancer patients; communication; internet; health care providers; videos; Web-based tool

Introduction

Effective patient-provider communication is an important condition to deliver optimal care, and it supports patients in coping with their disease. The complex and emotionally loaded setting of oncology care challenges both health care providers (HCPs) and patients in reaching effective communication. Elderly patients with cancer find it difficult to communicate their informational needs or preferences, and, in general, their participation during interactions with HCPs is low [1,2]. In a recent study, 47% of elderly patients with cancer reported barriers in communicating with their oncological HCP, for example, not wanting to be bothersome, remembering topics to discuss only afterwards, and feeling nervous [3]. In addition, HCPs not always check whether or not patients understand the information, do not continuously explore what patients already know, and what information they still need [4,5]. In this vulnerable setting, elderly patients are additionally challenged by age-related deficiencies, like comorbidity, memory loss, hearing and vision problems, and having a smaller network [6,7]. These age-related deficiencies can hinder the interaction with HCPs and have an impact on the outcomes of the communication, as information recall [1]. They require sensitive communication of HCPs, taking patients' needs into account.

These findings indicate the importance of supporting both HCPs and elderly patients with cancer in their communication. Preparing an encounter by watching modeling videos, that is, demonstrating different communication strategies of simulated patient-provider encounters, has been found to have positive effects on the quality of patient-provider interactions [8-10]. Relistening an audiorecording of one's own clinical encounter is another intervention that has proven to support patients in various ways—by enhancing recall, improving decision making and the communication with family members, and reducing anxiety [11-13]. With the aim to overcome communication barriers by having elderly patients with cancer and their oncological HCPs (better) prepare the clinical encounter, we combined these 2 techniques and developed ListeningTime, a Web-based preparatory communication tool, based on needs assessment among elderly patients with cancer and their oncological HCPs [3,14]. A Web-based intervention was chosen, as the internet is a valuable source of information and support, also for elderly patients with cancer [15,16]. In the Netherlands, 88.3% of the elderly aged ≥ 65 years use the internet [17]. In addition, the content of Web-based interventions can be computer-tailored to patients' needs and preferences; Web-based interventions are easily accessible and time-efficient and the cost of implementation is minimal once developed [18,19].

ListeningTime contains 2 video diaries, with each 12 short video fragments of simulated patient-HCP encounters. The video fragments demonstrate different communication strategies. At the end of every fragment, a simulation question is formulated (eg, "what would you do if...emotions get in your way/you do not understand what your doctor is talking about?"). Patients are asked to watch a set of 6 personally relevant video

fragments, selected by an algorithm. HCPs are asked to watch one entire diary with 12 fragments. Patients and HCPs can furthermore relisten their audiorecorded encounter through the available audio-facility. Moreover, they can access the website anywhere, at any time, with a personal log-in. The participatory development process of ListeningTime is described in a previous publication [14].

A problem with many electronic health (eHealth) interventions is that they often remain unused after being developed. One of the reasons is that in daily practice, the intervention is not easy to use. The usability and perceived usefulness are preconditions for the actual use of websites like ListeningTime.

Therefore, this study aims to evaluate the usability, perceived usefulness, and actual use of ListeningTime, through the eyes of elderly patients with cancer and their oncological HCPs. The ultimate goal is, in case of high rating of ListeningTime, to make this Web-based communication tool publicly available.

Methods

Aim of ListeningTime

ListeningTime, a Web-based preparatory communication tool for elderly patients with cancer, was developed to help patients (better) prepare their encounters with oncological HCPs. In addition, the tool was designed to support HCPs in preparing their encounters with elderly patients. An overarching aim of the project was to develop ListeningTime in a participatory way to increase its uptake and use. The participatory development process of ListeningTime, including the content and techniques used, was extensively described in a previous publication [14]. In short, ListeningTime is a website, containing 2 video diaries of simulated patient-HCP encounters in which different communication strategies are demonstrated. Patients are asked to watch a selection of personally relevant video fragments, based on an algorithm. HCPs are asked to watch one entire diary. Furthermore, the website contains an audio-facility. Patients and HCPs can relisten their audiorecorded encounter through the facility. For this study, ListeningTime was evaluated in real-life clinical practice among both patients and providers.

Design

A cross-sectional design was used to evaluate the usability, perceived usefulness, and actual use of ListeningTime, according to and by elderly cancer survivors and patients and their oncological HCPs. First, members of a patient panel were approached to evaluate ListeningTime through a Web-based questionnaire. Second, ListeningTime was evaluated in real-life clinical practice through a pilot study in Dutch hospitals, using a Web-based questionnaire and examining user statistics and log files.

Ethics

This study was conducted according to the Dutch privacy legislation. According to the Dutch legislation, approval by a medical ethics committee was not required. Participation was

voluntary, and participants gave their informed consent at the start of their participation.

Recruitment

Elderly patients with cancer were approached through the Dutch patient panel “kanker.nl” (translated as “cancer.nl”); this patient panel consists of 169 cancer survivor or patients aged ≥ 65 years, of which 88 were invited to evaluate ListeningTime. In March 2016, they were invited to fill in a Web-based questionnaire to evaluate ListeningTime. They were asked to navigate through the website while answering the questions. Oncological HCPs (ie, oncologists and oncology nurses) from 3 Dutch hospitals were invited to partake in the pilot study to evaluate ListeningTime.

At the start, HCPs were asked to visit the website ListeningTime, create a personal log-in account, sign the digital informed consent, fill in a baseline questionnaire, and watch one of the 2 video diaries of simulated patient-HCP encounters containing 12 short video fragments (Textbox 1). After HCPs had watched the video diary (or diaries), they were asked to include patients for the pilot study.

From April to December 2016, HCPs approached eligible patients during their medical visits, and handed out a leaflet to patients asking to visit the website ListeningTime before their next visit. Patients were eligible if they were aged ≥ 65 years, diagnosed with cancer, had internet access, spoke and read Dutch, and were not in the palliative or terminal phase of the disease. Interested patients who visited the website were informed about the study, instructed on the website to create a personal log-in and sign a digital informed consent form and fill in a baseline questionnaire to get access to the selection of 6 personally relevant video fragments. The selection of 6 personal relevant video fragments and the order of the fragments varied per patient, based on the algorithm. The algorithm was based on the level of patients’ confidence in communication with the oncological HCP (through the Perceived Efficacy in

Patient-Physician Interactions Questionnaire [20]), the importance of discussing several subjects (eg, quality of life, intimate issues as based on patients’ needs assessment [3]) and their sex (male or female).

Fragments 1 and 2 were always offered as first 2 fragments (Textbox 1). The stories of patients in the 2 diaries differed (ie, one diary tells the story of a female patient with lymphoma, the other diary that of a male patient with prostate cancer) and also their participation level during the stimulated encounters differed (ie, one diary represents a more “active or assertive” patient, the other diary a more “passive” patient). Figure 1 shows a screenshot of the video fragments.

On the informed consent form, patients could opt for audiorecording of their next encounter with their oncological HCP. In case of consent, their HCP audiorecorded this next visit and uploaded the recording on ListeningTime; this enabled patients, their spouses, and HCPs to relisten their audiorecorded encounter, using their personal log-in.

Within 1 week after the (audiorecorded) visit to their HCP, patients were asked to evaluate ListeningTime through a Web-based questionnaire. At the end of the study, HCPs were also asked to evaluate ListeningTime through a Web-based questionnaire.

Web-based Questionnaires

The Web-based questionnaire of the patient panel was used to assess the usability and perceived usefulness of ListeningTime; this questionnaire inquired about patients’ sociodemographic characteristics, their first impression of the website, textual parts of the website, log-in procedure, video fragments, audio-facility, and other remarks. The Web-based questionnaire in the pilot study was used to evaluate the perceived usefulness of ListeningTime, according to patients and oncological HCPs in hospital-based care. Furthermore, this questionnaire assessed the textual parts of the website, log-in procedure, video fragments, audio-facility, and other remarks.

Textbox 1. Overview of the topics of the video fragments.

<ol style="list-style-type: none"> 1. Introduction patient and companion 2. The role of the companion 3. Emotions 4. Choices about treatment options concerning the quality of life 5. Remembering information 6. Need for support 7. Prior to the encounter 8. Asking questions (about prognoses; where treatment takes place; wait-and-see policy; intimacy or sexuality; fear of dead) 9. Indicating your complaints or concerns 10. Asking all your questions 11. Complex information 12. Various information sources

Figure 1. Screen captures of ListeningTime video fragments.



Usability

The usability of ListeningTime was measured with the System Usability Scale (SUS) [21]. The SUS includes 10 items about several facets of usability, for example, the complexity of the website and the ease of using it, scored on a 5-point Likert scale, ranging from 0 (strongly disagree) to 4 (strongly agree). SUS scores were calculated following the guidelines from the original publication [21]. As individual items of the SUS are not meaningful on their own, a total SUS score will be calculated. SUS scores range from 0 to 100; higher scores indicate higher usability. A previous study, evaluating nearly 10 years of SUS data collected, indicated that the SUS is a highly robust and versatile tool and also provides details on what constitutes an acceptable SUS score [22].

Perceived Usefulness

The perceived usefulness of ListeningTime, that is, “the degree to which a person believes that using a particular system would enhance his or her job performance” [23], was measured using questions and statements. Similar questions and statements were used in previous studies [24,25]. [Multimedia Appendix 1](#) describes the questions that were asked through the patient panel (18 questions), and questions and statements included in the

pilot study (14 questions or statements for patients; 13 questions or statements for HCPs).

Use

The actual use of ListeningTime by patients and HCPs in the pilot study was examined using user statistics and log files, that is, automatically generated files mapping the interactions between program and users; this allowed us to get insight into what extent patients and HCPs actually used the website, including the log-in frequency, playing video fragments, and using the audio-facility.

Overall Rating of ListeningTime

We considered the rating of ListeningTime “high” in case $\geq 70\%$ of cancer survivors or patients perceived ListeningTime as useful (in both the patient panel and pilot study), the usability was rated as “good” or higher [22], and 70% of the included patients actually used ListeningTime (ie, logged on, watched the video fragments) in the pilot study [26]. As the use of the audio-facility was optional, we considered the rating of the audio-facility “high” in case all patients who made use of it found it useful.

Implementation Strategy

The ultimate goal was to implement ListeningTime, in case of high rating, as a publicly available, standalone intervention, that

is, without the research context and without support of professionals. Therefore, we collaborated from the start of the project with several partners. This participatory development method was pursued to create awareness of the potential of ListeningTime and to prepare for a successful implementation (see for more details about the participatory development process of ListeningTime [14]). These partners included representatives from hospitals, the Nederlandse Federatie van Kankerpatiënten organisaties, the “Quality institute for oncological and palliative research and practice” (IKNL: Integraal Kankercentrum Nederland) and “kanker.nl” During the project, implementation of ListeningTime by one or several of these partners was discussed.

Statistical Analyses

Descriptive statistics were used to analyze the results. Data analyses were performed in Stata version 14.

Results

Patient Panel

Study Sample

Of 88 members of the patient panel who were invited to evaluate ListeningTime, 30 members responded and filled in all questions. Respondents were on average aged 69 (range 65-78) years, 73% (22/30) were males, 43% (13/30) were highly educated (ie, higher professional education or university), and 83% (25/30) were married or had a registered partnership. In addition, 60% (18/30) were diagnosed with urological cancer (kidney, prostate, and bladder); 40% (12/30) indicated that they were currently being treated for cancer, and 33% (10/30) had completed treatment. Other respondents were awaiting treatment, following a wait-and-see policy or indicated that they completed treatment.

Usability of the Website

Patients had a mean SUS score of 73.2 (SD 18.5, range 30-100, n=30), which indicates good usability [21,22].

Perceived Usefulness of the Website

At first impression, 50% (15/30) of respondents found the website clear, 43% (13/30) found the website reliable, 37% (11/30) professional, 17% (5/30) inviting, and 13% (4/30) attractive. The website was not experienced as boring, busy, gloomy, or confusing.

Next, respondents evaluated the subpages of the website: “About ListeningTime” and “Patients.” Overall, 83% (25/30) of respondents could easily find the page “about ListeningTime,” 97% (29/30) found it clear to whom the website is intended, 93% (28/30) found it clear what the website has to offer, and 83% (25/30) stated that they did not miss any information about ListeningTime. Respondents who missed information (n=3) indicated that the website lacked information about a second opinion, how to inform more experienced patients, and which hospitals are cooperating with this research. The information about the participating hospitals was added to the website, and the topic of a second opinion was included in the script of a diary.

In addition, 80% (24/30) of respondents were able to easily find the page “patients.” Seven respondents explicitly mentioned that the page is clear, clean, well designed, and easy to search. Two respondents indicated that the amount of text could be less. Therefore, the amount of text on the website was reduced to a necessary minimum.

Respondents made the following, partly contrary remarks about the website:

a good website with many possibilities

I thought it was a bit boring and educational, I hope this will not stop people from using it

if possible, implementation via the website ‘kanker.nl’

video fragments were very weak

nice addition to the information from oncology

Perceived Usefulness of the Video Fragments

In this study, 70% (21/30) of respondents were able to watch the video fragments. The remaining respondents did not log-in to watch the video fragments (n=5), indicated to watch the video fragments another time (n=2), were abroad (n=1), or too emotional to watch the video fragments (n=1). Almost all respondents were satisfied with the selection and playing of the video fragments. They made the following comments about the video fragments: *easy; good; simply click; fine; without hesitation or interruption; sound was pleasant and clearly spoken; video’s played without problems.*

In addition, almost all were satisfied with the “simulation questions” (eg, “what would you do if...emotions get in your way/you do not understand what your doctor is talking about?”) at the end of every video fragment. Respondents stated the following about the simulation questions: *clear; fine; encourage thoughts; focus; encouragement to watch the video again; very personal questions; good questions but not complete.* Five respondents missed the question or did not watch the entire fragment.

Respondents found the video fragments easy to follow (20/21, 95%), clear (19/21, 90%), clearly spoken (18/21, 85%), good (17/21, 81%), realistic (16/21, 76%), credible (16/21, 76%), simple (15/21, 71%), reliable (15/21, 71%), complete (14/21, 67%), professional (12/21, 57%), and instructive (8/21, 38%). Among other things, they found the following things “good” about the video fragments: *recognizable; realistic; simplicity and clarity; dialogue; calm; well structured; HCP asks for and gives correct answers; effective; clear step by step method; good idea of how to communicate with the HCP and to bring certain aspects to their attention; powerful; very accommodating to the patient; answer to some questions.*

Respondents mentioned the following improvement points: *acting performance; more depth; identification with actors was not present (although maybe not necessary); more realistic situations (eg, bad news conversation).*

Perceived Usefulness of the Audio-Facility

Most respondents (21/30, 70%) were (very) enthusiastic about the possibility to audiorecord their conversation with the HCP and relisten this recording on the website. Respondents

mentioned the following: *very commendable; excellent idea; awesome; fantastic; it would be very nice to take this opportunity; after a while you forget things or you do not know exactly what has been said, so this is a good thing*. Nine respondents were not interested in this because they already made their own recordings, brought a companion to the encounter, did not feel the need to record their encounter, found it a violation of the privacy of the HCP.

Perceived Usefulness of ListeningTime

Overall, 40% (12/30) of respondents would like to follow the entire program of ListeningTime, 20% (6/30) were considering it, and 40% (12/30) were not interested. In addition, 83% (25/30) found ListeningTime, or a similar program where patients see video fragments as an example of how certain topics can be discussed with their HCP, helpful for patients. Five patients did not agree and preferred a personal conversation with their HCP or found the video fragments to superficial because they already had a lot of (disease) experience.

This [ListeningTime] can help in processing

I think this is much clearer than reading information in a folder

You know what to ask for

It is a kind of training and sometimes a patient does not think of everything, especially when there is a lot of emotion

You can prepare your encounter with the video examples

Pilot Study in Hospitals

Study Sample

A total of 17 patients and 8 oncological HCPs participated in this part of the study. Overall, 88% (15/17) of patients were treated for their disease, 1 patient had just undergone surgery, and 1 patient was in remission.

Two of the HCPs (one per hospital) included patients for the study. Seven of the HCPs completed the evaluation questionnaire after completing the communication training (ie, watching one entire diary of ListeningTime). Tables 1 and 2 present the characteristics of participants and health care providers, respectively.

Perceived Usefulness of the Website

Patients considered the website easy to use (17/17, 100%), clear (17/17, 100%), interesting (14/17, 82%), and well designed (15/17, 91%). All patients indicated to (probably) recommend the website to other patients. Moreover, 91% (15/17) of patients considered ListeningTime as useful for patients.

All HCPs found the website interesting, nicely designed, well organized, and easy to use. In addition, 43% (7/17) would recommend the website to colleagues, and 86% (15/17) of HCPs missed no information. One HCP indicated that written information on the website about what is important in communication could be added.

Close to reality [patient]

You know what you can and may ask [patient]

Remembering easier what the doctor has told [patient]

Table 1. The characteristics of patients (n=17).

Characteristics	Value
Age in years, mean (range)	74 (66-89)
Male, n (%)	9 (53)
High educational level ^a , n (%)	6 (35)
Household size, n (%)	
1	6 (35)
2	11 (65)
Diagnosis, n (%)	
Stomach, liver, or bowel cancer	9 (53)
Breast cancer	6 (35)
Gynecological cancer	1 (6)
Unknown	1 (6)
Attending clinical encounters, n (%)	
Always alone	2 (12)
Sometimes alone	1 (6)
Always with companion	14 (82)

^aHigher professional education or university.

Table 2. The characteristics of health care providers (n=8).

Characteristics	Value
Age in years, mean (range)	42 (31-61)
Male, n (%)	1 (13)
Working experience in years, mean (range)	7 (1-17)
Profession, n (%)	
Nurse	5 (63)
Medical oncologists	2 (25)
Doctors assistant	1 (12)

Perceived Usefulness of the Video Fragments

In this study, 10 patients watched the video fragments before their oncological encounter, 1 only after the encounter. Five patients watched the fragments again after the encounter. On average, patients watched the fragments 1.4 times (range 1-3). The video fragments were considered well designed (10/11, 91%), useful (10/11, 91%), interesting (9/11, 82%), realistic (9/11, 82%), and informative (8/11, 73%).

In addition, 86% (7/8) of HCPs found the video fragments nice, 50% (4/8) found them interesting, and 29% (2/8) found the fragments useful for themselves and realistic. HCPs indicated that the reactions of oncologists in the fragments were not always feasible in practice (eg, taking a pause in-between a conversation) or that they could not find out which learning moments there were for patients and were, therefore, curious about the evaluation by patients. Furthermore, 86% (7/8) of HCPs thought that a program such as ListeningTime could be helpful for patients; they indicated that the fragments are not useful for themselves, but may be for patients.

The video fragments are clear, but for more experienced patients not very much to the point.
[patient]

The fragments are too simple. Most patients are already familiar with the tips that were given in the fragments. [HCP]

Perceived Usefulness of the Audio-Facility

Eight patients indicated that they audiorecorded their encounter and replayed it on the website. Three patients relistened alone, 3 with their spouse, and 2 relistened twice—once alone and once with their spouse. All patients considered relistening their encounter as useful for themselves and their spouse, and it all helped them to remember the conversation with their HCP.

As a patient, it is very useful to listen back to your encounter, good service.

All HCPs indicated that they did not relisten the audio recordings of their conversations with patients; this was confirmed by the user statistics. One HCP did not feel the need to relisten the audiorecordings and other HCPs did not find it useful to relisten all audio recordings. Nevertheless, HCPs were positive about the possibility of recording conversations. They indicated that the recording of the conversation is useful for

themselves and patients and that it provides insight into their own communication skills.

Use of ListeningTime by Patients

The user statistics show that 17 patients logged on to the website, 5 times on average (range 1-17). Furthermore, 4 patients relistened the full audiorecording of their encounter, and other patients listened to a part of their audiorecorded encounter.

In addition, the user statistics show that 12 patients (12/17, 71%) fully watched ≥ 1 video fragments. On average, they viewed 9 fragments (range 1-20). Of note, 4 of 12 patients viewed the 6 personally selected fragments, as intended. The introductory fragments about patients and the role of the companion were viewed by almost all patients (as intended part of the algorithm). Next, patients fully viewed the following fragments (≥ 1 times; in order of frequency)—choices about treatment options concerning the quality of life (n=12, diary 1: 6 patients, diary 2: 6 patients); emotions (n=11, diary 1: 5 patients; diary 2: 6 patients); remember information (n=11, diary 1: 5 patients; diary 2: 6 patients); and need for support (n=10, diary 1: 6 patients; diary 2: 4 patients). The following fragments were watched by <4 patients: prior to the encounter; asking questions (about prognoses, where treatment takes place, wait-and-see policy, intimacy and sexuality, and fear of death); indicate your complaints or concerns; asking all your questions; complex information and various information sources.

Three patients watched some of the video fragments. In particular, they looked at the fragments about “choices about treatment options concerning the quality of life” and “remembering information.”

Implementation

As mentioned before, the ultimate goal was to implement ListeningTime as a publicly available, standalone intervention, without the research context and the involvement of professionals. As of June 2017, the educational video fragments of ListeningTime are publicly available for all (elderly) patients with cancer through the Dutch website “kanker.nl.”

Discussion

Principal Findings and Comparison With Prior Work

ListeningTime is a useful and user-friendly communication tool for elderly patients with cancer. It helps patients to (better)

prepare the clinical encounter with their oncological HCP and overcome communication barriers. Patients most valued the video fragments and the audio-facility to relisten their recorded consultations. They mentioned that ListeningTime supported their informational needs (eg, know what you can ask), emotional needs (eg, how to deal with emotions and ask for support), and their cognitive needs (eg, better remember what the doctor has told).

Patients often feel emotionally overwhelmed after diagnosis or during cancer treatment and have a need for emotional support. In addition, most patients with cancer report difficulties in understanding and fully processing the HCPs' information [27,28]. ListeningTime seems to offer an opportunity to fulfill these needs.

Previous research found that combining audiovisual information with conversational style is the best way to present eHealth information about cancer treatment to (younger and older) adults [29]; this can explain patients' high rating of ListeningTime as we used a combination of audiovisual information with conversational style in the video fragments. However, for more experienced patients, the video fragments seem less useful. Future research is necessary to get insight into which moment is or are (most) appropriate to use ListeningTime (eg, at the start of a disease trajectory).

Likewise, oncological HCPs were positive about ListeningTime as a supportive tool for patients. They valued the video fragments and the possibility to relisten the audiorecorded consultation. However, they also mentioned that the video fragments were too simple for patients. It is possible that HCPs overestimate their patients' communication skills or that they included mainly experienced patients during the pilot study. Analyzing real-life, video- or audiorecordings of patient-provider encounters in this setting can provide insights into the communication process and role of both patients and providers. As only 8 patients audiorecorded their encounter during this study, it is not possible to draw conclusions. As mentioned before, HCPs were positive about the possibility to relisten the audiorecordings. However, they did not relisten their own recorded encounters; this could be attributed to several reasons, for example, owing to the lack of time or not feeling the need to relisten. For this study, the main aim was to support elderly patients with cancer in overcoming their communication barriers; ListeningTime seems to offer this opportunity. Although oncological HCPs participated in this study to support patients in their communication skills and, therefore, used ListeningTime, we did not offer a specific communication training for HCPs. The high use of ListeningTime by patients, however, can also be attributed to the involvement of HCPs in including patients and asking them to visit the website. Over recent years, many eHealth interventions have been developed. However, numerous eHealth interventions have not been evaluated, have reported attrition (like dropout and nonusage) and adoption problems (ie, poor uptake after implementation) [26,30,31]. By actively involving elderly patients with cancer and their providers in developing ListeningTime, the use and uptake of this intervention was expected to increase [32,33]. The evaluation of ListeningTime, indeed, showed that patients valued ListeningTime and, as a result, the video fragments

became publicly available for all elderly patients with cancer. A previous study found similar results and concluded that actively involving patients with cancer in designing and evaluating a Web-based tool is feasible and appreciated [34]. For the design of the website, guidelines for targeting elderly patients online were followed, that is, avoiding large amounts of text by using "pull out" menus for more detailed information and larger font size [16]; this could have supported the use of ListeningTime.

Although ListeningTime was developed to support elderly patients with cancer especially, the tool might be very useful for younger patients as well. A recent study found no differences in website satisfaction between younger and older patients with cancer using a mode-tailored website [35]. Nevertheless, it should be tested if ListeningTime is also useful for younger patients with cancer. To this extent, it would be interesting to know how many (elderly and younger) patients (and their significant others) use the educational video fragments of ListeningTime since the implementation on the website "kanker.nl."

In this study, we evaluated a Dutch Web-based communication tool. However, the results might be useful and relevant at the international level as well. As our results indicate, a tool as ListeningTime can be highly valuable to offer to elderly patients with cancer. It consists of multiple useful techniques, that is, a tailoring algorithm, modeling videos (including simulation questions), and an audio-facility [14], which can be useful for other countries and settings as well.

To the best of our knowledge, this is one of the first studies using a participatory process to develop a Web-based intervention, that is, with the help of elderly patients with cancer and their providers [30,34]. In addition, the educational video fragments of ListeningTime were implemented through the website "www.kanker.nl." This success can be attributed to the participatory nature of the development process and the inclusion of partners from the start of the project. Unfortunately, it was not technically possible to include the tailoring algorithm and the audio-facility of ListeningTime on the website of "kanker.nl." For further implementation of ListeningTime, the involvement of HCPs (or hospitals) might be necessary. Unfortunately, this was beyond the scope of this project.

For future research, it might be interesting to investigate the (combined) effect of the video fragments and audiorecordings on real-life communication between patients and HCPs; examine the effect of the simulation question at the end of each video fragment (eg, how do patients use or reflect on these questions, is it a crucial part of the video fragment, what is a good simulation question); explore other ways to provide patients with educational videos and audiorecordings of their clinical encounters; and how to implement interventions like ListeningTime in close collaboration with HCPs. A necessary first step before developing eHealth interventions is to investigate if the targeted patient population feels the need for the proposed eHealth intervention.

Limitations

This study has some limitations. First, the results may be influenced by the relatively small study sample. However, this is an exploratory pilot study. Larger, controlled studies are necessary to replicate (or contradict) our findings. Second, it is possible that only interested patients participated. However, this is also the targeted group that will watch the video fragments on “kanker.nl.” Third, we aimed to include a wide range of elderly patients with cancer, with different (stages of) disease and different levels of participation (eg, active and passive). As patients volunteered to partake, it is possible that the results of

this study represent the more “active” patients—those who feel confident in participating during medical encounters. In addition, we are not aware of the number of patients approached by providers in the hospital and the number nonresponders.

Conclusions

ListeningTime was highly rated, both by elderly patients with cancer and their oncological HCPs. As a result, the video fragments of ListeningTime are publicly available for all (elderly) patients with cancer through the Dutch website “kanker.nl,” without the research context and the involvement of professionals.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Perceived usefulness questions and statements.

[[PDF File \(Adobe PDF File\), 21KB - cancer_v5i1e11556_app1.pdf](#)]

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Abbreviations

eHealth: electronic health

HCP: health care provider

SUS: System Usability Scale

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Original Paper

Potential of Using Twitter to Recruit Cancer Survivors and Their Willingness to Participate in Nutrition Research and Web-Based Interventions: A Cross-Sectional Study

Laura Keaver¹, MPH, RD; Aisling McGough^{2,3}, MSc; Mengxi Du², MPH; Winnie Chang⁴, BSc; Virginia Chomitz³, PhD, FACS; Jennifer D Allen⁵, SCD, MPH; Deanna J Attai⁶, MD, FACS; Lisa Gualtieri³, PhD; Fang Fang Zhang², MD, PhD

¹Clinical Health and Nutrition Centre, Department of Health and Nutritional Science, Institute of Technology Sligo, Sligo, Ireland

²Friedman School of Nutrition Science and Policy, Tufts University, Boston, MA, United States

³Department of Public Health and Community Medicine, Tufts University School of Medicine, Boston, MA, United States

⁴Smith College, Northampton, MA, United States

⁵Department of Community Health, Tufts University School of Arts and Sciences, Medford, MA, United States

⁶Department of Surgery, David Geffen School of Medicine, University of California Los Angeles, Los Angeles, CA, United States

Corresponding Author:

Fang Fang Zhang, MD, PhD

Friedman School of Nutrition Science and Policy

Tufts University

150 Harrison Ave

Boston, MA, 02111

United States

Phone: 1 6176363704

Email: fang_fang.zhang@tufts.edu

Abstract

Background: Social media is rapidly changing how cancer survivors search for and share health information and can potentially serve as a cost-effective channel to reach cancer survivors and invite them to participate in nutrition intervention programs.

Objective: This study aimed to assess the feasibility of using Twitter to recruit cancer survivors for a web-based survey and assess their willingness to complete web-based nutrition surveys, donate biospecimens, and to be contacted about web-based nutrition programs.

Methods: We contacted 301 Twitter accounts of cancer organizations, advocates, and survivors to request assistance promoting a web-based survey among cancer survivors. The survey asked respondents whether they would be willing to complete web-based nutrition or lifestyle surveys, donate biospecimens, and be contacted about web-based nutrition programs. Survey promotion rate was assessed by the percentage of Twitter accounts that tweeted the survey link at least once. Survey response was assessed by the number of survey respondents who answered at least 85% (26/30). We compared the characteristics of cancer survivors who responded to this survey with those who participated in the National Health and Nutrition Examination Survey (NHANES) 1999-2010 and evaluated factors associated with willingness to complete web-based surveys, donate biospecimens, and be contacted to participate in web-based nutrition programs among those who responded to the social media survey.

Results: Over 10 weeks, 113 Twitter account owners and 165 of their followers promoted the survey, and 444 cancer survivors provided complete responses. Two-thirds of respondents indicated that they would be willing to complete web-based nutrition or lifestyle surveys (297/444, 67.0%) and to be contacted to participate in web-based nutrition interventions (294/444, 66.2%). The percentage of respondents willing to donate biospecimens were 59.3% (263/444) for oral swab, 52.1% (231/444) for urine sample, 37.9% (168/444) for blood sample, and 35.6% (158/444) for stool sample. Compared with a nationally representative sample of 1550 cancer survivors in NHANES, those who responded to the social media survey were younger (53.1 years vs 60.8 years; $P < .001$), more likely to be female (93.9% [417/444] vs 58.7% [909/1550]; $P < .001$), non-Hispanic whites (85.4% [379/444] vs 64.0% [992/1550]; $P < .001$), to have completed college or graduate school (30.1 [133/444] vs 19.9% [308/444]; $P < .001$), and to be within 5 years of their initial diagnosis (55.2% [244/444] vs 34.1% [528/1550]; $P < .001$). Survivors younger than 45 years, female, and non-Hispanic whites were more willing to complete web-based nutrition surveys than older (65+ years), male, and

racial or ethnic minority survivors. Non-Hispanic whites and breast cancer survivors were more willing to donate biospecimens than those with other race, ethnicity or cancer types.

Conclusions: Twitter could be a feasible approach to recruit cancer survivors into nutrition research and web-based interventions with potentially high yields. Specific efforts are needed to recruit survivors who are older, male, racial and ethnic minorities, and from socioeconomically disadvantaged groups when Twitter is used as a recruitment method.

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KEYWORDS

social media; nutrition survey; cancer survivors

Introduction

Background

Nearly two-thirds of American adults (65%) use social networking sites, with a particular increase among those 65 years and older (35% in 2015, more than tripled since 2010) [1]. The use of social media has shifted from a focus on personal use to almost all domains including health [1]. Cancer survivors are increasingly utilizing social media to obtain and share health-related information among themselves and with health care providers [2,3]. Social media is also becoming a popular tool for cancer survivors and their caregivers to seek support [4,5].

Cancer survivors have substantially reduced quality of life because of physical and psychosocial late effects [6,7] and are at significantly elevated risk of cancer recurrence and premature death [8]. There is clear evidence to support the benefits of optimal nutrition, ranging from relieving symptoms and treatment-related side effects to improving survival and quality of life among cancer survivors [9-14]. Traditional methods of providing nutrition programs to cancer survivors through outpatient oncology clinics face challenges when cancer survivors experience transportation difficulties or scheduling constraints to participate in these programs in person [15]. Nutrition programs delivered through web-based platforms can potentially circumvent these barriers and reach a broader range of cancer survivors in the community [16-20]. For example, Gorman et al utilized a variety of recruitment methods including social media to recruit young adult female cancer survivors into a research study for reproductive health [16]. The authors collaborated with organizations that support and advocate for adolescent and young adult survivors by posting the recruitment advertisements on Facebook and Twitter approximately every 2 months over a 12-month period and subsequently recruited a total of 381 eligible adolescent and young adult survivors [16]. Compared with other recruitment strategies (eg, clinical-based or community-based) that were also utilized by Gorman et al, social media recruitment provided the highest number of enrolled participants [16]. Attai et al surveyed the knowledge level and psychosocial outcomes in breast cancer survivors who were participants of a Twitter support community for breast cancer survivors by posting the survey link on its Twitter, Facebook page, and blog [4]. This method yielded 206 responses after 2 weeks of survey promotion. In addition, a recent meta-analysis [21] of 12 studies that enrolled 7441 participants for social network site interventions revealed not only favorable outcomes in promoting health behavior change such as weight

management, physical activity, and smoking cessation but also a high retention rate: 4 [17-20] of the 6 studies reported a retention rate above 80%, and 2 [22,23] reported retention rates between 65% and 75%. Taken together, social media may represent a cost-effective method for health care providers and cancer support groups to reach cancer survivors in the community and invite them to participate in web-based nutrition intervention programs.

Objectives

The primary purpose of this study was to evaluate the feasibility of using social media such as Twitter to recruit cancer survivors into nutrition research and web-based interventions and to further assess survivors' willingness to complete nutrition surveys delivered through this medium, donate biospecimens, and be contacted to participate in future web-based nutrition intervention programs. In addition, this study aimed to compare the demographic and cancer-related characteristics between cancer survivors approached using social media and those from a nationally representative survey.

Methods

Study Population and Survey Instruments

We administered the Cancer survivors Adherence to Recommendations for healthy Eating (CARE) survey to cancer survivors. Eligible participants were cancer survivors who were 18 years or older and had been told by a doctor or other health professional that they had cancer or a malignancy of any kind. The survey was self-administered online and included 30 questions. A total of 24 questions asked cancer survivors' demographic and cancer or treatment-related characteristics, lifestyle habits, perceived barriers for healthy eating and physical activity, and sources of seeking nutrition information. Findings for these questions have been submitted for publication elsewhere. This study specifically focused on the 6 questions about survivors' willingness to complete web-based nutrition and lifestyle surveys (ie, would you be willing to complete other online surveys about diet, exercise, and lifestyle at a later date?), willingness to donate biospecimens such as oral swab, urine, or blood (ie, would you be willing to use an oral swab kit that we mail to you and you mail back to us? Would you be willing to provide a urine sample using a kit that we mail to you and you mail back to us? Would you be willing to provide a blood sample from a full venous draw, similar to the type of blood draw you would receive at your doctor's office?), and also survivors' willingness to be further contacted to participate in nutrition interventions (ie, would you be willing to be further

contacted to participate in nutrition programs offered online?), with the available responses being yes, no, or maybe. The study was approved by the institutional review board at Tufts Medical Center/Tufts University.

Strategies for Survey Promotion

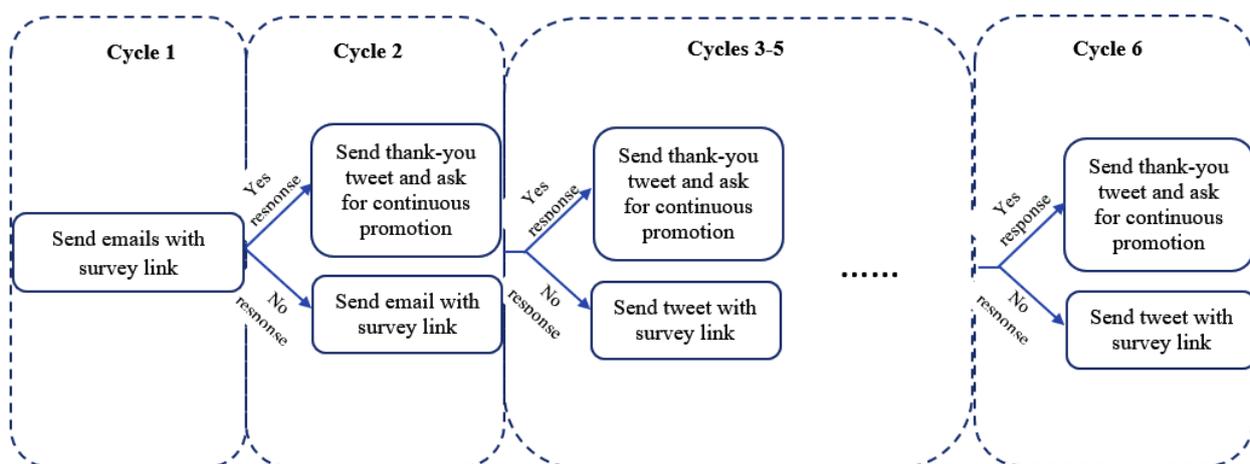
We conducted web-based searches to identify cancer organizations, advocates, and survivors that have active presence in 1 major social media platform, Twitter. To reach active Twitter accounts with a cancer focus, we first located Twitter accounts using the search terms “Cancer Survivor(s),” “Cancer Advocate(s),” “Cancer Support,” “Cancer,” and “Cancer Nutrition” in November 2015. We identified the top 50 Twitter accounts under each of these 5 search terms that met the following inclusion criteria: (1) having 500 or more followers for large cancer organizations (eg, the American Cancer Society) or 200 or more followers for smaller cancer advocate/survivor groups and (2) having contact information such as email address. Due to limitations in resources, we chose to target Twitter accounts that can potentially reach a large number of cancer survivors for survey promotion, such as large cancer organizations that tend to have powerful social media platforms to reach cancer survivors in the community. We also included Twitter accounts of smaller cancer advocate/survivor groups that had a certain number of followers. Although arbitrary, the number of followers specified in the inclusion criteria was chosen to target Twitter accounts that could potentially result in high survey yields. Twitter accounts that advertise or sell nutrition products to cancer survivors or were primarily in a language other than English were excluded. Second, we conducted additional searches in December 2015 in

collaboration with Symplur to identify additional accounts that were deemed active in Twitter based on Symplur’s Healthcare Social Graph algorithm [24]. The algorithm ranks Twitter accounts based on (1) the ratio of reactions that each account generates compared with the content it shares and (2) the selectiveness of the social network that each account interacts with. For this additional search, the top 100 Twitter accounts using search term “Cancer” in each of the 2 categories—organizations and advocates—were identified in Symplur. Finally, we created a Twitter account for the CARE survey and identified additional accounts that met the study inclusion criteria among the followers of our Twitter account. Twitter accounts that were identified using all 3 search strategies were subsequently merged, and duplicate or ineligible accounts were removed. A list of Twitter accounts was then finalized, and data were extracted on account name, category, cancer type, contact information, country of origin, and number of followers.

Survey Administration

A web-based version of the survey was created using SAP Qualtrics survey tools and published with a URL. To administer the CARE survey, we applied 6 rounds (ie, cycles) of contacts to the Twitter accounts identified in the above search (Figure 1). During the first cycle of contact (ie, initial contact), an email was sent to each account. The email included a cover letter that introduced the survey, defined its purpose, and asked the account owner to promote the survey by posting the URL link of the survey on their social media platforms, along with the time frame of survey promotion and sample messages they could post on social media (Textbox 1).

Figure 1. Survey promotion cycles.



Textbox 1. Sample Twitter messages for survey promotion.

Sample Twitter messages:

- Cancer Survivors Share Your Thoughts about Nutrition with @TuftsNutrition in @CARE_Study survey link
- Change Eating Habits after Cancer Diagnosis? Tell Scientists @TuftsNutrition in @CARE_Study survey link

In the situation where the email was returned, alternative contact was made through Twitter by sending a tweet with the "@" symbol before the name of the Twitter account. For those who responded to the initial contact by posting the survey link on their social media, a thank you tweet was sent along with a request to continuously promote the survey, by tweeting a link to the survey, until the survey closed. For those who did not respond to the initial contact, a second cycle of contact was made with email or tweet by sending the same cover letter. As tweets were found to generate more responses than emails, after the first cycle, contact was made exclusively by sending tweets that included the survey link. All Twitter accounts were contacted for survey promotion at each cycle even if they had already promoted the survey. The research staff actively followed each account for survey promotion activities at each cycle, for example, tweeting a link to the survey, and recorded in an Excel sheet whether each account tweeted the survey link at least once (yes vs no) per cycle. The number of tweets sent by each account was not recorded. The research staff also monitored survey promotion activities of the followers of the Twitter accounts. The follower accounts were not included in our original list for survey promotion. However, if they promoted the survey by tweeting the survey link, they were subsequently contacted to continuously promote the survey until the survey closed. A total of 6 cycles of contacts were made within about 10 weeks from February 9 to April 23, 2016, and each cycle lasted approximately 1.5 weeks. Respondents who clicked on the survey link were provided with information about the study and asked to provide consent before being able to proceed with the survey. Survey responses completed after each cycle were retrieved from SAP Qualtrics.

Statistical Analysis

We first described the survey promotion rate achieved at each cycle by calculating the percentage of the Twitter accounts that promoted the survey by tweeting the survey link at least once among those being contacted. We then described the survey response at each promotion cycle by the number of survey respondents who provided complete responses, defined as answering 85% or more of all survey questions. After the survey closed, we exported survey responses from Qualtrics and imported them into SAS 9.4 (SAS Institute) for data checking

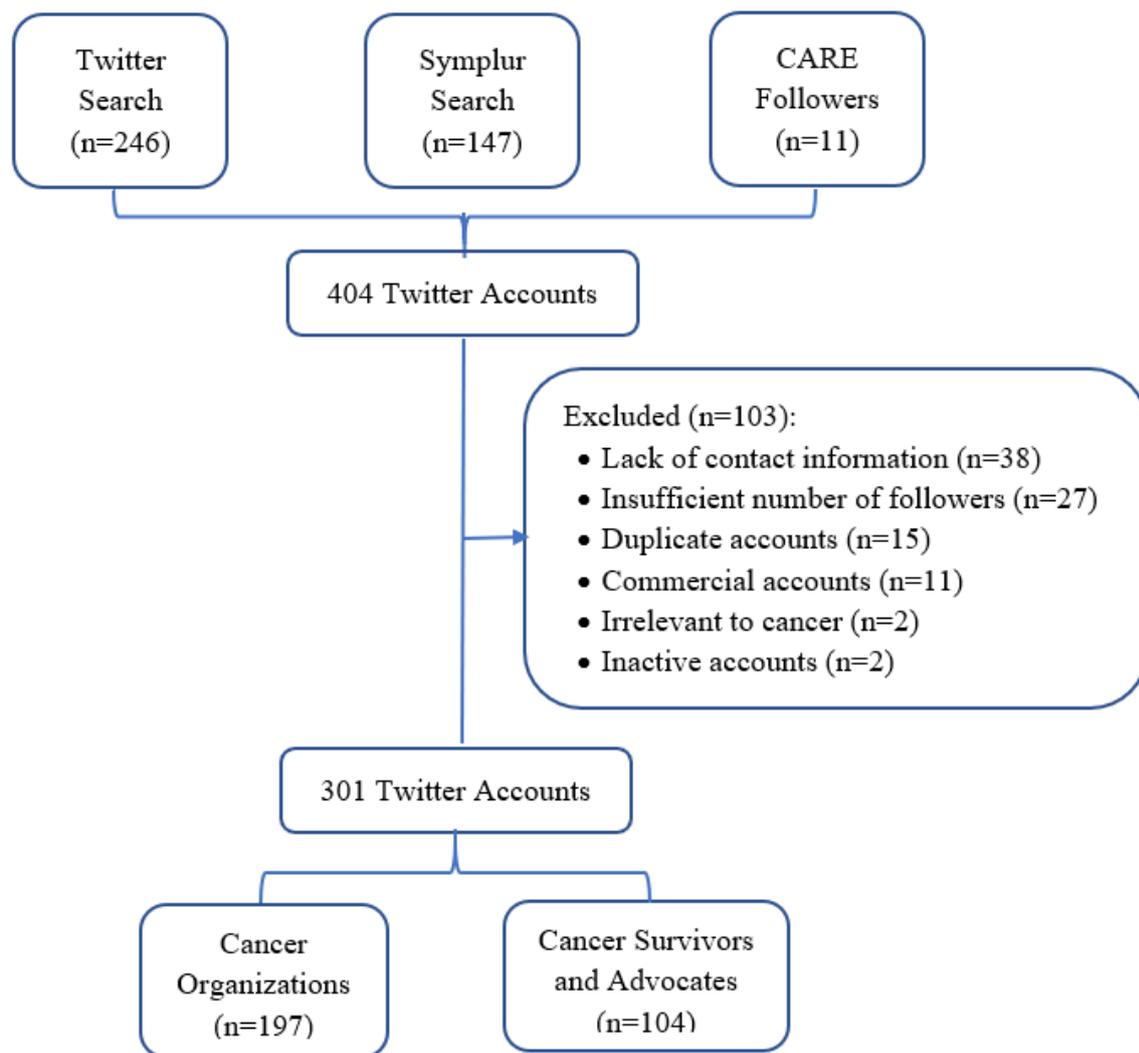
and cleaning. To assess whether cancer survivors approached using social media such as Twitter differ from cancer survivors in the community in demographic and cancer-related characteristics, we compared cancer survivors who provided complete responses to the CARE survey with those who participated in the 1999-2010 National Health and Nutrition Examination Survey (NHANES), a nationally representative survey that assesses information on health and nutritional status of the noninstitutionalized civilian population in the United States [25]. Continuous variables were compared using analysis of variance, and categorical variables were compared using the chi-square test. Among cancer survivors who provided complete responses to the CARE survey, we further described the percentages of those who indicated that they would be willing to be further contacted for additional nutrition and lifestyle assessments, biospecimen collection, and web-based nutrition interventions. In addition, we evaluated factors associated with willingness to complete web-based nutrition and lifestyle assessments, donate biospecimen, and to be contacted to participate in web-based nutrition programs among survey respondents using logistic regression models adjusted for age, sex, and race/ethnicity. All data analyses were conducted using SAS 9.4.

Results

Twitter Accounts

Our initial search identified a total of 404 Twitter accounts, with 246 accounts identified through direct Twitter search, 147 accounts identified through Symplur search, and 11 accounts identified from CARE Twitter followers. Among these accounts, 103 accounts were excluded because of lack of contact information (n=38), the number of followers smaller than the predetermined threshold (n=27), duplicate accounts identified in both Twitter account search and Symplur search (n=15), commercial accounts (n=11), irrelevant to cancer (n=2), and inactive accounts defined as no messages posted in the past 30 days (n=2). The remaining 301 accounts were included in the database for survey promotion at each cycle, including 197 accounts for cancer organizations such as the American Cancer Society and 104 accounts for cancer advocates or survivors such as the Breast Cancer Social Media (#BCSM; Figure 2).

Figure 2. Identification of Twitter accounts for survey promotion. CARE: Cancer survivors Adherence to Recommendations for healthy Eating.



Survey Promotion and Response Rates

A total of 113 of the 301 accounts (ie, original accounts) promoted the survey over 6 cycles. At each cycle, 28/301 (9.3%), 18/301 (6.0%), 31/301 (10.3%), 21/301 (7.0%), 6/301 (2.0%), and 9/301 (3.0%) promoted the survey, yielding an average promotion rate of 6% per cycle (Table 1). The cancer advocate/survivor accounts yielded a substantially higher average promotion rate (12/104, 11.5%) than cancer organization accounts (6.8/197, 3.5%; $P<.001$). New accounts ($n=165$) that came from the followers of those originally identified accounts also promoted the survey. The majority of these new accounts were cancer advocates/survivors (133/165, 80.6%) and about one-fifth were Twitter accounts for cancer organizations

(32/165, 19.4%). These new accounts were included in the final 4 cycles for survey promotion and the average promotion rate was 20.7% per cycle and 7% (7/99), 19.4% (25/129), 25.9% (38/145), and 26.3% (35/133), respectively, at each cycle (Table 1). There was no significant difference in the average promotion rate of new accounts that were cancer advocates/survivors (23/109, 21.1%) or cancer organizations (3/18, 17%; $P=.51$).

A total of 6 cycles of survey promotion resulted in a total of 584 survey responses, among which 29 respondents identified themselves as not having a cancer diagnosis, and 111 did not provide complete responses (ie, answering at least 85% of the survey questions) and were excluded. Thus, a total of 444/584 (76.0%) cancer survivors provided complete responses to the survey over 10 weeks.

Table 1. Survey promotion rates by original and new accounts at each cycle.

Survey cycle	Cancer organization accounts			Cancer advocate or survivor accounts			All accounts		
	Number approached	Number promoted	Promotion rate, %	Number approached	Number promoted	Promotion rate, %	Number approached	Number promoted	Promotion rate, %
Old accounts									
Cycle 1	197	9	4.6	104	19	18.3	301	28	9.3
Cycle 2	197	12	6.1	104	6	5.8	301	18	6
Cycle 3	197	11	5.6	104	20	19.2	301	31	10.3
Cycle 4	197	9	4.6	104	12	11.5	301	21	7.0
Cycle 5	197	0	0	104	6	5.8	301	6	2
Cycle 6	197	0	0	104	9	8.7	301	9	3
Mean per cycle	— ^a	—	3.5	—	—	11.5	—	—	6.3
New accounts									
Cycle 3	9	1	11.1	90	6	6.7	99	7	7.1
Cycle 4	32	6	18.8	97	19	19.6	129	25	19.4
Cycle 5	32	6	18.8	115	32	27.8	145	38	25.9
Cycle 6	0	0	0	133	35	26.3	133	35	26.3
Mean per cycle	—	—	17.8	—	—	21.1	—	—	20.7

^aNot applicable.

Characteristics of Cancer Survivors Approached Using Social Media Versus a National Representative Sample of Cancer Survivors

Compared with a nationally representative sample of 1550 cancer survivors who participated in the NHANES survey, those who responded to the survey promoted using Twitter were significantly younger (53.1 years vs 60.8 years) and more likely to be female (93.9% [417/444] vs 58.7% [909/1550]; $P < .001$), non-Hispanic white (85.4% [379/444] vs 64.0% [992/1550]; $P < .001$), and to have completed college education or higher (30.1% [133/444] vs 19.9% [308/1550]; $P < .001$; [Table 2](#)). The majority of survey respondents were from the United States

(360/444, 81.1%), with the remaining respondents from Canada (17/444, 3.8%), United Kingdom (13/444, 2.9%), and other countries (54/444, 12.2%).

Breast cancer survivors were the largest survivor group in both surveys, but a substantially higher percentage of breast cancer survivors responded to the social media survey than the national survey (71.2 [316/444] vs 46.2% [716/1550]; $P < .001$). Cancer survivors who responded to the social media survey reported a shorter interval from diagnosis (6.1 years vs 10.5 years; $P < .001$) and were more likely to be within 5 years of their initial diagnosis (55.2% [244/444] vs 34.1% [528/1550]; $P < .001$). In addition, nearly one-third of the respondents to the social media survey were still receiving treatment.

Table 2. Characteristics of adult cancer survivors in a social media survey compared with a national sample of cancer survivors.

Characteristics	CARE ^a (N=444)	NHANES ^b (N=1550)	P value ^c
Age at survey completion (years), mean (SD)	53.1 (10.6)	60.8 (14.2)	<.001
<45, n (%)	97 (21.9)	237 (15.3)	<.001
45-54.9, n (%)	143 (32.3)	221 (14.3)	— ^d
55-64.9, n (%)	138 (31.2)	336 (21.7)	—
65-74.9, n (%)	54 (12.2)	506 (32.7)	—
≥75, n (%)	11 (2.5)	250 (16.1)	—
Gender, n (%)			
Male	27 (6.1)	641 (33.5)	<.001
Female	417 (93.9)	909 (58.7)	—
Race/ethnicity, n (%)			
Non-Hispanic white	379 (85.4)	992 (64.0)	<.001
Non- Hispanic black	13 (2.9)	287 (18.5)	—
Hispanic	20 (4.5)	226 (14.6)	—
Other	32 (7.2)	45 (2.9)	—
Education, n (%)			
Grades 0-12	37 (8.4)	837 (54.0)	—
Some college	120 (27.2)	404 (26.1)	—
College graduates or above	133 (30.1)	308 (19.9)	<.001
Primary diagnosis, n (%)			
Breast cancer	316 (71.2)	716 (46.2)	<.001
Other cancer type	128 (28.8)	834 (53.8)	—
Time from diagnosis (years), mean (SD)	6.1 (6.5)	10.5 (10.6)	<.001
<5, n (%)	244 (55.2)	528 (34.1)	<.001
5-9, n (%)	116 (26.2)	385 (24.8)	—
≥10, n (%)	82 (18.6)	637 (41.4)	—

^aCARE: Cancer survivors Adherence to Recommendations for healthy Eating.

^bNHANES: National Health and Nutrition Examination Survey.

^cFor continuous variables (eg, age and time from diagnosis), the *P* values were generated from the analysis of variance (ANOVA) comparing the mean distribution between the 2 groups. For categorical variables (eg, age group, gender, race or ethnicity, education, primary diagnosis, and time from diagnosis group), the *P* values were generated from the Chi-square test comparing the frequency distribution between the 2 groups.

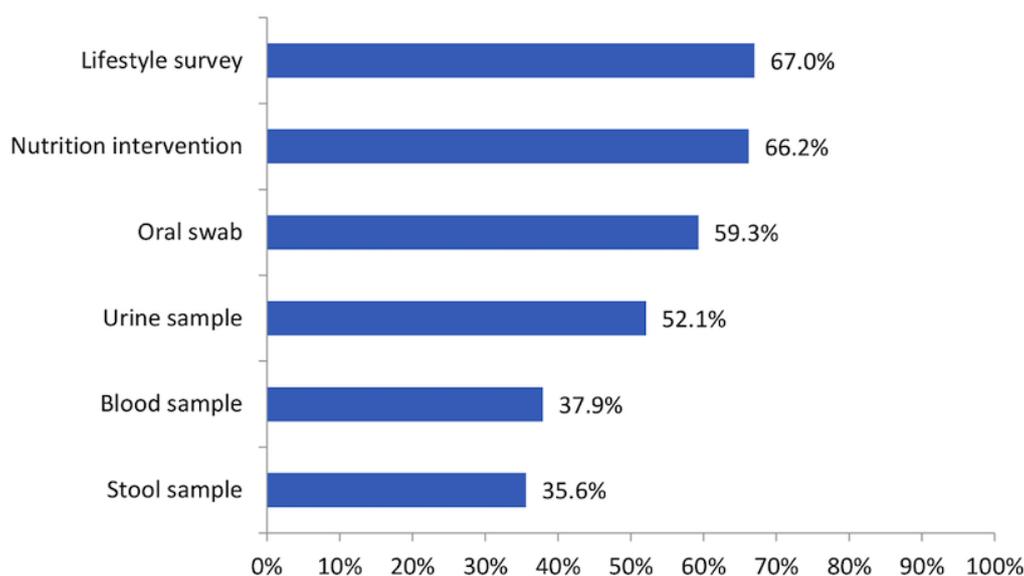
^dNot applicable.

Willingness to Participate in Nutrition Research and Interventions

About two-thirds (297/444, 67.0%) of the survivors indicated that they would be willing to complete web-based surveys about their nutrition, physical activity, and lifestyle behaviors. The percentages of the cancer survivors who indicated that they

would be willing to donate biospecimens were 59.3% (263/444) for oral swab, 52.1% (231/444) for urine sample, 37.9% (168/444) for blood sample, and 35.6% (158/444) for stool sample. About two-thirds (294/444, 66.2%) of the cancer survivors indicated that they would be willing to be contacted further to participate in web-based nutrition intervention programs (Figure 3).

Figure 3. Percentages of the 444 cancer survivors who indicated willingness to complete online nutrition survey, donate biospecimens for research, and willingness to be contacted to participate in online nutrition programs.



Factors Associated With Willingness to Complete Online Nutrition Survey, Donate Biospecimen, and to Be Contacted to Participate in Web-Based Nutrition Programs

Survivors' willingness to complete web-based nutrition surveys, donate biospecimens, and be contacted to participate in future nutrition programs through web-based platforms did not differ by survivors' demographic and cancer-related characteristics with a few exceptions: survivors who were 65 years or older

were less willing to complete web-based nutrition surveys compared with survivors who were younger than 45 years (odds ratio, OR=0.4, 95% CI 0.2-0.8); female survivors were more willing to complete web-based nutrition surveys than male survivors (OR=2.8, 95% CI 1.2-6.6); and survivors who had race other than non-Hispanic white were less willing to complete surveys (OR=0.6, 95% CI 0.3-1.0) or donate biospecimens (OR=0.4, 95% CI 0.2-0.7) compared with non-Hispanic white survivors, whereas breast cancer survivors were more willing to donate biospecimens than survivors of other cancer types (OR=1.7, 95% CI 1.0-2.8; [Table 3](#)).

Table 3. Factors associated with willingness to complete web-based lifestyle survey, donate biospecimen, and to be contacted to participate in web-based nutrition programs online among adult cancer survivors.

Variable	Willingness to complete web-based nutrition survey, OR ^a (95% CI) ^b	Willingness to donate biospecimen, OR (95% CI) ^b	Willingness to be contacted to participate in web-based nutrition programs, OR (95% CI) ^b
Age at survey completion (years)			
<45	Ref ^a	Ref	Ref
45-54.9	0.9 (0.5-1.6)	0.9 (0.5 – 1.6)	1.0 (0.6-1.8)
55-64.9	1.4 (0.8-2.5)	1.3 (0.8 – 2.4)	1.1 (0.6-2.0)
≥65	0.4 (0.2-0.8)	0.6 (0.3 – 1.1)	0.6 (0.3-1.2)
Gender			
Male	Ref	Ref	Ref
Female	2.8 (1.2-6.6)	1.7 (0.7 – 3.9)	1.9 (0.8-4.4)
Race/ethnicity			
Non-Hispanic white	Ref	Ref	Ref
Other	0.6 (0.3-1.0)	0.4 (0.2- 0.7)	0.8 (0.4-1.4)
Education			
Grades 0-12	Ref	Ref	Ref
High school/some college	1.5 (0.9 – 2.6)	1.0 (0.4 – 2.4)	0.6 (0.3 – 1.6)
College graduate or higher	1.2 (0.7 – 2.1)	1.0 (0.4 – 2.2)	1.2 (0.5 – 2.7)
Body mass index (kg/m²)			
<25	Ref	Ref	Ref
25-29.9	0.4 (0.3 – 0.7)	1.0 (0.6 – 1.6)	1.1 (0.7 – 1.8)
≥30	0.3 (0.2 – 0.5)	1.5 (0.9 – 2.6)	1.2 (0.7 – 2.0)
Primary diagnosis			
Other	Ref	Ref	Ref
Breast cancer	1.5 (0.9 – 2.5)	1.7 (1.0 – 2.8)	1.6 (1.0 – 2.7)
Treatment status			
On-treatment	Ref	Ref	Ref
Off-treatment	1.0 (0.6 – 1.6)	1.0 (0.6 – 1.5)	1.0 (0.7 – 1.6)
Time from diagnosis (years)			
<5	Ref	Ref	Ref
05-11	1.0 (0.6 – 1.7)	0.8 (0.5 – 1.3)	1.0 (0.6 – 1.6)
≥10	0.8 (0.5 – 1.5)	1.1 (0.6 – 2.0)	1.3 (0.7 – 2.3)

^aOR: odds ratios.

^bOdds ratios and 95% CIs were adjusted for age, sex, and race/ethnicity.

^cRef: reference.

Discussion

Principal Findings

Our study is among the first that utilizes Twitter as an exclusive method to recruit cancer survivors for web-based survey that assessed survivors' willingness to participate in nutrition research and to be contacted to participate in future web-based interventions. Our results suggest that Twitter is a feasible approach to reach cancer survivors in the community and

supports the potential of delivering web-based nutrition interventions to this population.

Using a systematic approach, we identified a list of Twitter accounts of both large cancer organizations and smaller cancer advocate and survivor groups to promote the survey. Although the average promotion rate among the original accounts was low, the total yield for survey responses was still promising: a total of 584 individuals responded to the survey, and 444 cancer survivors provided completed responses over 10 weeks.

Interestingly, the Twitter accounts that were not originally included in the contact list (ie, new accounts) had a much higher promotion rate, which may reflect the chain referral effect of snowball sampling associated with social media promotion. Despite the survey spanning over 10 weeks, the majority (74.1%) of our survey responses were received during the first cycle of survey promotion (ie, the initial 1.5 weeks), and fewer survey responses were received beyond the first 3 cycles of survey promotion. Thus, the initial 1 to 3 cycles (ie, the first 5 weeks) of the survey promotion is likely to result in the highest yield. These findings may represent the unique characteristics of survey promotion using Twitter.

Comparison With Prior Work

Similar to cancer survivors who responded to a social media survey reported by Attai et al [4], cancer survivors who responded to this Twitter survey tended to be young, female, non-Hispanic white, and receive a high level of education. As such, specific efforts are needed to enhance the representativeness of cancer survivors in a social media survey by reaching those who are older, male, and from racial/ethnic minorities or socioeconomically disadvantaged groups. Although social media recruitment was particularly effective in reaching breast cancer survivors, additional efforts are required to recruit cancer survivors with other cancer diagnoses that tend to be under-represented using social media recruitment. Future research should look to determine why this medium poses a challenge for recruitment of these particular groups, such as potential barriers in accessing or using social media and differences in motivations for participating in nutrition-related research [26,27]. Recruiting through social media groups of specific cancer types or reaching socioeconomic disadvantaged groups through community-based organizations may be combined with general social media recruitment to improve the representativeness of the population. Over half of the cancer survivors in our sample were within 5 years of their initial cancer diagnosis and nearly one-third were still receiving cancer treatment. This contrasts the finding that the majority of the cancer survivors in the general population who participated in NHANES were long-term survivors (ie, ≥ 10 years post diagnosis). These findings suggest that cancer survivors who are recently diagnosed might be more responsive to social media recruitment than long-term survivors.

Nearly two-thirds of the cancer survivors who responded to our survey reported that they were willing to participate in future nutrition research and to be contacted about future interventions. This finding supports the feasibility of utilizing Twitter to recruit cancer survivors for intervention and to employ it as a tool to deliver the intervention. Although social media holds great promise as a means of delivering health promotion, its use in the context of cancer research is still in its infancy. Few studies have utilized social media as a channel to deliver lifestyle interventions to cancer survivors [2]. One study that delivered

educational materials and messages to promote physical activity within closed Facebook groups reported a significantly greater increase in light physical activity (135 min/week) and weight loss (2.1 kg) over 12 weeks among 86 young adult cancer survivors [23]. The fact that the intervention was delivered entirely using Facebook and a self-monitoring site is promising and supports the feasibility of utilizing social media or other online platforms to deliver interventions to cancer survivors at a lower cost with a broader reach. Studies are needed to further evaluate how to leverage social media to promote health behaviors in cancer survivors and whether the behavioral change can be sustained. More broadly, research is needed to understand how social media is changing health communication in cancer care and to evaluate the possibility of incorporating social media into cancer care to provide optimal nutrition support [2,28].

Limitations

Our study has limitations. Although we developed a systematic approach to identify influential social media accounts for survey promotion, the number of followers we used to determine influential Twitter accounts is arbitrary. There are no standard or accepted methods to rate the influence of social media accounts. When identifying influential Twitter accounts through Symplur search, we adopted the ranking algorithm of the Symplur that provides specific assessments on Twitter accounts' active presence in health care. However, there have been few evaluations on Symplur's ranking algorithm; and it is possible that we failed to include other Twitter accounts that have an impactful social media platform to reach cancer survivors in the community. Second, we did not intend to identify accounts from other social media platforms such as Facebook. As Twitter accounts may be more heavily used by younger individuals, whereas Facebook can potentially reach more diverse groups, our findings may not be generalized to other social media recruitment methods [28].

Conclusions

In summary, the use of Twitter could be a promising approach to recruit cancer survivors in the community into nutrition research and interventions. About two-thirds of the cancer survivors reached through Twitter were willing to complete web-based nutrition and lifestyle surveys, donate biospecimens, and to be contacted to participate in future web-based nutrition programs. However, cancer survivors who responded to this social media recruitment tended to be younger, female, non-Hispanic white, and have a high level of education and were skewed to breast cancer survivors. Future research is warranted to identify effective approaches to reach a diverse and representative sample of cancer survivors using social media and to evaluate the cost-effectiveness of adapting nutrition interventions for web-based or social media delivery to improve the nutritional intake and long-term health of cancer survivors in the community.

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Conflicts of Interest

None declared.

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Abbreviations

CARE: Cancer survivors Adherence to Recommendations for healthy Eating

NHANES: National Health and Nutrition Examination Survey

OR: odds ratio

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Original Paper

A Smartphone App to Support Carers of People Living With Cancer: A Feasibility and Usability Study

Natalie Heynsbergh^{1*}, BNurs (Hons); Leila Heckel^{1*}, PhD; Mari Botti^{1,2*}, PhD; Patricia M Livingston^{3*}, BA (Hons), PhD

¹School of Nursing and Midwifery, Faculty of Health, Deakin University, Geelong, Australia

²Epworth HealthCare, Melbourne, Australia

³Faculty of Health, Deakin University, Geelong, Australia

*all authors contributed equally

Corresponding Author:

Natalie Heynsbergh, BNurs (Hons)

School of Nursing and Midwifery

Faculty of Health

Deakin University

Geelong,

Australia

Phone: 61 392446333

Email: nheynsb@deakin.edu.au

Abstract

Background: Carers experience unique needs while caring for someone with cancer. Interventions that address carers' needs and well-being have been developed and tested; however, the use of smartphone apps to support adult carers looking after another adult with cancer has not been assessed.

Objective: The objective of this study was to test the feasibility, usability, and acceptability of a smartphone app, called the Carer Guide App, for carers of people with colorectal cancer.

Methods: We recruited carers of people with colorectal cancer from outpatient day oncology units and provided them with access to the smartphone app for 30 days. Carers had access to video instructions and email contact details for technical support. Carers received 2 email messages per week that directed them to resources available within the app. Carers completed demographic questions at baseline and questions related to feasibility and usability at 30 days post app download. We used recruitment and attrition rates to determine feasibility and relevance of content to carers' needs as self-reported by carers. We assessed usability through the ease of navigation and design and use of technical support or instructional videos. Acceptability was measured through self-reported usage, usage statistics provided by Google Analytics, and comments for improvement.

Results: We recruited 31% (26/85) eligible carers into the trial. Of the 26 carers, the majority were female (19, 73%), on average 57 years of age, were caring for a spouse with cancer (19, 73%), and held a university degree (19, 73%). Regarding feasibility, carers perceived the content of the Carer Guide App as relevant to the information they were seeking. Regarding usability, carers perceived the navigation and design of the app as easy to use. Of the 26 carers, 4 (15%) viewed the downloading and navigation video and 7 (27%) used the contact email address for queries and comments. Acceptability: On average, carers used the smartphone app for 22 minutes (SD 21 minutes) over the 30-day trial. Of 26 participants, 19 completed a follow-up questionnaire. Of 19 carers, 7 (37%) logged on 3 to 4 times during the 30 days and 5 (26%) logged on more than 5 times. The majority (16/19, 84%) of carers stated that they would recommend the app be available for all carers. Comments for improvement included individualized requests for specific content.

Conclusions: The Carer Guide App was feasible and usable among carers of people with colorectal cancer. Acceptability can be improved through the inclusion of a variety of information and resources. A randomized controlled trial is required to assess the impact of the Carer Guide App on carers' health and well-being.

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KEYWORDS

cancer; carer; mobile app; smartphone; technology; mobile phone

Introduction

In Australia, there are over 2.86 million informal carers who are not paid for the care they provide [1] and who often perform caring duties with limited training or guidance [2]. Many people with cancer rely on carers, such as family members or friends, for support during their illness trajectory [3] and for management of the side effects of treatment [3]. Carers looking after someone with cancer may experience unique needs related to their own health and well-being while in the caring period [4] and for as long as 5 years after the caring period [5].

A systematic review highlighted that Web-based interventions were feasible for use among cancer carers [6]; however, carers' preference for information delivery varies across the disease trajectory. Smartphone apps can support carers by providing access to information, support, and resources from any place where an individual has internet connection [7]. Smartphone ownership continues to increase worldwide [8], creating an opportunity for apps to deliver health care content to large audiences [9]. Previous studies have assessed the use of smartphone apps among carers looking after a child with cancer [10] and looking after people with a variety of chronic illnesses [11]. Smartphone apps have been shown to improve participation in self-management of chronic illness [11], improve communication with health professionals [11], and promote detection of changes in cancer-related pain in children [10]. Further, several studies have evaluated the development of smartphone apps for carers of people with diabetes [12], adults looking after a child with cancer [13], and people living with back and spinal cord anomalies and their carers [14] and have described positive attitudes toward receiving support through smartphone apps. To our knowledge, no smartphone app has been trialed among carers looking after another adult with cancer [6]. In this study, we aimed to test the feasibility, usability, and acceptability of a smartphone app, called the Carer Guide App, in addressing the unmet needs of cancer carers.

Methods

Design

This study was a 30-day, single-arm pilot trial involving carers supporting people diagnosed with cancer. We chose colorectal cancer as it affects both men and women and is the third most common cancer worldwide [15,16].

We recruited carers of colorectal cancer patients from the second largest public health service and the largest not-for-profit private health service in Victoria, Australia. During 6 months, the public health service treated 105 people with colorectal cancer and the private health service had 273 admissions. Between October 2017 and May 2018, we approached carers during the patients' chemotherapy appointment and provided them with an overview of the study. Patients nominated carers as being their main support person at home. Interested carers were provided with a recruitment pack (participant information sheet, consent form, and demographic questionnaire) to take home. When carers were unavailable at appointments, we approached patients, gave them an overview of the study, and asked whether their carer would be willing to participate. We asked the patients to take

home the carer recruitment pack and sought initial consent via telephone to the carer within 48 hours to confirm participation. All carers provided written informed consent.

Adult carers of adult patients with colorectal cancer who were receiving chemotherapy or radiation treatment as day patients, either initial, recurrent, or secondary to surgery, were invited to participate. Carers were required to be in possession of a smartphone or tablet device and have internet access. At the end of the 30-day trial, carers received 2 reminder phone calls to return follow-up questionnaires. Follow-up occurred between November 2017 and May 2018. We obtained ethics approval from Deakin University (2017-218), Eastern Health (HREC/17/EH/24), and Epworth HealthCare (EH2016-169).

Intervention

We developed the Carer Guide App using a codesign approach to address needs that carers identified in previous research [6,17,18]. A full description of the development process of the Carer Guide App is currently under review. The Carer Guide App was organized into 7 sections, each providing detailed information to address carers' needs: Cancer Information, Carer Information, Well-being, My Social Network, Financial and Legal, Hospital Information, and Medical Terminology. In addition, two resources were provided: a Notepad and Contacts, which contained contact details for national information and support organizations and allowed carers to enter personal contact information. All carers had access to the Carer Guide App for 30 days and received 2 email messages each week directing them to information and services available within the app. Email messages related to carer health and well-being and support were available to carers. Messages were developed for each section of the Carer Guide App and provided information or reminders about the support that was available and where to locate this information within the Carer Guide App.

Upon enrollment in the study, carers provided a contact email address. We entered the nominated email address into the Carer Guide App system, which sent an automatically generated welcome email to carers. The welcome email included a link to download the Carer Guide App, a user identification number, password, and links to videos with instructions on how to download and navigate the Carer Guide App on both Android and iOS devices. Carers were provided with an email address to contact the research team for further technical support if required.

Measures

Demographic Characteristics

We collected information on carers' age, gender, living situation, relationship to the patient, level of education, and device type used for the study. Likert scales were developed to measure elements of feasibility, usability, and acceptability.

Feasibility

Feasibility included carers' perception of the relevance of app content and accompanying email messages. We measured app content on a scale from extremely unuseful (1) to extremely useful (5). The helpfulness of email reminders was measured on a scale of extremely unhelpful (1) to extremely helpful (5).

For the relevance of the content and usefulness of messages, carers could also respond with option 6, which represented “I did not use this icon” and “did not apply to me,” respectively. We developed Likert scales for the purpose of informing the relevance of each section of the Carer Guide App to inform future iterations. This follows guidelines where testing evaluation procedures can occur during feasibility studies [19]. A similar process has been used in the development of Web-based interventions, where scales have been validated during subsequent trials [20].

Usability

Usability included the navigation and readability of the app and was measured from strongly disagree (1) to strongly agree (5). We included open-ended questions to allow carers to provide comments for improving the Carer Guide app. We also measured usability by the number of people who accessed the instructional videos and who emailed the research team for technical support.

Acceptability

Acceptability included responses about carers' use of the Carer Guide App for information and support, their desire to continue to use the app after the 30-day trial, and their feelings toward the Carer Guide App being made available to all carers. We measured items from strongly disagree (1) to strongly agree (5). App usage was measured quantitatively through self-reported usage and through Google Analytics records. Google Analytics tracked the number of log-ins, the duration of log-in, and the pages accessed.

Statistical Analysis

We analyzed data using IBM SPSS (Version 25; IBM Corp). Feasibility, usability, and acceptability were analyzed by the frequency of agree (4) and strongly agree (5) responses. Demographic data and app usage from Google Analytics were analyzed using descriptive statistics.

Results

Demographic Characteristics

Of 85, a total of 26 (31%) carers consented to participate in the study, of which 20 (77%) used the Carer Guide App and 19 (73%) completed the follow-up questionnaires (attrition rate 7/26, 27%). Of the 7 carers who did not complete the follow-up questionnaire, 1 used the app and 6 did not use the app. There was 1 person who completed the follow-up questionnaire but did not use the app as he or she was not in need of it at the time. [Figure 1](#) outlines the recruitment process.

The mean age of carers was 57 (SD 12; range 30-79) years. Of the 26 carers, the majority were female (19, 73%), caring for a spouse (26, 73%), and held a tertiary-level qualification (19, 73%); furthermore, the main device type used by carers was smartphones (15, 58%). There were 2 carers who accessed the Carer Guide App on their desktop computers (Web app version). [Table 1](#) outlines the full demographic characteristics of the sample.

Feasibility

Appropriateness of App Content

Of 19, the majority of carers rated Cancer Information (13, 68%), Carer Information (12, 63%), and Medical Terminology (12, 63%) as somewhat or extremely useful; the sections with the lowest agreement rate for usefulness were My Social Network (3, 16%) and Financial and Legal (4, 21%). Overall, the vast majority (16/19, 84%) of carers agreed or strongly agreed that the built-in links went to relevant websites. [Table 2](#) provides detailed information on the usefulness of each section of the Carer Guide App.

Reminder Emails

Reminder emails were perceived as helpful by one-third of carers. The prompt to *take time out for yourself* related to well-being and was rated as helpful by the majority of carers (12/19, 63%), followed by Contact reminders for *information on holiday house programs* (10/19, 53%) and Carer Information reminders to *stay physically active* (10/19, 53%).

Usability

The appearance and function of the Carer Guide App were reported as usable by the majority of carers; 17/19 (89%) found the font size appropriate, 13/19 (68%) found it easy to move between pages, and 11/19 (58%) stated that required information was easy to find. There were 4 carers who viewed the video instructions on how to download and navigate the Carer Guide App. The Carer Guide App's email address was used by 7 carers to contact the research team with questions related to setting up the app on their phone or to provide comments in response to reminder emails sent.

Acceptability

The majority of carers (16/19, 84%) agreed that the Carer Guide App should be available for all carers. Furthermore, 42% (8/19) stated that they used the app when they wanted more information and 42% (8/19) stated that they would like to continue using the app, while only 11% (2/19) reported that they used the app for support.

Usage

Findings from Google Analytics showed that over the 30-day trial period, a total of 71 log-ins occurred on the app. Of 19, more than one-third of carers (7, 37%) logged in 3-4 times during the 30 days and one-quarter (5, 26%) of carers logged in more than 5 times. On average, carers used the Carer Guide App twice (range 0-11), and median use was 17 minutes (interquartile range 4-35). Nearly half, 8/19 (42%) of carers used the Carer Guide app for longer than 30 minutes. According to self-reported usage, one-quarter (5/19, 26%) of carers used the Carer Guide App once a week. The top three most frequently used sections of the Carer Guide App were Cancer Information, Notepad, and Well-being, which were accessed 33, 33, and 31 times, respectively. [Table 3](#) provides details of usage statistics.

Figure 1. Flowchart of the recruitment process.

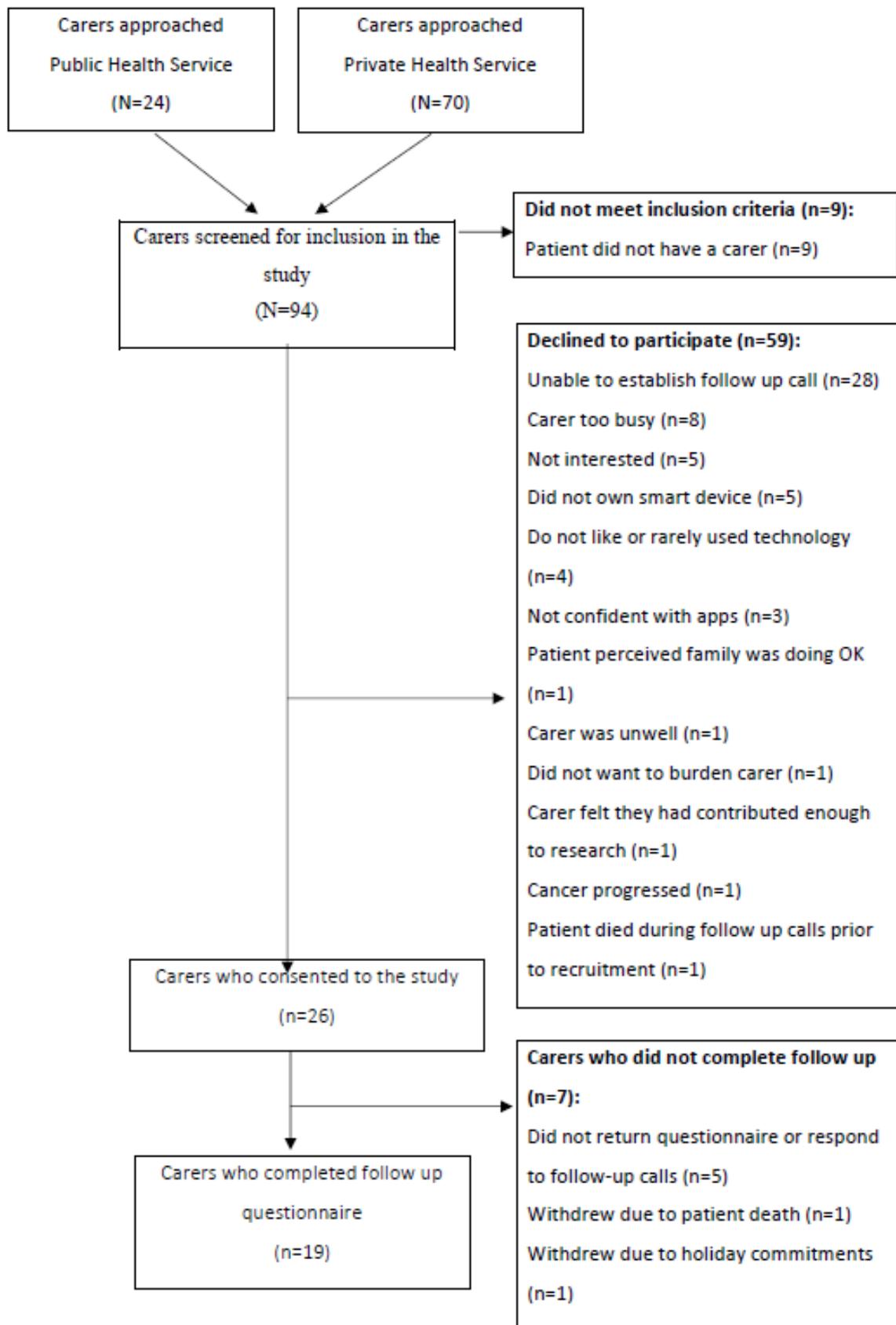


Table 1. Demographic characteristics of the recruited carer participants (N=19).

Characteristics	Participants, n (%)
Device used	
Android mobile phone	5 (19)
iOS mobile phone	10 (38)
iOS tablet	3 (12)
Computer desktop	2 (8)
Gender	
Female	19 (73)
Male	7 (26)
Relationship status	
Spouse	19 (73)
Other (parent, adult child, or sibling)	7 (27)
Living with patient full time	
Yes	21 (81)
No	5 (19)
Education level	
Secondary	7 (27)
Tertiary	19 (73)

Table 2. Carers' responses of the usefulness of each section of the Carer Guide App (N=19).

App section	Median ^a	Agree or strongly agree responses (n=19), n (%)
Cancer Information	4	13 (68)
Carer Information	4	12 (63)
Medical Terminology	4	12 (63)
Well-being	4	9 (47)
Email messages	4	8 (42)
Contacts	3	8 (42)
Hospital Information	3	7 (37)
Notepad	3	6 (32)
Financial and Legal	3	4 (21)
My Social Network	3	3 (16)

^aResults from a 5-point Likert scale (1=extremely unuseful to 5=extremely useful).

Qualitative Feedback

Of 19, 11 (58%) carers provided comments for improvements to the Carer Guide App. The majority of comments related to additions of items to the content, including the ability to journal events and symptoms, record a medical history and medical alerts, send to others for their use, and print off information sheets for the patient. Other comments related to content included more specific information about "red flags" for patients and carers; when to call the doctor; symptom information and

management; medication information; contact details of doctors, nurses, and oncology wards; and information in different languages. Other comments included discrepancies in the tone of language used in medical terminology definitions, that the app should be delivered earlier in the caring period, and that the role of the carer needs to be more clearly highlighted, in particular, that the role varies across the illness trajectory.

Of all carers, 2 noted that the Carer Guide App gave them the confidence to deal with cancer-related issues and that it was the first time they felt someone cared about their needs.

Table 3. Carer Guide App usage including frequency of log-ins, duration of log-ins, and sections visited (N=19).

Characteristic	Value
Frequency of log-ins (n=19), n (%)	
1-2 log-ins in 30 days	7 (37)
3-4 log-ins in 30 days	7 (37)
>5 log-ins in 30 days	5 (26)
Duration of use per log-in (minutes)	
Mean (SD)	22 (21)
Range	0-68
Total duration of use over 30 days	403
Total number of visits per Carer Guide App section (n=207), n (%)	
Cancer information	33 (16)
Carer information	26 (13)
Well-being	31 (15)
My social network	19 (9)
Financial and legal	16 (8)
Contacts	14 (6)
Hospital information	20 (10)
Notepad	33 (16)
Medical terminology	15 (7)

Discussion

Principal Findings

The Carer Guide App was developed in collaboration with carers to improve their access to information and support while looking after another adult with cancer. Overall, the Carer Guide App was a feasible option given the feedback received from participants. Carers perceived the content to be appropriate, and the links within the Carer Guide App led to relevant information. Certain sections of the app were perceived as more useful than others. However, all sections of the app received positive responses. These findings are comparable with Web-based interventions among people living with prostate cancer, where 47% of the people were satisfied with the program [21]. Differences in the perceived usefulness of the app sections may have several explanations. The type and amount of unmet needs experienced by carers constantly change [5]; therefore, a 30-day period to assess the appropriateness of content in addressing carers' needs may not be long enough. Similarly, carers may experience different types of needs during different stages of the illness trajectory [22-25]. The static information provided in the Carer Guide App may not support needs as they evolve. Further, carers who had been in the carer role for a prolonged period may already have sourced the information and support required. It is possible that the Carer Guide App provided carers with information and resources that they were previously unaware of; however, more research is required to assess this. Despite these findings, 85% (16/26) of carers stated that the Carer Guide App should be available to all carers, and this is comparable to other studies evaluating the feasibility of cancer-related Web-based interventions [21].

Generally, carers found the email messages helpful in highlighting resources available within the Carer Guide App. Carers perceived the structure of the Carer Guide App as easy to navigate and locate information. Email support was used by several carers to enhance their experience and provide further instruction on using the app. These findings confirm the usefulness of technical support to aid the use of technology-based interventions for carers previously reported in the literature [6].

With a total of 71 log-ins and an average usage of 22 minutes over the 30-day trial period, the Carer Guide App was assessed to be acceptable to carers. Users often disengaged from sites within 10-20 seconds if they were unable to locate information [26]. As the average use in our sample was 22 minutes, this suggests that the Carer Guide App was acceptable for the information and resources provided within it. App usage varied greatly depending on the purpose of the app, and previous research has required participants to log in a specific number of times [10]. In another study involving a smartphone app providing static information for dementia, usage was on average 5 minutes for the duration of the 4-week period [27]. Further, findings of previous research suggested that smartphone apps did not impose a time burden on participants, and they could be incorporated into a daily routine from anywhere between 3 days to 1 year [10,11]. Carers reported that the Carer Guide App should be available to all carers, and suggestions for further improvements were mainly individual requests for specific information, resources, or design changes.

The recruitment rate of the study was modest (26/85, 31%); however, this is consistent with findings from previous research,

where recruitment among this population can vary from 20% to 60% for technology-based intervention studies [6].

Future Research Directions

Carers' willingness to use smartphone apps and their need for this type of support may be impacted by patients' stage of illness, carers' knowledge of support available, and carers' current support network. Future research may consider assessing smartphone app support at a certain stage of patients' illness, for example, at diagnosis, to test its potential impact. This may provide information about the relevance of content to carers' current and future needs, the ability of a smartphone app to meet needs, and carers' likelihood of using a smartphone app during this stressful period. Future studies may also consider measuring carers' knowledge of alternative support available and the presence and strength of their support network.

Limitations

The sample was largely homogenous, with the majority of participants being female and highly educated, with all participants speaking English. In the general population in Australia, 31% has tertiary-level educational qualifications, [28]

compared with 73% (19/26) of our sample, and 21% speak a language other than English at home [29]. Future studies should include larger samples to gain insights into feasibility, usability, and acceptability among a more heterogeneous sample. The duration of the caring period and patients' stage of illness were not collected, which further limited the ability to determine whether the Carer Guide App was more feasible during specific stages of the caring or illness trajectory.

Conclusions

A smartphone app may be appropriate for providing carers with more information and resources if the content is specific to their needs and provided at an optimal time during the caring period. The Carer Guide App is a feasible and acceptable method for delivering information and support to carers of people with colorectal cancer. Future iterations should include more specific information to enhance the acceptability of the App. Further research, including a randomized controlled trial, is recommended to assess whether a smartphone app has the potential to improve health and well-being outcomes and reduce unmet needs among carers.

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Conflicts of Interest

None declared.

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Original Paper

Usability, Acceptability, and Usefulness of an mHealth App for Diagnosing and Monitoring Patients With Breakthrough Cancer Pain

Jaime Boceta^{1*}, MD; Daniel Samper^{2*}, MD; Alejandro de la Torre^{3*}, MD; Rainel Sánchez-de la Rosa^{4*}, MD, PhD; Gloria González^{5*}, MSc

¹Unidad de Hospitalización Domiciliaria y Cuidados Paliativos, Servicio de Medicina Interna, Hospital Universitario Virgen de la Macarena, Sevilla, Spain

²Servicio de Anestesiología, Clínica del Dolor, Hospital Germans Trias i Pujol, Badalona, Spain

³Servicio de Oncología Radioterápica, Hospital Universitario Puerta del Hierro, Madrid, Spain

⁴Medical Department, Teva Pharmaceutical, Madrid, Spain

⁵Adelphi Spain, Barcelona, Spain

*all authors contributed equally

Corresponding Author:

Jaime Boceta, MD

Unidad de Hospitalización Domiciliaria y Cuidados Paliativos

Servicio de Medicina Interna

Hospital Universitario Virgen de la Macarena

Avd. Doctor Fedriani, 3

Sevilla, 41071

Spain

Phone: 34 955 00 80 00

Email: bocetajaime@gmail.com

Abstract

Background: Breakthrough pain is a major problem and a source of distress in patients with cancer. We hypothesized that health care professionals may benefit from a real-time mobile app to assist in the diagnosis and monitoring of breakthrough cancer pain (BTcP).

Objective: This study aimed to test the usability, acceptability, and usefulness in real-world practice of the mobile App INES·DIO developed for the management of patients with BTcP.

Methods: This study consisted of a survey of a multidisciplinary sample of 175 physicians who evaluated the mobile app after testing it with 4 patients with BTcP each (for a total of 700 patients). The digital profile of the physicians, use of the different resources contained in the app, usefulness of the resources, acceptability, usability, potential improvements, intention to use, and additional resources to add were recorded.

Results: Of the 175 physicians, 96% (168/175) were working in public hospitals. They had an average of 12 (SD 7) years of experience in BTcP and almost all (174/175, 99.43%) had an active digital profile. The Eastern Cooperative Oncology Group and Karnofsky performance scales, the Visual Analogue Scale, and the Davies algorithm to diagnose BTcP were the most frequently used tools with patients and were assessed as very useful by more than 80% (140/175) of physicians. The majority (157/175, 90%) answered that App INES·DIO was well designed and 94% (165/175) would probably or very probably recommend it to other colleagues. More than two-thirds indicated that the report provided by the app was worth being included in patients' clinical records. The most valued resource in the app was the recording of the number, duration, and intensity of pain flares each day and baseline pain control to enhance diagnosis of BTcP. Additional patient-oriented cancer pain educational content was suggested for inclusion in future versions of App INES·DIO.

Conclusions: Our study showed that App INES·DIO is easy to use and useful for physicians to help diagnose and monitor breakthrough pain in patients with cancer. Participants suggested the implementation of additional educational content about breakthrough pain. They agreed on the importance of adding new clinical guidelines/protocols for the management of BTcP, improving their communication skills with patients, and introducing an evidence-based video platform that gathers new educational material on BTcP.

KEYWORDS

breakthrough cancer pain; mHealth; mobile app; App INES·DIO

Introduction

Background

Pain is one of the most prevalent health-related concerns and most common clinical conditions for seeking medical help [1]. In cancer patients, pain is a frequent and distressing symptom, which occurs in up to 40% of patients in the early stages of the disease and rises to 70%-90% in its most advanced stages [2-4]. Despite adequately controlled background pain, many patients experience transient exacerbations of severe pain, known as breakthrough cancer pain (BTcP), a complicated state of pain that negatively impacts patients' quality of life and provokes intense suffering. Indeed, BTcP episodes are associated with increased levels of depression and emotional disorders, interfering with other aspects of the disease, and result in higher health care costs both for patients and society [5,6].

With the aim of improving BTcP management, the Spanish Society of Medical Oncology published recommendations in 2013 for the diagnosis and treatment of BTcP and launched a program for the diffusion and implementation of these recommendations [7]. However, even today there is no unanimous consensus among specialists on the clinical features for defining BTcP.

Factors considered in the definition of BTcP as well as the procedures for its diagnosis, assessment, and monitoring may influence the choice of a treatment and consequently, patient outcomes. Hence, it was important to obtain a consensus on these issues from a broad group of experts in cancer pain.

Recently, Boceta et al published the results of a two-round Spanish multicenter exploratory Delphi study that investigated the opinion of an expert panel in cancer pain to conclude how to define, diagnose, assess, treat, and monitor BTcP [8]. The study intended to seek consensus in the definition of BTcP and identify the challenges regarding a set of recommendations for the complete management of BTcP in clinical practice. Regarding the clinical aspects for diagnosing BTcP, it was generally agreed that (1) background pain should be controlled, but not necessarily with opioids, (2) there must be exacerbations (no matter whether the number of flares per day are ≥ 4 or not), (3) the duration of an episode should be ≤ 1 hour, (4) intensity of pain greater than 7 out of 10, and (5) it is not considered the same as an end-of-dose effect. The Davies algorithm was recommended for diagnosing BTcP. All these recommendations should be followed in the day-to-day clinical practice to enhance the management and control of patients with BTcP.

The results of the Delphi study were used for the development of a real-time mHealth cancer pain app named App INES·DIO

(the abbreviation in Spanish for Instrument for the Assessment and Monitoring of Breakthrough Cancer Pain).

Internet-based and mHealth apps are transforming how people monitor, manage, and communicate health-related information [9]. mHealth supports public health interests through the use of mobile devices [10,11]. Mobile apps to improve health are proliferating, but before health care providers or health care organizations can recommend an app, strategies for evaluating them are necessary. More primary research is needed to identify apps that are effective, provide accurate information, and are user-friendly [12].

The App INES·DIO

App INES·DIO was developed by an international information technology expert company (Virtualware, Bizkaia, Spain), which was licensed by the Spanish Agency of Medicines and Medical Devices in 2014. The contents of App INES·DIO as well as the test phase of the app were the responsibility of Adelphi Spain, a health and marketing research group. Of note, the usability testing will be removed from the mHealth app as this study phase is completed, and the name of the app, when commercially launched, will be different.

With the rise of smartphone usage in the medical field, the Food and Drug Agency announced in 2013 that it would regulate mobile medical apps to protect users. European and other regulatory agencies soon followed suit [13]. App INES·DIO is certified as a CE-mark Class-1 medical device used to produce or change data on individual cancer patients with the aim of a better management and control of the breakthrough pain.

It has been reported that native mobile apps are better accepted by end users than webpages or Web apps and provide better support for customization of device characteristics [14,15]. Our idea was to create a mobile app able to run as a native app on various mobile platforms and operating systems (eg, Android, iOS). The content of App INES·DIO gathered the most significant results of a Spanish Delphi study about the consensus and controversies in the definition, assessment, treatment, and monitoring of BTcP [8]. This app allows the physician to generate an individual patient register to be included (via email) in the patient's clinical history.

The app development process was conducted following three steps: (1) enter a new case (ie, use the app with a new patient) with complete information on the breakthrough pain, (2) create a new report with all input data on the cancer patient, and (3) complete an assessment test related to the usability of the app (Figures 1 and 2). This last step will be no longer available upon the completion of this study and will therefore not be present in the future version of the App INES·DIO. The app was developed in the Spanish language.

Figure 1. Screenshots of App INES-DIO: a) starting workflow of the app, b) general information and toolbar for a new patient registry, c) definitions of breakthrough cancer pain (BTcP), d) diagnosis of BTcP.



Figure 2. Screenshots of App INES-DIO: e) other considerations for diagnosing breakthrough cancer pain (BTcP), f) evaluation of baseline pain, g) diagnosing neuropathic pain, and h) Edmonton’s Classification of cancer pain.

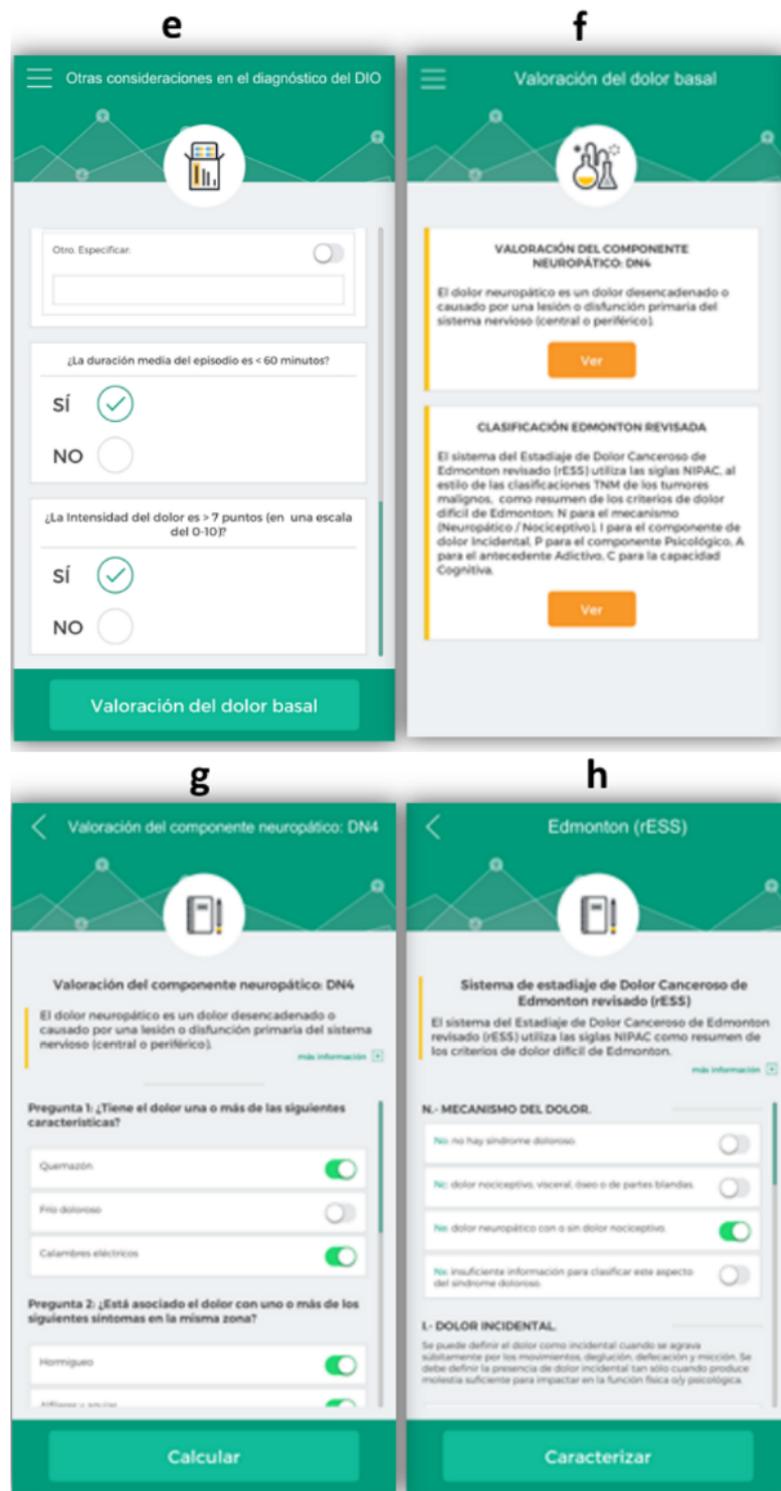
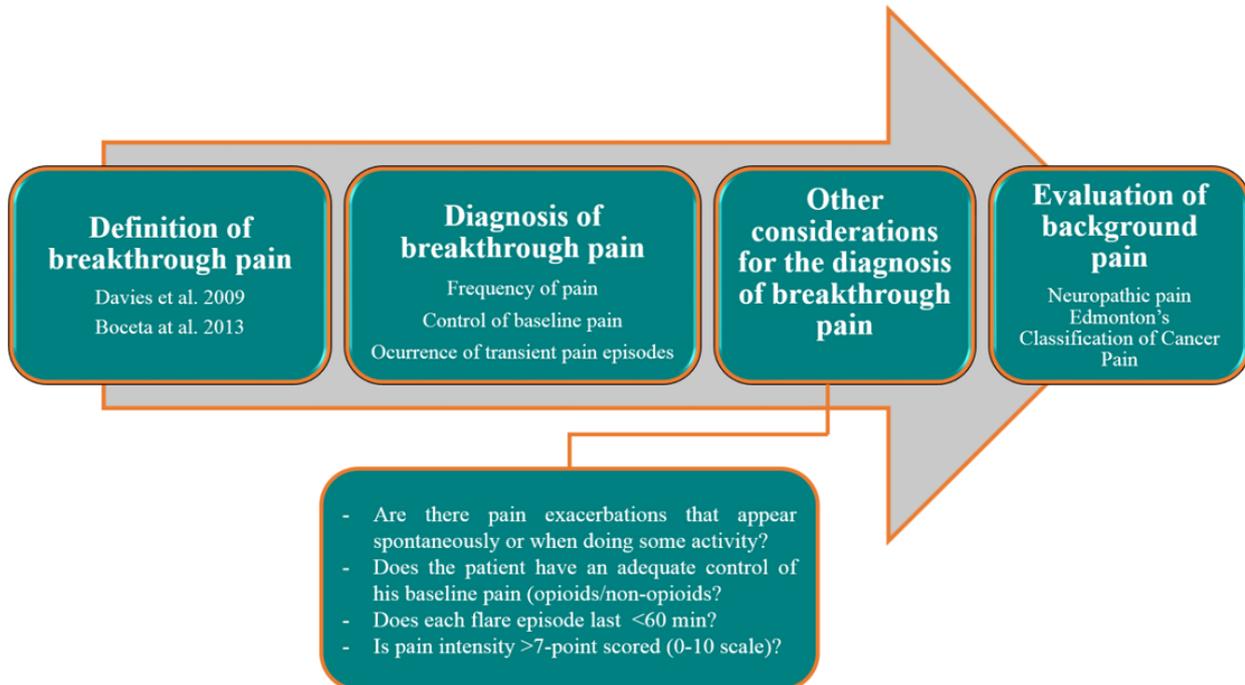


Figure 3. App INES-DIO workflow that guides a clinician to open a new patient registry.



When launching the app, the user is requested to open a new registry for each patient and to go through four sequential steps (Figures 1 and 2). The workflow of a new register is summarized in Figure 3. After reading two different definitions of BTcP (Figures 1 and 2), additional information related to the Davies algorithm for BTcP diagnosis (ie, frequency and control of baseline pain, and the occurrence of transient pain episodes) is introduced (Figures 1 and 2). Davies et al [6] defined BTcP as a transitory exacerbation of pain that occurs, either spontaneously or may be associated with predictable factors, even though the baseline pain is relatively stable and well controlled. In line with Davies' definition, Escobar et al [16] adopted the term "breakthrough pain" to describe a sudden and transient exacerbation of pain of high intensity and short duration (<20-30 minutes), which appears over the baseline of a stable persistent pain, when this has been reduced to a tolerable level by the use of strong opioids [6,16,17]. Both definitions allow us to distinguish BTcP from end-dose pain flares and those flares that occur during the drug analgesics titration of the background pain.

The clinician is then asked to fill in other considerations for a better diagnosis of BTcP (Figures 1 and 2). Once this last item is completed, the app immediately allows remote clinicians to assess each patient's baseline pain (Figures 1 and 2). They are then asked to evaluate the neuropathic component of cancer pain using the DN4 questionnaire (Douleur Neuropathique 4) (Figures 1 and 2) and the last revised Edmonton Classification System for Cancer Pain (Figures 1 and 2).

Additionally, below the general information compiled to diagnose BTcP when registering a new patient, there is a toolbar incorporated into the app to help physicians diagnose and monitor patients with BTcP (Figures 1 and 2). Tools included were as follows: (1) Opioid rotation refers to a switch from one opioid to another in an effort to improve the response to

analgesic therapy or reduce adverse effects, (2) Functional scales to assess the quality of life of cancer patients: the Karnofsky index (an attempt to quantify cancer patients' general well-being and activities of daily life) and the Eastern Cooperative Oncology Group (ECOG) Scale (standard criteria for measuring how the disease impacts cancer patients daily living abilities such as ability to care for themselves, daily activity, and physical ability like walking, working, etc), (3) Pain rating scales include the Visual Numeric Scale (VNS), which is a segmented numeric version of the Visual Analog Scale (VAS) in which a respondent selects a whole number (0=no pain, 10=worst pain) that best reflects the intensity of pain, and the Categorical Scale (CS) (none/mild/moderate/severe), used only when the patient is not able to self-assess pain with any of the former scales, (4) the Charlson Comorbidity Index, which predicts 10-year survival in patients with multiple comorbidities (ie, age, acute myocardial infarction, congestive heart failure, peripheral arterial disease, cerebral-vascular disease, dementia, chronic pulmonary disease, connective-tissue disease, peptic ulcer, liver disease, diabetes mellitus, hemiplegia, renal failure, solid tumors, blood malignancies, and AIDS), and (5) PQRST pain assessment questions (P: provocative and palliative factors; Q: qualitative description of pain, "What does it feel like?"; R: region and radiation of pain; S: severity or intensity of pain after being scored by means of VNS and CS; T: timing or pain changes over time).

It is both interesting and critical to evaluate and improve information and communication technology tools before trying to distribute them. The ergonomic approach consisting of evaluating first in order to improve later may fulfil this goal. We therefore used an ergonomic framework where the quality of the App INES-DIO was defined by its usability, acceptability, and usefulness. These three elements have been already defined elsewhere [18]. Usability refers to ease of use and can be

evaluated with criteria such as efficiency, acceptability (to address each physician's desire to use App INES·DIO in the future), and lastly, usefulness (ie, relevance or efficacy), answering the question of whether the app allows physicians to reach their goal in BTcP management. The primary objective of this study was to carry out first-of-its-kind testing on App INES·DIO to understand usability, acceptability, and usefulness in real-world practice as well as the need to include new information and recommendations for better care of cancer patients with BTcP.

Methods

Study Design

To evaluate App INES·DIO, we performed a survey research study of both the mobile phone and tablet computer versions of the app. This research consisted of testing the usability of a novel prototype to validate the acceptability and usefulness of mobile app tools in the daily clinical practice of patients with BTcP.

Usability testing was conducted using a structured questionnaire to collect responses to 33 questions divided into three different blocks: (1) demographic and professional profile of participants, including gender, age, professional background, experience in treating BTcP patients, (2) participants' digital profile, focused on previous experiences with mobile phone and tablet devices, and previous use of mHealth apps, and (3) a patient-related questionnaire based on those clinical features that could help when diagnosing and monitoring BTcP in cancer patients. At the end of testing period, participants were asked to answer follow-up questions about the app design and its features, its overall usefulness, their intention to use it in other type of patients (not only those BTcP-related), the acceptability of the mobile app and its features in everyday health management, and new interesting content to be included in the mobile app in the future.

Participants

Our study sample consisted of 175 medical doctors from all over Spain from different health care units: medical oncology (n=66), radiation oncology (n=48), palliative care (n=42), pain units (n=18), and others (n=1). Participants worked in public hospitals (96%) and were highly experienced in BTcP (>12 years with more than 412 patients attended in the last year).

Every participant was asked to test the usability and the value in the clinical setting of App INES·DIO in 4 cancer patients each (this makes a total of 700 patients), with a different clinical profile of BTcP: newly diagnosed or in follow-up.

Data Analysis

A descriptive study of the variables was carried out according to their type. For numeric variables, measures of central tendency and dispersion (eg, sample size, mean, median, minimum, maximum, standard deviation, 95% confidence interval) were applied. For the categorical variables, frequency distribution tables and percentages (n, %) were provided.

To evaluate some of the answers, a 7-point Likert-type rating scale was used (1=strongly disagree/never/never recommend, and 7=strongly agree/always/always recommend).

Results

Professional and Digital Profile of Participants

The survey showed 48.6% of participants (85/175) were female and 51.4% (90/175) male, and 37.6% of participants (64/175) were between 36-45 years old. Over three-quarters (134/175, 76.6%) of the sample were physician assistants, and all BTcP-related medical specialties were represented among participants. Panelists mostly worked at public health care centers (168/175, 96%) and half of them (87/175, 49.7%) in large hospitals (≥ 500 beds). Participants had >12 years (SD 7) experience managing patients with BTcP, with an average of >400 patients attended during the last year. About a fifth (36/175, 20.5%) of physicians recruited for the study had also participated in the previous Delphi consensus study [8]. Most of the sample (155/175, 88.9%) was aware of the recommendations and (150/175, 85.5%) considered them to be useful for their clinical daily practice. Table 1 shows the digital profile of the sample. All participants owned a private mobile phone and had access to different types of apps for private use (ie, maps, email, press news, instantaneous communication platforms) and professional use (20% of downloaded apps are for clinical use). The most commonly used function on the Web related to at least one social network (ie, Facebook, LinkedIn).

Mobile App Intervention in Patients

App INES·DIO was tested by 175 panelist clinicians after using it with 700 patients (4 patients per participant). Patients had been diagnosed with BTcP on average 3.77 months before this study. The app was mainly used to help physicians during their visit with cancer patients (79/175, 45.1%), followed by the course of BTcP flares (48/175, 27.6%), diagnosis of BTcP (42/175, 24.3%), and drug titration/change of treatment to control BTcP (39/175, 22.3%).

As described above, when initiating the app, every clinician was requested to open a new profile for each patient, going through four sequential steps to collect relevant clinical information for an enhanced diagnosis procedure of BTcP. After testing the different levels of usage of this diagnostic workflow, the BTcP definition by Davies et al [6] and Escobar et al [16], along with the Davies algorithm were shown to be used most frequently (Table 2). For defining each patient's baseline pain, the DN4 neuropathic scale and Edmonton scale were used by 69.5% (121/175) and 63.4% (111/175) of participants, respectively.

The panel also rated the usability of the tools incorporated into the app to help physicians monitor pain, functional performance, and comorbidity of BTcP patients (Table 2). Both pain-rating and functional assessment scales were the most frequent tools used by clinicians, with a peak of 93.3% (163/175) for the VNS followed by the ECOG scale (147/175, 84.1%) and Karnofsky scale (142/175, 81.3%).

Table 1. Digital profile of participants (N=175).

Characteristics	n (%)
Clinician is user of a social network	
Yes	174 (99.43)
No	1 (0.57)
Operating system of your private mobile	
iOS	99 (56.57)
Android	76 (43.43)
Apps already downloaded on your mobile	
Number of apps (n=123)	24 (19.5)
Clinical use only (n=144)	5 (20)
Use of mobile services (News/Press/Online journals)	
Social networks (eg, Facebook, LinkedIn, Twitter)	146 (83.43)
Instant messaging (eg, WhatsApp, Snapchat)	119 (68)
Email	154 (88)
Online banking	162 (92.57)
Information of interest	122 (69.71)
Never used	0 (0)

Participants responded to the question about utility of each corresponding app tool, indicating that the utility of all app tools was considered as highly important (5-7 scored) on a Likert scale (71%-87% of panelists). Whenever these tools were considered of little use, this fact was highly attributable (80%-90% of panelists) to a lack of need during the patient's examination, although the tools might be used in further visits.

Acceptability and Usefulness of the App

The level of acceptability for App INES·DIO was tested among the sample. By the end of testing, all participants (N=175) had gained some experience with the system and the mobile app features. Most clinicians (157/175, 89.7%) concluded that the mobile app is well designed and easy to use, and 94.9% (166/175) of participants would likely/most likely recommend the use of App INES·DIO.

A report including all the information collected by physicians from each patient was provided by the app. This report was always/almost always indicated as being worth including in the patient's clinical records by 68% (119/175) of panelists (Table 2). The app was used as often as two or three times a week by 41.7% (73/175) of clinicians, and it would even be worth using it in another patient's profile (ie, not exclusively in cancer) to assess the diagnosis and control of pain (Table 2).

Clinicians were questioned about the usefulness of each app tool for the diagnosis and monitoring of patients with BTcP. Both most and least useful app features are shown in Figure 4. Davies and Escobar definitions of BTcP (93/175, 53.1%), the use of Davies diagnostic algorithm (96/175, 54.9%) and other considerations for a better diagnosis of BTcP (eg, the number of flares per day, their duration and intensity as well as the control of baseline pain) (100/175, 57.1%), were understood as the most useful tools of App INES·DIO. Conversely, the least useful tools valued by professionals were the ECOG Scale (52/175, 29.7%), the Categorical Scale (59/175, 33.7%), and the Charlson Comorbidity Index (68/175, 38.9%).

The feedback about future content (five different proposals) to be included in the app given by participants who used the App INES·DIO takes the format of a statement based on a fully anchored 3-point Likert-type response, with options being "Disagree" (score 1-3), "Undecided" (score 4), and "Agree" (score 5-7). The sample strongly suggested the implementation of new educational material for patients about the pathology and treatment of breakthrough pain (Figure 5). They strongly agreed on the importance (mostly scores between 5-7) of adding new clinical guidelines/protocols for the management of BTcP, improving their communication skills with the patient, and introducing an evidence-based medicine video platform to gather new educational material on BTcP.

Table 2. Usability testing of the app (N=175 clinicians who used each resource).

Type of testing	n (%)
Usability testing of the BTcP^a diagnostic workflow	
Definitions of BTcP by Davies et al [6]/Escobar et al [16]	146 (83.4)
Davies algorithm	141 (80.7)
Other considerations of BTcP diagnosis	46 (26.4)
DN4 neuropathic scale ^b	122 (69.5)
Reviewed Edmonton scale ^b	111 (63.4)
Usability testing of the app's pain tools	
Opioid rotation	92 (52.8)
Karnofsky scale ^c	142 (81.3)
ECOG ^d scale of performance status ^c	147 (84.1)
Visual Numeric Scale ^e	163 (93.3)
Categorical Scale ^e	124 (70.8)
Charlson Comorbidity Index	97 (55.4)
PQRST ^f questionnaire	111 (63.7)
Usability testing of App INES·DIO	
Would you include the app report with the clinical history of the patient?	
Always	65 (37.1)
Almost always	54 (30.9)
Occasionally	52 (29.7)
Never	4 (2.3)
Would you use App INES·DIO in a different patient profile?	
Most likely	70 (40.0)
Likely	52 (29.7)
Least likely	49 (28.0)
Unlikely	4 (2.3)
How many days have you used App INES·DIO on average?	
Everyday	31 (17.7)
4-6 times per week	38 (21.7)
2-3 times per week	74 (42.3)
Once per week	32 (18.3)

^aBTcP: breakthrough cancer pain.

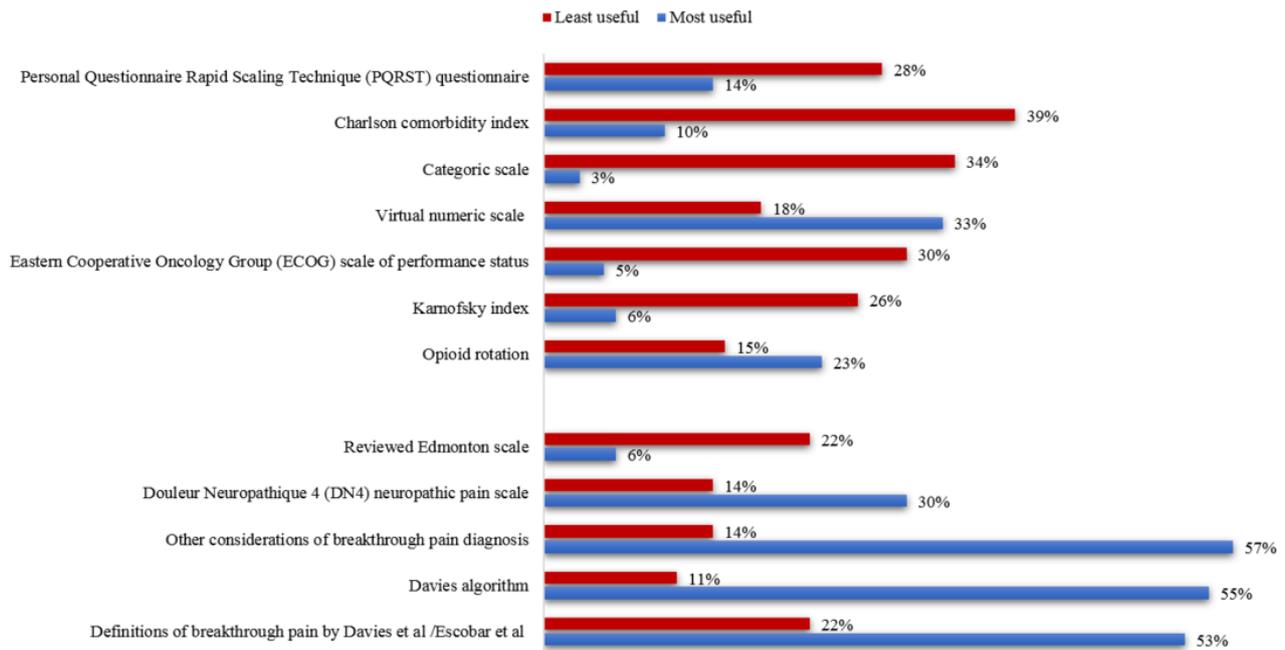
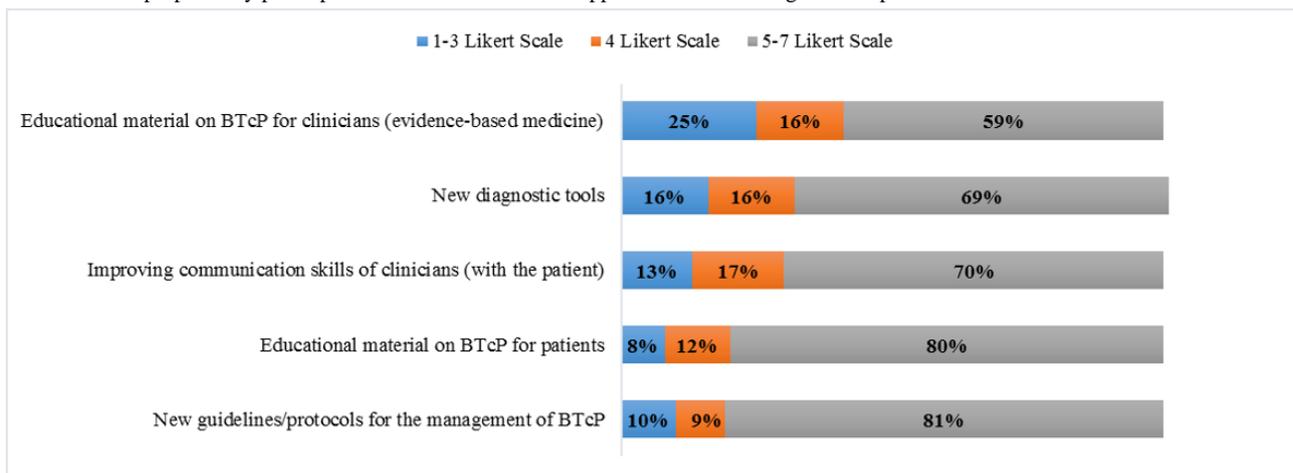
^bTools to assess baseline pain.

^cFunctional scales.

^dECOG: Eastern Cooperative Oncology Group.

^ePain scales.

^fPQRST: (P) provocative and palliative factors; (Q) qualitative description of pain; (R) region and radiation of pain; (S) severity or intensity of pain after being scored by means of VNS and CS; (T) timing or pain changes over time.

Figure 4. App INES·DIO tools rated for clinical usefulness by professionals.**Figure 5.** Content proposed by participants for a future version of app. BTcP: breakthrough cancer pain.

Discussion

Principal Findings

Mobile devices are continuously present in people's everyday lives [19], and many individuals are firmly tied to their mobile phones, which are typically customized to their specific needs [20,21]. Evolving technical capabilities of mobile devices enable delivery of various services independent of users' time and place, and their dynamic adaptation to current context of use and users' personal preferences [22]. These features make mobile devices well-suited platforms for apps that allow easier monitoring and managing of pre-existing health conditions, the delivery of more efficient individually tailored care at the point-of-need, and promotion of a better collaborative work between patients and health care providers [23,24].

To our knowledge, this was the first study to report on the development, usability, usefulness, and acceptability testing of a mobile app to be used as an adjunct to BTcP intervention.

Given the popularity of mobile apps within our sample (Table 2) and the difficulties related to management of BTcP, we anticipated that a mobile app would be a useful tool to assist in the diagnosis and monitoring of patients with BTcP and the results of this study support this. This study included the participation of a group of medical experts in the iterative development process. They were selected to achieve a fair distribution across the four professional profiles involved in the management of BTcP: medical oncology, radiation oncology, palliative care, and pain.

Most of the sample recruited was aware of the consensus and controversies driven by the original Delphi study [8] that had set the groundwork for the development of App INES·DIO and the subsequent usability testing described in this study. Moreover, conclusions reported by the Delphi study were perceived to have a positive impact on clinical daily practice when attending BTcP patients.

Ultimately, there has been a rapid proliferation of mHealth apps, and for pain in particular. As of 2015, around 280 apps were commercially available to monitor and track pain [23,24]. In our study, App INES-DIO was tested by 175 professionals in 700 cancer patients with a mean historical diagnosis of BTcP of 2 years. This result is particularly important, mainly because only 8.2% of these reported apps included a health care professional in their development, not a single app provided a theoretical rationale, and only 1 app has undergone scientific evaluation [24].

In the literature, the treatment of BTcP involves strategies such as the treatment of cancer disease, modification of the baseline analgesic treatment, nonpharmacological interventions, and an appropriate rescue medication [25]. In line with this, our app was mostly used to help physicians during the examination of patients, but also the diagnosis, course, and treatment of BTcP flares.

Some authors support the fact that pain history should include key elements that characterize the salient clinical features of breakthrough pain, in addition to standard approaches to cancer pain history [26]. Clinicians were requested to create a new profile with each patient (4 per clinician), going stepwise through the different validated tools incorporated into App INES-DIO to complement the patient's pain history. Testing the usability of these tools revealed that the BTcP definitions of Davies [6] and Escobar et al [16] and the Davies algorithm were the most used. One of the difficulties attributed to assessing the prevalence of BTcP in the cancer population lies in the variety of definitions that exist and are used for BTcP.

Furthermore, both pain-rating and functional assessment scales were highly used by clinicians, with a peak of 93.3% for the VNS followed by the use of ECOG scale (84.1%) and the Karnofsky scale (81.3%). These results are in line with other research on the use of these scales to test the control of baseline pain [26]. To consider baseline pain as adequately controlled, some authors assume that the average intensity of pain must be <4 on a categorical scale or somewhere on the VNS from 0-10 (0=no pain at all, 10=the worst pain ever possible). Numerical rating scales have shown high correlations with other pain-assessment tools in several studies [27,28], and the feasibility of its use and good compliance have also been proven [29].

During our study, the sample stated the usefulness of each app tool. Interestingly, the tool "Other considerations for the diagnosis of BTcP" was considered as the most useful, even above the use of the Davies diagnosis algorithm. In other words, the diagnosis of BTcP was interpreted by the sample to comprise those features that complete the information related to the definition of an episode: number, duration, and intensity of flares per day and the management of baseline cancer.

Comparing our study against others [23,24], it is clear that the acceptability and usefulness testing done by physicians is critical for the optimal design and development of mobile apps used in

clinical cohorts. With regard to user satisfaction, 90% of clinicians reported that they liked using this pain app and found it user friendly and well designed, while 95% reported that they would likely/most likely recommend it to other colleagues, even for use with other patient profiles. The generation of a report that physicians could attach to the clinical record of each patient was considered of great value.

Participants gave feedback about five different types of content to be included in future versions of App INES-DIO for a better interpretation of BTcP. Interestingly, the feedback revealed the need for future implementation of new educational material about the pathology and treatment of breakthrough pain. The sample agreed on adding some new educational tools to the app, such as consensus documents and clinical guidelines for the management of BTcP, improving their communication skills with the patient, and evidenced-based medicine platforms. Refreshing the knowledge and communication skills of health care providers may yield more favorable patient outcomes.

Limitations

The most significant limitation of this study was the use of a one-group design to pilot App INES-DIO. This design precluded assessment of the feasibility of randomization procedures, as well as recruitment, attrition, outcome measure completion, and acceptability in a control arm. However, although we can learn a lot about the usability of a mobile app in a controlled setting, it is important to test it in real-world situations, which are highly variable [30,31].

Future Work

Previously, we noted that there was limited related research on how mobile devices could be used in the context of health care information systems for cancer patients. Further work is needed to identify the primary factors and design issues influencing acceptability and usefulness of different system features of mHealth care information services. In our future research, we are planning to continue work on the development of a new version of App INES-DIO and investigate how this app should be designed and adjusted to best fit clinicians' needs in the care of BTcP patients. Some of the potential new app features were already identified throughout this survey study, and these will be considered for next version of the app, as well as the need for further exploration of how we can add rich media to this BTcP mobile app.

Conclusions

In summary, these results suggest that App INES-DIO could soon be used as a tool to help physicians make decisions around BTcP management. Indeed, this app can be a reference medical device to assess the diagnosis and monitoring of BTcP. Clinical use of diagnostic tools going beyond the Davies algorithm should be outlined in any patient with a history of cancer pain. The value of the app will be enhanced with the inclusion of new educational material on BTcP not only for medical professionals but also for patients.

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Conflicts of Interest

JB has received personal fees from Grünenthal, Esteve, and Teva Pharmaceutical Industries, and nonfinancial support from Grünenthal. DS has received personal fees from Teva Pharmaceutical Industries, and RSR works in the medical department of Teva Pharmaceutical Industries.

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Abbreviations

App INES-DIO: (abbreviation in Spanish) Instrument for the Assessment and Monitoring the Breakthrough Cancer Pain

BTcP: breakthrough cancer pain

CS: Categorical Scale

ECOG: Eastern Cooperative Oncology Group

PQRST: (P) provocative and palliative factors; (Q) qualitative description of pain; (R) region and radiation of pain; (S) severity or intensity of pain after being scored by means of VNS and CS; (T) timing or pain changes over time

VAS: Visual Analogue Scale

VNS: Visual Numeric Scale

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Original Paper

Impact of Electronic Self-Assessment and Self-Care Technology on Adherence to Clinician Recommendations and Self-Management Activity for Cancer Treatment–Related Symptoms: Secondary Analysis of a Randomized Controlled Trial

Robert Knoerl¹, PhD, RN; Fangxin Hong², PhD; Traci Blonquist², MS; Donna Berry¹, PhD, RN, AOCN, FAAN

¹Phyllis F. Cantor Center for Research in Nursing and Patient Care Services, Dana-Farber Cancer Institute, Boston, MA, United States

²Department of Biostatistics & Computational Biology, Dana-Farber Cancer Institute, Boston, MA, United States

Corresponding Author:

Robert Knoerl, PhD, RN

Phyllis F. Cantor Center for Research in Nursing and Patient Care Services

Dana-Farber Cancer Institute

450 Brookline Avenue

Boston, MA, 02215

United States

Phone: 1 617 632 6386

Email: robert_knoerl@dfci.harvard.edu

Abstract

Background: Patients undergoing cancer treatment experience symptoms that negatively affect their quality of life and adherence to treatment. The early identification and management of treatment-related symptoms are critical to prevent symptom distress due to unmanaged symptoms. However, the early identification and management of treatment-related symptoms are complex as most cancer treatments are delivered on an outpatient basis where patients are granted less face-to-face time with clinicians. The Electronic Symptom Assessment and Self-Care (ESRA-C) promotes participant self-management of treatment-related symptoms by providing participants with communication coaching and symptom self-report, education, and tracking features. While the ESRA-C intervention has been demonstrated to improve symptom distress significantly, little is known as to how the ESRA-C influenced participants' self-management practices and adherence to clinician recommendations for symptom/quality of life issues (SQIs).

Objective: To compare participant adherence to clinician recommendations and additional self-management strategy use for SQIs between ESRA-C intervention and control (electronic symptom assessment and participant symptom reports alone) group participants. Secondly, we explored the impact of participant adherence to clinician recommendations and additional self-management strategy use for SQIs on symptom control, symptom management satisfaction, and symptom distress. Lastly, we examined baseline predictors of participant adherence to clinician recommendations and additional self-management strategy use for SQIs.

Methods: This study presents an analysis of a randomized controlled trial. Participants beginning a new chemotherapy or radiotherapy regimen were recruited from oncology outpatient centers and were randomized to receive the ESRA-C intervention or control during treatment. Patients were included in this analysis if they remained on study through the duration of treatment and self-reported at least one bothersome SQI three-to-six weeks after beginning treatment. The Symptom Distress Scale-15 and Self-Management of SQIs Questionnaire were completed two weeks later. Based on Self-Management of SQIs Questionnaire ratings, participants were placed into adherence to clinician recommendations (adhered/did not adhere/did not receive recommendations) and additional self-management strategy use (yes/no) categories.

Results: Most participants were adherent to clinician recommendations (273/370, 73.8%), while fewer used additional self-management strategies for SQIs (182/370, 49.2%). There were no differences in the frequency of participant adherence to clinician recommendations (chi-square test, $P=.99$) or self-management strategy use (chi-square test, $P=.80$) between intervention ($n=182$) and control treatment groups ($n=188$). Participants who received clinician recommendations reported the highest treatment satisfaction ($n=355$, $P<.001$ by analysis of variance; ANOVA), although lowest distress was reported by participants who did

not follow clinician recommendations ($n=322$, $P=.04$ by ANOVA) for top 2 SQIs. Women ($n=188$) reported greater additional self-management strategy use than men ($n=182$, $P=0.03$ by chi-square test).

Conclusions: ESRA-C intervention use did not improve participants' adherence to clinician recommendations or additional self-management strategy use for SQIs in comparison to the control. Future research is needed to determine which factors are important in improving patients' self-management practices and symptom distress following ESRA-C use.

Trial Registration: ClinicalTrials.gov NCT00852852; <https://clinicaltrials.gov/ct2/show/NCT00852852> (Archived by WebCite at <http://www.webcitation.org/73rEhNWkU>)

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KEYWORDS

electronic symptom assessment; self-care; neoplasms; treatment adherence and compliance; quality of life

Introduction

Individuals undergoing chemotherapy and radiotherapy for the treatment of hematological and oncological malignancies may experience a variety of distressing symptoms (eg, pain, fatigue, nausea, vomiting, anxiety and depression) [1-3] that negatively affect the quality of life [4,5]. Increased symptom distress due to unmanaged cancer treatment-related symptoms may lead to decreased adherence to cancer treatments [6,7], subsequently increasing the risk of mortality. Thus, the early identification and management of treatment-related symptoms are critical to prevent severe symptom distress due to unmanaged symptoms.

The early identification and management of treatment-related symptoms in individuals undergoing anticancer therapy are complicated by the current norms of cancer treatment delivery. The majority of cancer treatment is now delivered in outpatient settings [8] where patients are granted less clinic time with clinicians to report treatment-related symptoms and review management recommendations than would be possible with inpatient care. Due to decreased face-to-face time with clinicians to review symptoms, patients are expected to seek out and implement strategies to self-manage treatment-related symptoms between clinic visits. Thus, interventions are needed that support patient self-identification and management of treatment-related symptoms during cancer treatment.

Electronic platforms are emerging as promising tools to deliver self-management strategies that aid patients in the assessment and management of treatment-related symptoms during and after the completion of cancer treatment [9-12]. According to a recent conceptual framework of self-management education support for patients with cancer [11], implementation of cancer self-management interventions are thought to improve health outcomes (eg, reduce symptom severity, improve quality of life, lower health care use) by increasing patients' skill acquisition (eg, disease knowledge, adherence to clinician recommendations, goal setting, self-efficacy, self-monitoring, communication with health care team)." The Electronic Symptom Assessment and Self-Care (ESRA-C) is a symptom assessment and self-management program for remote plus point of care use. The ESRA-C has been demonstrated to mitigate cancer symptom distress [13] in participants receiving chemotherapy and radiation. It is thought that ESRA-C use may decrease cancer symptom distress by enhancing participant-clinician communication about symptom management (eg,

participant adherence to clinician recommendations) and participants' self-management practices. However, it remains unknown how the effect of the ESRA-C intervention on participants' self-management practices and adherence to clinician recommendations for symptom/quality of life issues (SQIs) contributed to changes in symptom distress, perceived control over symptoms, or treatment satisfaction.

The primary aim of this study was to compare participant adherence to clinician recommendations and additional self-management strategy use for SQIs between individuals randomized to receive either the ESRA-C intervention or control [13]. The secondary aims were to (1) explore the impact of participant adherence to clinician recommendations and additional self-management strategy use for SQIs on perceived control over symptoms, satisfaction with symptom management, and symptom distress and (2) explore baseline characteristics predictive of participant adherence to clinician recommendations and additional self-management strategy use.

Methods

Design, Sample, and Setting

This study is an analysis of a secondary objective in a previously conducted randomized controlled trial (RCT) as described at Clinicaltrials.gov NCT00852852 [13], in addition to 2 exploratory analyses. Results of the original RCT revealed that intervention group participants reported significantly lower symptom distress compared to control group participants from baseline to end-of-study ($P=.02$) [13]. Eligible patients in the original RCT were >18 years of age, ambulatory, beginning a new treatment (eg, chemotherapy or radiation) for cancer, and spoke and read English. All recruitment and data-collection procedures occurred at 2 comprehensive cancer centers located in Seattle and Boston. The original RCT was conducted with oversight from the institutional review boards specific to each study site and written informed consent was obtained from all enrolled participants. From the pool of eligible patients in the original RCT ($N=752$), participants were included in this analysis if they had remained on study through the duration of anticancer therapy and self-reported at least one bothersome SQI 3 to 6 weeks after beginning treatment.

Procedures

The full procedures of the original RCT were reported elsewhere [13]. Participants were recruited using online and in-person

methods at the ambulatory clinics. After signing the informed consent, patients completed the Symptom Distress Scale-15 (SDS-15) [13,14] and a variety of standardized symptom assessment surveys (eg, pain, fatigue, depression, neuropathy, anxiety) before the start of treatment (T1). Next, participants were randomized (1:1 ratio; parallel group) to the ESRA-C intervention or electronic symptom assessment alone. Participants in both groups used the ESRA-C to complete the SDS-15 and the same set of standardized symptom assessment surveys 3 to 6 weeks after beginning treatment (T2) and then 2 weeks later (T3). Following SQI reporting at each time point and regardless of study group assignment, participants' clinicians (eg, physician, physician assistant or nurse practitioner involved in the care of each participant) received a printed summary of participant symptom reports. Clinicians were oriented to the trial and the use of the participant symptom reports by the principal investigator prior to study initiation, explaining that management of any symptom was at the discretion of the clinician and usual practice. Unique to the

intervention arm, the ESRA-C also coached participants with exemplary language regarding how to explain SQI concerns to clinicians, SQI monitoring charts and graphs, and SQI management education. This information was specifically delivered on-screen when an SQI was rated above a predetermined moderate-to-severe threshold, however, participants could access all management strategies through a drop-down menu. Participants were not directly instructed to adhere to the clinician-delivered instruction on SQI management. Examples of the self-management information provided to participants for different SQIs are provided in Figures 1 and 2. Previous analysis revealed that 233/374 (62.3%) intervention group participants in the original trial accessed the ESRA-C intervention (eg, at least two exposures to teaching tips or symptom reports) [15]. Specific to this analysis, participants in both groups reported their top 2 most bothersome SQIs (T2A and T2B) prior to the clinician visit using the ESRA-C at T2 [16] and completed the SDS-15 and Self-Management of SQIs Questionnaire at T3.

Figure 1. The Electronic Symptom Assessment and Self-Care generated self-management information for physical function.

Physical Function

Some of our patients have had concerns about their physical functioning as a result of their treatment.

Based on your report, you may have some concerns about your physical functioning.

[View My Reports For Physical Function](#)

Why does this happen? Problems with physical functioning, including difficulty getting around your house, doing daily activities and getting out in your community, may be due to the effect of cancer treatment or medications or the cancer itself.. At least 21% of our patients in our previous research have reported similar issues with physical functioning after starting treatment.

What can I do about this? Your physical functioning may be decreased temporarily while you receive treatment. There are things you can do at home to help deal with these changes, and there may be things that your clinical team will recommend for you. Read more about what you can do:

- [National Cancer Institute \(Home Care for Cancer Patients\)](#)
- [The American Society of Clinical Oncology \(Physical Activity: Suggestions and Tips\)](#)

What do I tell my clinical team? Be sure to talk with your clinical team during your next visit. You should tell your clinicians that you have concerns about your physical functioning and ask what they suggest to help. It is important that they know you are bothered by the effects of the treatment. You might say:

"I've noticed that _____ (fill in the blank to describe what you have difficulty doing). It's gotten _____ (better or worse) since I saw you last. What do you recommend to deal with this?"

Figure 2. The Electronic Symptom Assessment and Self-Care generated self-management information for sensory neuropathy.

Sensory Neuropathy

Some of our patients have had concerns about changes in nervous system function (neuropathy) as a result of their treatment.

Based on your report, you may have had trouble with uncomfortable sensations in your legs, feet, hands or arms. The sensations can range from tingling to coldness to numbness. You may have had trouble doing things with your feet (for example, walking or driving). Or you may have experienced other symptoms such as blurred vision.

Why does this happen? This happens sometimes due to the effect of cancer medications or the cancer itself.

What can I do about this? There are things you can do at home to help deal with this symptom and there may be things that your clinical team will recommend for you. The following websites provide useful information regarding peripheral neuropathy:

- [The Oncology Nursing Society \(Peripheral Neuropathy\)](#)
- [LiveStrong \(Neuropathy\)](#)
- [National Coalition for Cancer Survivorship \(Neuropathy\)](#)

What do I tell my clinical team? Be sure to talk with your clinical team about this the next time you see them in the clinic. Ask if there's something they can suggest to help. It's important that they know you're having these kinds of problems. We suggest saying something like this: "I've had a [little; a lot] of tingling in my feet. It started _____ (fill in the blank with when you first felt like this). It has gotten _____ (better or worse) since I saw you last. What do you recommend to deal with this?"

[View My Reports For Sensory Neuropathy](#)

Measures

Symptom Distress Scale

The SDS is a 13-item measure in which users rate the frequency and severity of several cancer treatment-related symptoms (eg, nausea, pain, fatigue, insomnia, cough) over the past 7 days [14]. In the primary randomized trial, 2 items (ie, sexual activity and fever/chills) were added to the SDS to form a 15-item version [13]. Items related to problems with sexual activity and fever/chills were added based on informal feedback from patients and clinicians prior to study initiation. Each item is scored from 1 to 5, with total scores ranging from 15 to 75 (higher scores represent worse symptom distress). The 15-item version has demonstrated sufficient internal consistency reliability as evidenced by the Cronbach alpha of .86 in individuals who completed anticancer therapy [13]. The validity of the 15-item SDS has not been tested to date, however, several studies support the concurrent validity of the 13-item version [17].

Self-Management of Symptom and Quality of Life Issues Questionnaire

This instrument contains 4 subscales that measure participants' self-management practices related to their self-reported top 2 bothersome SQIs at T2 (T2A and T2B): (1) adherence to treatment recommendations, (2) self-care activities, (3)

perceived control of SQIs, and (4) satisfaction with symptom management. The adherence to treatment recommendations subscale examines the extent to which participants follow clinician recommendations for the management of T2A and T2B. Participants report if they did not receive, did not follow, partly followed, or exactly followed clinician recommendations for the management of T2A and T2B. The self-care activities subscale assesses whether participants use any self-management strategies in addition to clinician recommendations to manage T2A and T2B (yes or no), respectively. The perceived control of SQIs subscale contains 3 questions that measure the degree of control participants perceive over managing T2A and T2B. Each question is scored from 1 to 5 (1 for strongly disagree to 5 for strongly agree), with higher scores representing greater control over SQIs. The Cronbach alpha for the perceived control of SQIs subscale is .74. Lastly, the satisfaction with symptom management subscale examines participants' satisfaction with T2A and T2B management (self- and clinician-initiated) using a 0 to 10 scale with higher scores representing greater satisfaction. A Cronbach alpha could not be calculated for 3 of the 4 Self-Management of SQIs Questionnaire subscales because they only contain 1 or 2 items that are identical (ie, both items measure T2A and T2B respectively).

Statistical Analyses

Based on responses to the adherence to treatment recommendations subscale of the Self-Management of SQIs Questionnaire, participants were classified into 3 adherence categories: (1) yes (those who partially/exactly followed recommendations for T2A and T2B), (2) no (did not follow recommendations for T2A and T2B), or (3) no recommendation (participant did not receive management recommendations for T2A and T2B). For participants who reported that no clinician recommendations for T2A and T2B were provided, data from the audio-recorded clinic visit at T2 was used to confirm participant self-report [18]. Participants also were categorized into 2 self-management categories based on responses to the self-care activities subscale: (1) yes (participants who reported using any self-management strategies in addition to clinician recommendations for the management of T2A and T2B) or (2) no (participants who reported no additional self-management strategy use for T2A and T2B).

Baseline characteristics (group assignment, age, gender, working status, employment status, education, ethnicity, cancer type) were described based on adherence to clinician recommendations and additional self-management strategy use categorization. Differences in adherence to clinician recommendations and self-management strategy use between study group and other baseline variables were compared using chi-square tests. Perceived control, satisfaction with symptom management (mean subscale scores were averaged when participants reported a score for both T2A and T2B), and SDS-15 scores were compared among adherence categories (using ANOVA) and additional self-management strategy use categories (by chi-square and two-sample *t* test). The relationship between adherence to clinician recommendations and additional self-management strategy usage were also assessed by a chi-square test. A *P* value of $<.05$ was considered statistically significant for all comparisons. A complete case analysis approach was used to handle missing data as missing data was minimal. All analyses were conducted using SAS version 9.4.

Results

Demographic Characteristics

Data from 370 (49.2%) participants were available for analysis out of the 752 participants that met eligibility criteria in the RCT. Baseline characteristics of the analyzed sample are summarized by adherence to clinician recommendations and additional self-management strategy use in Table 1. Most of the participants were over the age of 50, currently employed, college educated, under the care of the medical oncology service, and Caucasian. There was a fairly equal number of men and women in the analyzed sample. The median number of days between the T1 and T3 time points was 48 (range 23-159), while

the median number of days between T2 and T3 was 15 (range 10-105). Figure 3 describes the frequency of top two bothersome SQIs reported by participants at T2, 3 to 6 weeks after baseline. Fatigue was the most commonly reported bothersome issue, followed by sleep, pain, and skin problems.

Table 1 describes differences in participant adherence to clinician recommendations and additional self-management strategy use for SQIs among varying baseline characteristics, including treatment assignment. There were no significant differences between assigned groups in the frequency of participant adherence to clinician recommendations ($P=.99$) or additional self-management strategy use ($P=.80$). Women reported significantly greater ($P=.03$) additional self-management strategy use than men, but otherwise, there were no differences in frequency of participant adherence to clinician recommendations or additional self-management strategy use for any other baseline characteristics.

As there were no group differences in participant adherence to clinician recommendations or additional self-management strategy use for SQIs, all subsequent analyses were conducted using the full sample (regardless of the study group). Table 2 describes the frequency of participant adherence to clinician recommendations and additional self-management strategy use for SQIs. Most participants (273/370, 73.8%) partially or completely followed clinician recommendations, while less (182/370, 49.2%) used additional self-management strategies for SQIs. Of the participants that partially or completely followed clinician recommendations, 143/273 (52.4%) also used additional self-management strategies. Conversely, 36/370 (9.7%) participants did not follow clinician recommendations and of those, 23/36 (63.9%) did not use any additional self-management strategies for SQIs. Approximately 13.2% (49/370) of participants reported that they did not receive management recommendations from a clinician. There was no statistically significant association between adherence to clinician recommendations and additional self-management strategy use for T2A and T2B ($P=.16$).

Tables 3 and 4 describe SDS-15, perceived control over SQIs, and satisfaction with symptom management mean scores at T3 based on adherence to clinician recommendations and additional self-management strategy use. Results revealed significant differences in satisfaction with symptom management ($P<.001$) and SDS-15 scores ($P=.04$), and marginally significant differences in perceived control over symptoms ($P=.10$) across adherence categories. Specifically, participants who did not receive clinician recommendations for SQIs reported the lowest satisfaction with symptom management scores. Further, participants who did not follow recommendations reported the lowest symptom distress scores. There were no significant differences in symptom distress, perceived control over symptoms, or satisfaction with symptom management between additional self-management strategy use categories.

Table 1. Demographic and cancer treatment–related characteristics by adherence to clinician recommendations and additional self-management activity categorization (N=370).

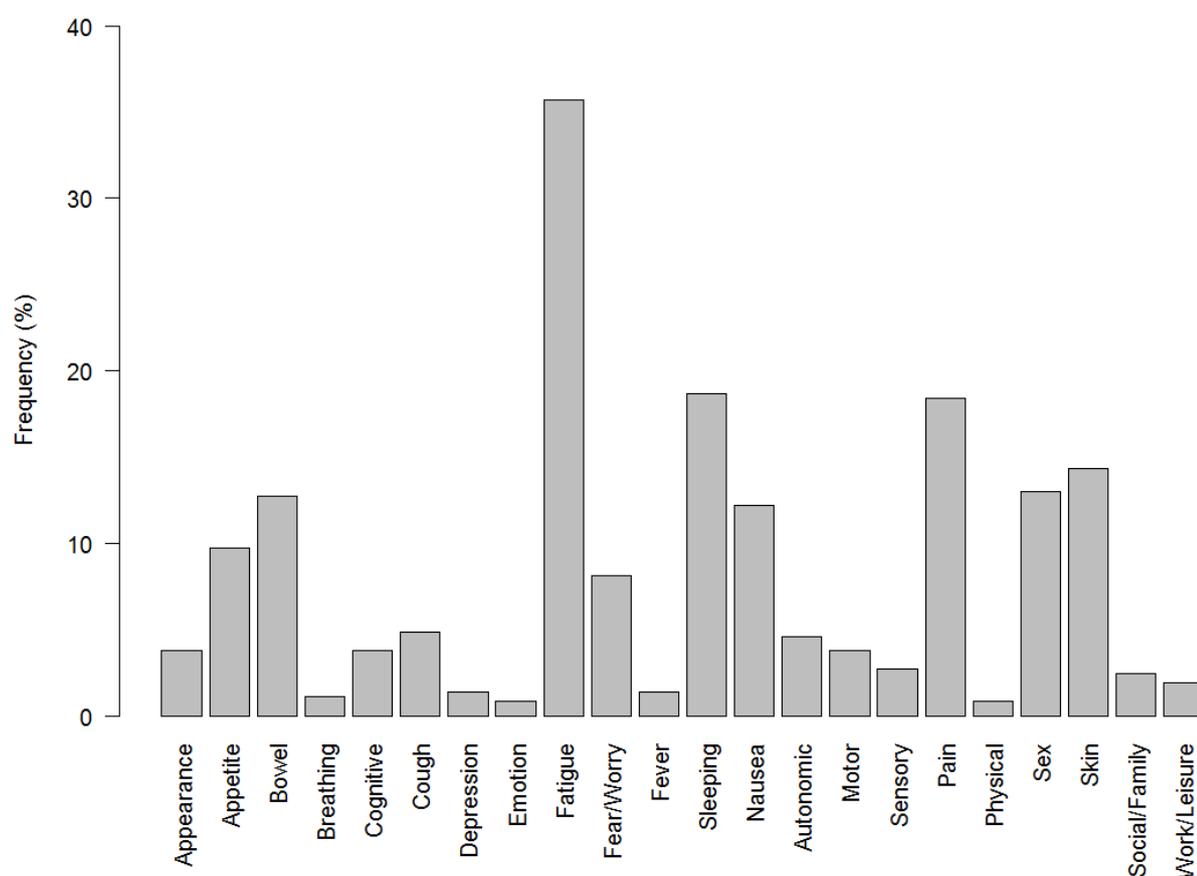
Characteristics	Adherence, n (%)				Self-management activity, n (%)		
	Missing	No recommendation	No	Yes	Missing	No	Yes
Study group							
Control (n=188)	5 (2.7)	25 (13.3)	18 (9.6)	140 (74.4)	5 (2.7)	88 (46.8)	95 (50.5)
Intervention (n=182)	7 (3.8)	24 (13.2)	18 (9.9)	133 (73.1)	8 (4.4)	87 (47.8)	87 (47.8)
Age at baseline							
<50 (n=110)	3 (2.7)	14 (12.7)	8 (7.3)	85 (77.3)	3 (2.7)	58 (52.7)	49 (44.6)
>50 (n=260)	9 (3.4)	35 (13.5)	28 (10.8)	188 (72.3)	10 (3.8)	117 (45.0)	133 (51.2)
Gender							
Men (n=182)	6 (3.3)	22 (12.1)	20 (11.0)	134 (73.6)	7 (3.8)	96 (52.8)	79 (43.4)
Women (n=188)	6 (3.2)	27 (14.4)	16 (8.5)	139 (73.9)	6 (3.2)	79 (42.0) ^a	103 (54.8) ^a
Education							
Missing (n=1)	0 (0.0)	0 (0.0)	1 (100.0)	0 (0.0)	0 (0.0)	1 (100.0)	0 (0.0)
<College (n=66)	5 (7.6)	6 (9.1)	8 (12.1)	47 (71.2)	5 (7.6)	31 (46.9)	30 (45.5)
>College (n=303)	7 (2.3)	43 (14.2)	27 (8.9)	226 (74.6)	8 (2.6)	143 (47.2)	152 (50.2)
Ethnicity/race							
Non-Hispanic white (n=303)	11 (3.6)	41 (13.5)	25 (8.3)	226 (74.6)	13 (4.3)	138 (45.5)	152 (50.2)
Missing (n=30)	0 (0.0)	3 (10.0)	5 (16.7)	22 (73.3)	0 (0.0)	16 (53.3)	14 (46.7)
Minority ^b (n=37)	1 (2.7)	5 (13.5)	6 (16.2)	25 (67.6)	0 (0.0)	21 (56.8)	16 (43.2)
Clinical service							
Medical oncology (n=236)	8 (3.4)	33 (14.0)	22 (9.3)	173 (73.3)	9 (3.8)	113 (47.9)	114 (48.3)
Radiation oncology (n=134)	4 (3.0)	16 (12.0)	14 (10.4)	100 (74.6)	4 (3.0)	62 (46.3)	68 (50.7)
Work status							
Missing (n=36)	1 (2.8)	3 (8.3)	7 (19.4)	25 (70.0)	2 (5.6)	17 (47.2)	17 (47.2)
Not working (n=113)	6 (5.3)	12 (10.6)	8 (7.1)	87 (77.0)	6 (5.3)	56 (49.6)	51 (45.1)
Working (n=221)	5 (2.3)	34 (15.4)	21 (9.5)	161 (72.8)	5 (2.2)	102 (46.2)	114 (51.6)
Cancer type							
Bladder (n=12)	1 (8.3)	3 (25.0)	1 (8.3)	7 (58.4)	1 (8.3)	3 (25.0)	8 (66.7)
Breast (n=120)	2 (1.6)	23 (19.2)	9 (7.5)	86 (71.7)	3 (2.5)	49 (40.8)	68 (56.7)
Gastrointestinal (n=74) ^c	5 (6.7)	6 (8.1)	9 (12.2)	54 (73.0)	4 (5.4)	38 (51.4)	32 (43.2)
Head and neck (n=34)	1 (2.9)	1 (2.9)	1 (2.9)	31 (91.3)	1 (2.9)	18 (53.0)	15 (44.1)
Prostate (n=63)	1 (1.6)	12 (19.0)	11 (17.5)	39 (61.9)	2 (3.2)	35 (55.5)	26 (41.3)
Other (n=63) ^d	2 (3.2)	4 (6.4)	5 (7.9)	52 (82.5)	2 (3.2)	31 (49.2)	30 (47.6)
Unknown (n=4)	0 (0.0)	0 (0.0)	0 (0.0)	4 (100.0)	0 (0.0)	1 (25.0)	3 (75.0)

^aStatistically significant ($P<.05$) difference between groups.

^bHispanic or non-white.

^cIncludes colorectal, esophageal, gastric, pancreatic, and other gastrointestinal cancers.

^dIncludes leukemia, lymphoma, myeloma, renal cell cancer, sarcoma, testicular cancer, and other cancers.

Figure 3. The frequency of the top two bothersome symptom/quality of life issues reported by participants at T2.**Table 2.** Relationships between adherence to clinician recommendations and additional self-management strategy use for symptom/quality of life issues (N=370).

Self-management activities	Adherence to clinician recommendation, n (%)				Total
	Missing	No recommendation given	Did not follow recommendation	Partially or completely follow recommendation	
Missing	10 (83.3) ^a	0 (0.0) ^a	0 (0.0) ^a	3 (1.1) ^a	13 (3.5) ^c
No	2 (16.7) ^a	23 (46.9) ^a	23 (63.9) ^a	127 (46.5) ^a	175 (47.3) ^c
Yes	0 (0.0) ^a	26 (53.1) ^a	13 (36.1) ^a	143 (52.4) ^a	182 (49.2) ^c
Total	12 (3.3) ^b	49 (13.2) ^b	36 (9.7) ^b	273 (73.8) ^b	370

^aThe percentage values indicate the frequency of participants within each additional self-management strategy use category out of the total number of participants within each adherence to clinician recommendation category.”

^bThe percentage values indicate the frequency of participants within each adherence to clinician recommendation category out of the total number of enrolled participants.

^cThe percentage values indicate the frequency of participants within each additional self-management strategy use category out of the total number of enrolled participants.

Table 3. T3 Self-management of Symptom/Quality of Life Issues Questionnaire and Symptom Distress Scale-15 mean scores by adherence to clinician recommendation categorization (N=370).

Measures	Adherence to clinician recommendation categorization ^a , mean (SD)			P value
	None given	Did not follow	Partially/completely followed	
Perceived control (n=355)	2.1 (0.7)	2.4 (0.8)	2.3 (0.7)	.10
Satisfaction with symptom management (n=355)	3.9 (2.5)	6.2 (2.2)	6.2 (2.1)	<.001
SDS-15 ^b (n=322)	28.1 (6.7)	24.9 (6.4)	28.4 (7.6)	.04

^aAs not all participants reported perceived control, satisfaction with symptom management, or symptom distress scale scores, the n for each of these respective measures are smaller than the total N enrolled in the study.

^bSDS-15: Symptom Distress Scale-15.

Table 4. T3 Self-management of Symptom/Quality of Life Issues Questionnaire and Symptom Distress Scale-15 mean scores by additional self-management strategy use categorization (N=370).

Measures	Additional self-management strategy use categorization ^a , mean (SD)		P value
	No	Yes	
Perceived control (n=353)	2.3 (0.7)	2.4 (0.7)	.19
Satisfaction with symptom management (n=354)	6.1 (2.5)	5.7 (2.2)	.18
SDS-15 ^a (n=322)	27.8 (7.3)	28.3 (7.5)	.56

^aAs not all participants reported perceived control, satisfaction with symptom management, or symptom distress scale scores, the n for each of these respective measures are smaller than the total N enrolled in the study.

^bSDS-15: Symptom Distress Scale-15.

Discussion

Principal Findings

The results of these analyses revealed no differences in participant adherence to clinician recommendations or additional self-management strategy use between participants randomized to receive the ESRA-C intervention or control. Additionally, participant adherence to clinician recommendations for SQIs, but not additional self-management strategy use, was associated with differences in symptom distress and satisfaction with symptom management ratings. Finally, women were more likely to report additional self-management strategy use than men.

Our findings are consistent with several recently conducted RCTs demonstrating that electronic cancer self-management interventions have no effect on self-management practices such as empowerment [19] or self-efficacy [20]. Similar to the original RCT [13], these trials [19,20] significantly improved symptom distress, but not markers of self-management. These findings call into question what exactly mediates improvements in symptom distress following electronic self-management interventions. A 2017 systematic review [11] identified 8 elements critical to the design of self-management education interventions for cancer: (1) facilitate self-efficacy to manage symptoms, (2) facilitate symptom monitoring, (3) support patient-clinician communication, (4) promote acquisition of problem solving skills, (5) facilitate knowledge and health behavior acquisition via goal setting, (6) garner support from health care team, (7) support patient coaching by trained instructor, and (8) tailor self-management toward individuals' preferences and treatment plan. However, it is unclear which combination of self-management education elements are

associated with improvements in patient outcomes [11]. Future research may be directed toward revising the ESRA-C intervention to address additional core self-management education elements and determine which factors are important in improving self-management practices and symptom distress. The identification of self-management factors that mediate symptom distress improvement following electronic cancer self-management interventions will allow for the tailoring of intervention components known to influence symptom distress.

Results demonstrated that participant adherence to clinician recommendations for SQIs, but not additional self-management strategy use, uniquely affected treatment satisfaction and symptom distress following use of the ESRA-C. Further, there was no significant association between participant adherence to clinician recommendations and additional self-management strategy use for SQIs. Because of the unique effects of participant adherence to clinician recommendations on the tested patient outcomes and the lack of association with additional self-management strategy use, these findings may indicate the relative importance of patient adherence to clinician recommendations for SQIs on patient outcomes. In particular, patient adherence to clinician recommendations may be a result of enhanced patient-clinician communication; if patients are clear on their responsibilities related to symptom management, they may be more likely to adhere to treatment. However, the role of improved patient-clinician communication on patient outcomes is unclear as previous analysis has demonstrated that ESRA-C-induced increases in verbal symptom reporting do not mediate symptom distress improvements ($P=.41$) [18]. Finally, those who adhered to clinician recommendations may not have perceived a need to implement additional self-management strategies.

Nevertheless, strategies to support patient-clinician communication are important, but often missing elements of self-management education for patients with cancer [11]. Recent evidence surrounding the use of patient question prompt lists [21], individualized clinician communication training [22], and recommendations from patient-clinician communication clinical practice guidelines [23] may be used to guide the integration of communication coaching strategies into self-management interventions that target both patients and clinicians.

Participants who did not receive clinician recommendations for SQIs had lower satisfaction with symptom management than participants who received recommendations (regardless of adherence to recommendations). Our findings related to participant satisfaction with symptom management and receipt of clinician recommendations are consistent with recent evidence demonstrating that several clinician-related factors, such as patient-clinician communication about oncology care [24], care coordination [25], and the amount of time spent with the clinician during the outpatient visit [26], predict patients' satisfaction with oncology care. Additionally, participants who did not follow clinician recommendations for SQIs had lower symptom distress scores than individuals who followed recommendations or did not receive them at all. It is possible that moderate-to-severe symptoms may have improved soon after T2, precluding the need to adhere to recommendations (when surveyed at T3). Alternatively, participants who did not follow clinician recommendations may have experienced lower symptom distress because the T2A and T2B selected were most bothersome, but not the most severe symptoms. Symptom distress refers to the frequency and severity of a symptom [27], whereas bother refers to the relative importance of a symptom (eg, incites feelings of worry) [16]. For example, severe or frequent symptoms may not be as bothersome (eg, effect on sexual activities) as symptoms that are less severe and frequent (eg, fatigue) [16]. Previous research analyzing participants' selections of T2A and T2B when using the ESRA-C technology revealed that participants did not always select the symptom with the highest SDS-15 score as the most bothersome issue [16]. Due to the small number of participants who did not follow clinician recommendations for SQIs, further research is needed to understand such a finding.

Most baseline characteristics were not predictive of participant adherence to clinician recommendations or additional self-management strategy use for SQIs. However, women were more likely than men to report additional self-management strategies for SQIs. Previous research involving the ESRA-C technology revealed that there were no statistically significant differences in the number of times men or women accessed self-management information within the ESRA-C platform [15]. Thus, due to the lack of differences in ESRA-C exposure between men and women, the observed gender differences in additional self-management strategy use for SQIs may be a result of the tendency for women in the United States to use

complementary and alternative medicine strategies for cancer self-management more often than men [28].

Limitations

Our sample was drawn from English speakers at 2 comprehensive cancer centers and cannot be generalized to other settings or non-English speakers. We were unable to determine the impact of ESRA-C use on the promotion of participant adherence to clinician recommendations or additional self-management strategy use for particular SQIs. The current analyses were likely underpowered as they only used a subset of the full sample from the primary trial. We did not collect information related to participants' opinions of the self-management information or clinician recommendations they received for bothersome SQIs. It is possible that participants did not use additional self-management strategies or adhere to clinician recommendations for bothersome SQIs because they did not find the self-management information or clinician's recommendations useful.

Conclusion

The results of these analyses revealed that there were no differences in the frequency of clinician recommendations or self-management strategy use for SQIs between intervention and control group participants. Additional analyses revealed that participant adherence to clinician recommendations was uniquely associated with differences in symptom management satisfaction and symptom distress scores. Further research is needed to determine how varying components of electronic symptom assessment and management platforms influence participant adherence to clinician recommendations or self-management strategy use for SQIs. Identifying which components of electronic symptom assessment and management platforms influence participant cancer symptom self-management may provide insight as to how the use of electronic symptom assessment and management platforms improve patient-reported outcomes such as symptom distress.

Practice Implications

Differences in participant adherence to clinician recommendations was a crucial factor in self-reported ratings of symptom management satisfaction and symptom distress. Clinicians must use effective communication (eg, establish goals for care and conversations with patients, gain insight surrounding patient's understanding of their condition, check for patient's understanding of information provided) [23] and spend sufficient time with the patient to vigilantly assess patients' self-reported symptoms as the most severe symptoms may not be the most bothersome. In addition, effective patient-clinician communication about symptom management may increase patient adherence to clinician recommendations. Clinicians also may encourage the use of self-management strategies to supplement recommendations for SQIs to increase patients' cancer symptom self-management behaviors.

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Conflicts of Interest

RK has received a consulting honorarium from System Analytic. The other authors report no conflicts of interest. All authors have approved the final article.

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Abbreviations

ANOVA: analysis of variance

ESRA-C: Electronic Symptom Assessment and Self-Care

RCT: randomized controlled trial

SDS-15: Symptom Distress Scale-15

SQI: symptom/quality of life issue

T1: timepoint 1

T2: timepoint 2

T3: timepoint 3

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Original Paper

Self-Care Behaviors of Ovarian Cancer Patients Before Their Diagnosis: Proof-of-Concept Study

James M Flanagan¹, PhD; Hanna Skrobanski^{2,3}, MSc; Xin Shi^{4,5,6}, PhD; Yasemin Hirst², PhD

¹Division of Cancer, Department of Surgery and Cancer, Imperial College London, London, United Kingdom

²Institute of Epidemiology and Public Health, Research Department of Behavioural Science and Health, University College London, London, United Kingdom

³School of Health Sciences, University of Surrey, Guildford, United Kingdom

⁴Business School, Manchester Metropolitan University, Manchester, United Kingdom

⁵School of Management, Shanghai University, Shanghai, China

⁶Karaganda State Medical University, Karaganda, Kazakhstan

Corresponding Author:

James M Flanagan, PhD

Division of Cancer

Department of Surgery and Cancer

Imperial College London

Hammersmith Campus, Du Cane Road

London, W12 0NN

United Kingdom

Phone: 44 20 75942127

Email: j.flanagan@imperial.ac.uk

Abstract

Background: Longer patient intervals can lead to more late-stage cancer diagnoses and higher mortality rates. Individuals may delay presenting to primary care with red flag symptoms and instead turn to the internet to seek information, purchase over-the-counter medication, and change their diet or exercise habits. With advancements in machine learning, there is the potential to explore this complex relationship between a patient's symptom appraisal and their first consultation at primary care through linkage of existing datasets (eg, health, commercial, and online).

Objective: Here, we aimed to explore feasibility and acceptability of symptom appraisal using commercial- and health-data linkages for cancer symptom surveillance.

Methods: A proof-of-concept study was developed to assess the general public's acceptability of commercial- and health-data linkages for cancer symptom surveillance using a qualitative focus group study. We also investigated self-care behaviors of ovarian cancer patients using high-street retailer data, pre- and postdiagnosis.

Results: Using a high-street retailer's data, 1118 purchases—from April 2013 to July 2017—by 11 ovarian cancer patients and one healthy individual were analyzed. There was a unique presence of purchases for pain and indigestion medication prior to cancer diagnosis, which could signal disease in a larger sample. Qualitative findings suggest that the public are willing to consent to commercial- and health-data linkages as long as their data are safeguarded and users of this data are transparent about their purposes.

Conclusions: Cancer symptom surveillance using commercial data is feasible and was found to be acceptable. To test efficacy of cancer surveillance using commercial data, larger studies are needed with links to individual electronic health records.

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KEYWORDS

cancer; early diagnosis; proof of concept; focus group; acceptability; data linkage; cancer surveillance

Introduction

Early diagnosis is key to increasing the chances of 10-year survival rates and the number of people living beyond cancer. However, when the symptoms first present, only a very small proportion of people believe that their symptoms might be a sign of cancer; failure to recognize the signs and symptoms of cancer have been strongly linked to delays in help-seeking [1,2]. While greater symptom awareness and body vigilance are a key part of the patient appraisal and help-seeking [3], it has been suggested that people might use past experiences to reassure themselves that their symptoms are normal [4]. Ovarian cancer symptoms (eg, feeling bloated and abdominal pain) [5,6] and women's personal experiences are prime examples of how symptoms can be normalized and potentially lead to delays in diagnosis [7].

Epithelial ovarian cancer has no specific recognizable symptoms and, as a result, most women are diagnosed at a late stage when the cancer has already spread around the peritoneum and the prognosis is poor. Approximately 7400 new cases of ovarian cancer are diagnosed each year in the United Kingdom, with over 4000 women dying from the disease each year [8]. The 10-year survival rate is only 35% in the United Kingdom; the survival rate is dramatically different if patients are diagnosed earlier with stage 1 disease (90%) compared with stage 3 or 4 (5%-15%), which unfortunately includes the majority of patients. Given that screening with cancer antigen 125 (CA 125) and transvaginal ultrasound do not appear to reduce mortality associated with ovarian cancer [9,10], the key to reducing this mortality is earlier diagnosis among women who are symptomatic, identifying those at high risk, and prevention.

Women with ovarian cancer usually report to primary care with symptoms at least six months before diagnosis; this suggests that symptom presentation and management are key parts of understanding ovarian cancer prognosis better [11]. A previous study showed a third of patients with ovarian cancer receive prescription medication to manage irritable bowel disease, constipation, stress, and depression before being diagnosed with cancer [12]. Qualitative studies on patients' symptoms appraisal support the fact that women with ovarian cancer self-medicate their symptoms before they become debilitating [7]. If ovarian cancer symptoms overlap with patients' sense of self and normality before they are perceived as signs of pathology [13], persistent use of over-the-counter medication could be an indication of ovarian cancer.

Most self-care evidence prior to diagnosis comes from retrospective studies with cancer patients, by the use of self-reported data from surveys and qualitative interviews [14]. Although they are important in understanding what may have caused delays in help-seeking, they have limited applications in real-life interventions. On the contrary, *big data* refers to massive amounts of data collected at rapid and efficient rates due to technological advances [15]. Big data in health care has the major potential to connect information from different sources to generate real-time datasets and outputs to monitor illnesses [16,17]. For instance, recent studies have utilized digital data to gain a better understanding of online

health-information-searching by conducting large-scale analyses of search engine logs. By analyzing the sequence of terms inputted about health, studies have demonstrated the ability to detect influenza [18] and dengue [19] outbreaks, to discover side effects of medications [20], to assess effectiveness of internet-based preventative health programs [21], and to predict the changing information needs of women with breast cancer, from diagnosis to treatment [22].

Furthermore, a recent study has shown the feasibility of using online search terms describing cancer-relevant symptoms to predict forthcoming diagnoses of early-stage pancreatic cancer [23]. In addition to the use of online search engine logs to forecast early signs of cancer, future studies could use other sources of commercial data (ie, loyalty card and tracker data, as well as social media data collected by commercial organizations to understand consumer behaviors) to further understand how people evaluate and implement self-care for their cancer symptoms. However, one of the key challenges of using personal, commercial big data in cancer research is not knowing whether using commercial data to predict cancer is an acceptable approach within this decade, and whether it will provide meaningful insights into symptom appraisal and help-seeking.

Here, we aimed to evaluate inquiries on both acceptability and feasibility of cancer symptom surveillance using commercial data with a proof-of-concept study. Proof-of-concept studies are used to establish whether the proposed methodology or the concept is valid and feasible [24]. We used ovarian cancer as our primary cancer for our case study. We investigated the proof-of-concept evidence within the purchasing behaviors of women pre- and postdiagnosis using data from a high-street retailer that contains purchases of pain and indigestion medications. Furthermore, to better understand public attitudes and whether this project can be carried out with prospective real-time data, we assessed the acceptability of commercial- and health-data linkage for cancer symptom surveillance among a healthy population.

Methods

Ovarian Cancer Case Study

Study Design and Setting

We conducted a retrospective study of purchasing behaviors using ovarian cancer patients' pre- and postdiagnosis data held in connection with a high-street retailer loyalty card. The study was facilitated by the Economic and Social Research Council (ESRC)-funded Consumer Data Research Centre (CDRC), which is based at University College London (UCL), London, United Kingdom. The CDRC has a license agreement with the high-street retailer, which agreed to support the study. Under CDRC guidelines, the data we requested were considered controlled data, which are defined as "data which need to be held under the most secure conditions with stringent access restrictions." This meant that all data analysis was performed at a secure data laboratory based at UCL. JMF and YH were the only people with access to the data.

Data Collection

With the support from a patient representative group from a charity, Ovarian Cancer Action, 70 patients who were not under treatment for ovarian cancer from January to May 2017 received an invitation pack, including a study information sheet, a self-report survey, a consent form, and a free-post envelope. Once consent forms and surveys were returned, the researcher provided the high-street retailer with the unique loyalty card ID and a unique study ID for each of the consenting participants. The high-street retailer extracted data to be transferred into the CDRC secure lab using an encrypted server. The researchers used the unique study IDs to merge the survey data with the retailer data. The individuals' data collected through the survey were not accessible to the retailer and the CDRC. Due to time restrictions, we included one healthy subject in the study.

Self-Report Survey

A self-report survey was designed to obtain information about the timeline of the cancer diagnosis, symptoms observed, demographics, and the loyalty card usage (see [Multimedia Appendix 1](#)). We asked the participants to report the first time they recognized signs and symptoms, the first time they booked an appointment with a health care professional, and the month and year of diagnosis. The symptoms included irregular periods or vaginal bleeding after menopause, back pain, lower-tummy pain, passing urine more than usual, constipation, pain during sex, weight loss, persistent bloating, loss of appetite, and feeling tired. Patients were given *other* as a response option. In addition,

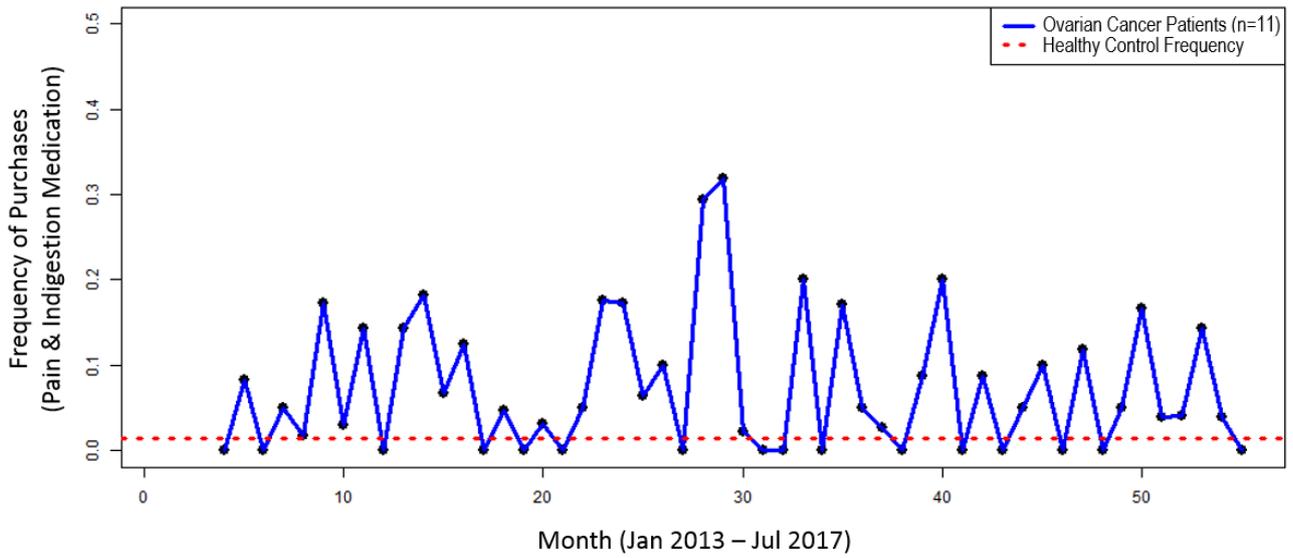
the survey recorded self-reported purchases of over-the-counter medication.

Data Analysis

Feasibility outcomes and participant characteristics were demonstrated using descriptive statistics. Due to variance in the frequency of purchases, we calculated the proportion of individual purchases matching the categories of interest—*hair care products* as one category and *pain plus indigestion medication* as the other category. For each category, the monthly ratio of each individual purchase to the overall purchases was computed. For example, the proportion of *pain plus indigestion medication* was calculated as $(\text{pain medication} + \text{indigestion medication}) / \text{all purchases in the month}$. The overall proportions, as reported in [Figure 1](#), were calculated as averages for the calendar months across the study period. In [Figure 2](#), patients were aligned with their diagnosis dates; an average proportion was calculated across the patients for each month prior to diagnosis (6/11, 55%) and postdiagnosis (11/11, 100%). Month and year of diagnosis were recorded for each ovarian cancer patient using the self-report survey and all purchase dates were aligned with pre- or postdiagnostic times. Where an ovarian cancer patient diagnosis was prior to the earliest purchase data, all data points were recorded as postdiagnosis from the date of the earliest purchase. The confidence interval of the mean was calculated using the R package *Publish* and *ci.mean* function. The data were analyzed using R version 3.2.3 (The R Foundation).

Figure 1. Overall purchase proportions. For each month between April 2013 and July 2017, the total purchases for each category were summed and divided by the number of all purchases in that month for the ovarian cancer patients (blue line), compared with the average monthly purchase proportion for that category for the healthy control subject (red dotted line). A. Purchases of pain and indigestion medication. B. Purchases of hair care products.

A



B

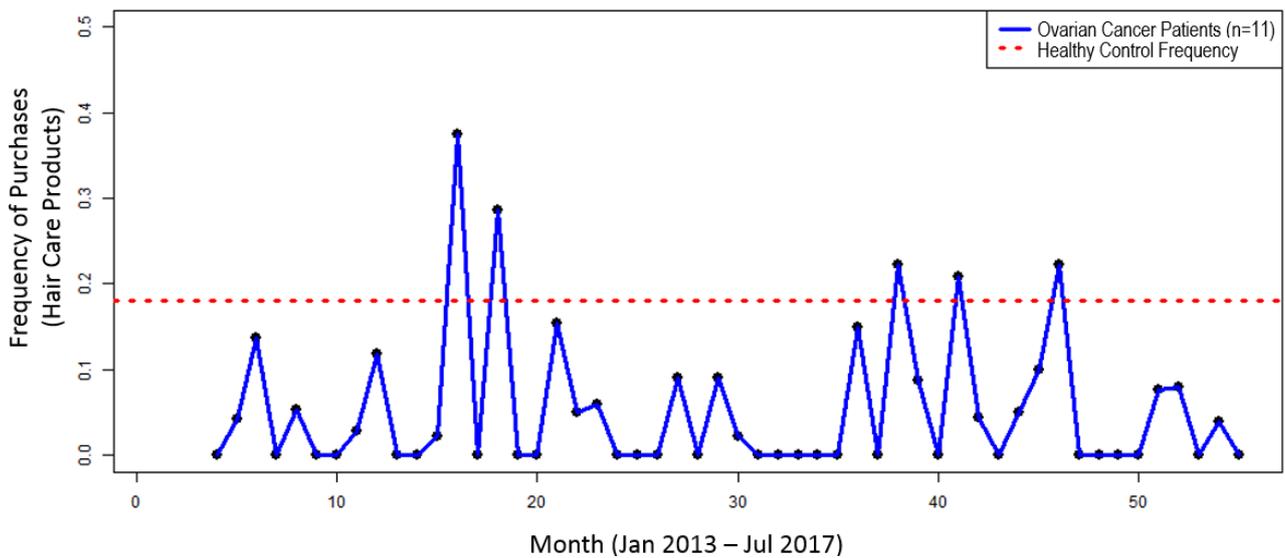
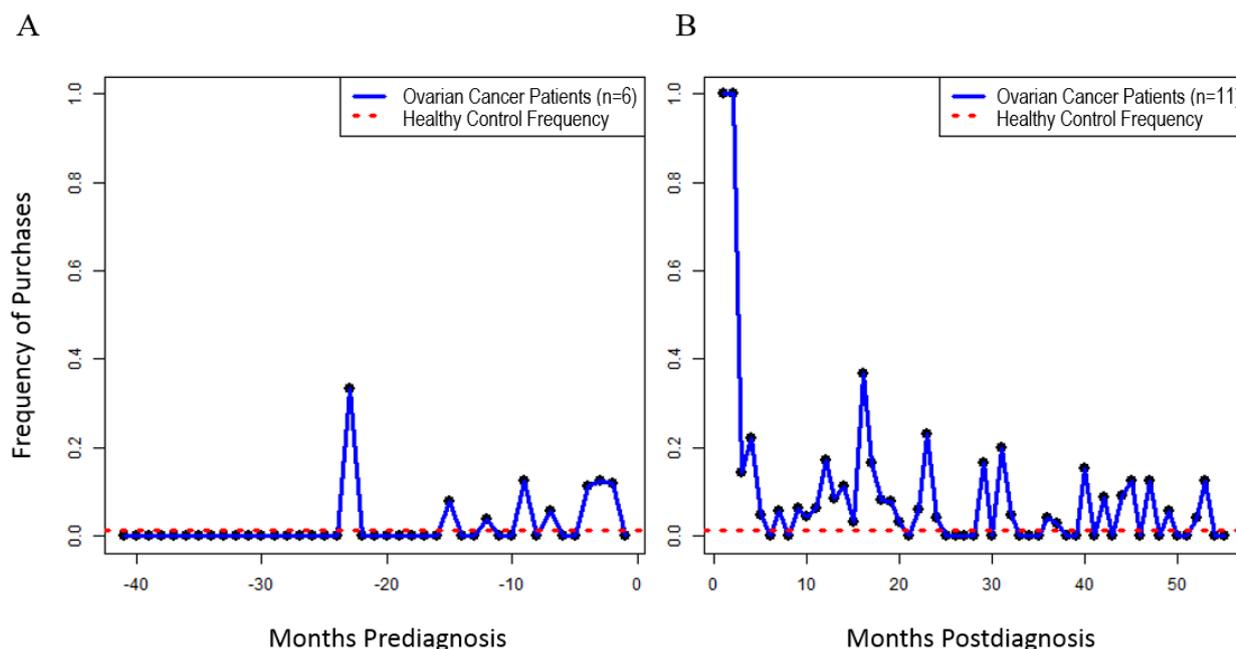


Figure 2. Pain and indigestion medication purchases stratified into pre- and postdiagnosis. Average monthly purchase proportions for ovarian cancer patients (blue line) were compared with those of the healthy control subject (red dotted line). A. Purchases for the pain and indigestion medication category during the prediagnostic period. B. Purchases for the pain and indigestion medication category during the postdiagnostic period.



Focus Group Study

Study Design and Setting

Between January and April 2017, we conducted four focus groups with members of the general public, 25–74 years of age, aiming to explore their acceptability of, and their attitudes toward, using commercial-data linkage for the purpose of cancer symptom surveillance. Participants from all parts of the United Kingdom were invited to attend a focus group based at the researchers' offices at UCL in London, United Kingdom.

Research participants were recruited by placing an online recruitment advertisement on Twitter and Facebook, as well as by asking friends and colleagues of the researchers to share an email invitation. The online recruitment advertisement and email invitation promoted the fact that travel expenses would be reimbursed and focus groups would take place during lunchtime—with free refreshments included—so that participants could enjoy an afternoon in London afterward. Those interested in participating were instructed to click on a link to an online survey that asked individuals for their contact details and age. Individuals were selected for the study through the use of purposive sampling, which ensured that each focus group included individuals of different ages. Purposive sampling was used in this study, as previous research has shown a difference by age in the acceptability of sharing personal data, with younger individuals being more accepting of providing their personal information to commercial companies [25].

Each focus group was conducted for approximately one hour, facilitated by two members of the research team; all focus groups were led by one researcher, with another researcher assisting with facilitating the sessions. The role of the lead facilitator was to lead the discussion by asking the questions in the topic guide, encouraging all members to participate, and

qualitatively balancing the amount of content that came from any one participant. The role of the assistant facilitator was to write field notes and to keep track of the timing.

At the beginning of each focus group session, participants were asked to complete a paper survey measuring demographic characteristics—age, gender, ethnicity, employment, and education—and use of the following: loyalty cards, online search engines, online shopping sites, health trackers, and social media (eg, Facebook, Twitter, and Instagram). The survey took no longer than five minutes to complete. The survey items have not been validated, but were included to allow us to describe the sample and to identify whether there were any biases in the groups (ie, if any group was overrepresented by participants of a particular demographic or by those who were more likely to use the apps or online services of interest).

Focus group questions were developed by the research team and reviewed for content and reliability. Two patient representatives from Cancer Research UK also reviewed the acceptability and the readability of the topic guide and provided further guidance. During the focus groups, the concept of data linkage was first introduced by asking participants how they felt about sharing their personal information with commercial companies and what they thought their data were used for. The discussion then moved on to asking participants about their attitudes toward researchers linking their commercial data with their health records to understand how their behaviors and that of others are linked to health conditions. The end of the discussion then focused more specifically on understanding participants' thoughts on the potential to use commercial- and health-data linkage to predict cancer in the future using machine learning. The lead facilitator provided a description of this feasibility study in order for participants to understand the context for this discussion and the types of commercial data

that may be used for the purpose of cancer surveillance in the future (eg, Fitbit and loyalty card data; see [Multimedia Appendix 2](#)).

Data Analysis

The focus groups were audiotaped and the audio files were transcribed verbatim. The researchers validated the accuracy of transcripts by comparing them with the audio files and the facilitators' notes. The transcripts were analyzed using thematic analysis [26] using NVivo 11 software (QSR International). Interview transcripts were read repeatedly to extract themes, which were formatted into matrices to allow comparison of themes across participants and to identify the salient and prevalent dimensions of attitudes.

Ethics Approval and Consent to Participate

Both studies have been reviewed by the University College London Research Ethics Committee and received favorable opinions (case study reference No. 6769/004 and focus group study reference No. 4657/002). The case study was also submitted to be reviewed by the CDRC Research Approvals Group (reference No. CDRC 018), which assessed the feasibility of the study and facilitated engagement with the high-street retailer. YH, JMF, and XS received the Safe User of Research Data Environments (SURE) training from the UK Data Service and had been subject to criminal records checks to receive permission to have access to data at the secure laboratories.

Consent for Publication

We received individual consent from focus group participants to use their anonymized data in research publications, reports, webpages, and other research outputs. All anonymized outputs from the ovarian cancer case study were approved in accordance with CDRC data dissemination policies. Individual consent forms are being kept in a secure locker at YH's department based at UCL for 10 years, in line with UCL's data retention regulations.

Results

Ovarian Cancer Case Study

Feasibility Outcomes

Of the 70 patients who received the invitation, 18 women (26%) consented to take part in the study (see [Table 1](#)). Two people contacted the research team and reported not having a loyalty card as their reason for not participating. Of the 18 women who returned their consent, the median age was 55 (35-69) years and 17 women (94%) were white British. Of the 18 subjects, 7 (39%) had an unverified name or loyalty card number. We found that 17 out of the 18 (94%) participants recalled at least one symptom before their first visit to primary care; pain and fatigue were the most recognized symptoms. In total, purchase data from 11 ovarian cancer patients and one control subject were included in the final database. The high-street retailers retain individual purchase data for three years before aggregating the past purchase data. As a result, data from 1118 individual purchases

were obtained from the retailer data ranging from April 2013 to July 2017. Of the final sample, 5 out of 11 patients (45%) were diagnosed before April 2013; therefore, all of their data were treated as postdiagnosis.

Proof-of-Concept Outcomes

Due to the higher patient recall of pain as one of the recognized symptoms before diagnosis, pain medication inclusive of indigestion and gastrointestinal tablets was chosen as the primary medication to monitor retrospectively. We selected *hair care products* as the control purchase category, which was expected to be unrelated to ovarian cancer symptoms. During the analysis period, there were 88 individual purchases of pain or indigestion medication. The monthly proportion of purchases of pain and indigestion medication in ovarian cancer patients ranged from 0% to 30% (8/27) across each of the months, in comparison to that of the healthy control subject, which accounted for approximately 1% (1/72) of all of their purchases (see [Figure 1A](#)). In comparison, there were 74 individual purchases of hair care products among the purchases. Hair care products accounted for approximately 18% (13/72) of all purchases by the healthy control compared with 0% to 38% (9/24) each month for the ovarian cancer patients (see [Figure 1B](#)).

To test for self-care behaviors before diagnosis, we split the timeline and demonstrated the purchasing trends by calculating the purchases for each month pre- and postdiagnosis. [Figure 2](#) shows that around 12 months before diagnosis, women started purchasing pain and indigestion medication, while their behavior is the same as the healthy control individual before their potential nonapparent symptoms might have started to present themselves. We found pain and indigestion medication representing 12 out of 202 (5.9%, 95% CI 1.0-8.8) purchases prediagnosis and 73 out of 1011 (7.22%, 95% CI 4.5-15.0) purchases postdiagnosis, compared with the healthy control at 1 out of 72 (1%) purchases (see [Figure 2](#)). In comparison, the hair care products represented 24 out of 202 (11.9%, 95% CI 5.3-26.7) purchases before diagnosis and 37 out of 1011 (3.66%, 95% CI 2.3-6.6) purchases postdiagnosis in the ovarian cancer patients, compared with 13 out of 72 (18%) purchases in the healthy control.

Focus Group Studies

Acceptability of Commercial- and Health-Data Linkage for Cancer Symptom Surveillance

In total, 27 people took part in one of four focus groups (see [Table 2](#)). Overall, 19 out of the 27 participants (70%) were female with at least one to three male participants in each group. Distribution of participant characteristics is presented in [Table 2](#). Four key themes were identified from the discussions in all the focus groups: conditional acceptance of commercial- and health-data linkage and symptom surveillance, beliefs about accuracy of the data, perceived benefits, and considerations for communication strategies.

Table 1. Ovarian cancer case study participant characteristics.

Participant characteristics	All respondents (N=18)	Ovarian cancer patients (N=11)
Age in years, median (range)	55 (35-69)	56 (35-69)
Ovarian cancer diagnosis, n (%)		
Yes	17 (94)	11 (100)
No	1 (6)	0 (0)
Ethnicity, n (%)		
White	17 (94)	10 (91)
Missing	1 (6)	1 (9)
Symptoms observed before diagnosis (all respondents, N=17), n (%)		
Any	15 (88)	9 (82)
Irregular periods	1 (6)	1 (9)
Pain (back, tummy, urinary, during sex)	12 (71)	6 (55)
Constipation	1 (6)	1 (9)
Weight loss	1 (6)	1 (9)
Bloating	3 (18)	1 (9)
Loss of appetite	4 (24)	2 (18)
Fatigue	7 (41)	6 (55)
Perceived health, n (%)		
Excellent to very good	4 (22)	3 (27)
Good to fair	10 (56)	5 (45)
Poor	4 (22)	4 (36)
Loyalty card use, n (%)		
All the time/often	13 (72)	8 (72)
Sometimes/not very often	4 (22)	2 (18)
Not at all	1 (6)	1 (9)
Subscription to loyalty cards provided by high-street retailers, n (%)		
Tesco	17 (94)	10 (91)
Boots	15 (83)	11 (100)
Sainsbury	13 (72)	8 (73)
All three above	10 (56)	7 (64)
Coop	8 (44)	4 (36)
Morrison	1 (6)	1 (9)
Superdrug	4 (22)	3 (27)

Table 2. Focus group study participant characteristics.

Participant characteristics	Participants (N=27), n (%)
Focus group distribution	
Group 1	5 (19)
Group 2	6 (22)
Group 3	7 (26)
Group 4	9 (33)
Age in years, median (range)	55 (25-71)
Gender	
Male	8 (27)
Female	19 (70)
Ethnicity	
White British	25 (93)
Other white	1 (4)
Other mixed	1 (4)
Employment	
Full-time employee	13 (48)
Part-time employee	3 (11)
Retired	7 (26)
Student	2 (7)
Disabled or too ill to work	1 (4)
Full-time homemaker	1 (4)
Education	
GCSE ^a /O Level ^b /CSE ^c , vocation qualifications, or A Level ^d	6 (22)
Higher education (degree or higher)	18 (67)
No formal qualifications	3 (11)
Number of loyalty cards	
None	10 (37)
One card	2 (7)
Between two and five cards	11 (41)
More than five cards	4 (15)
Use of Facebook	
Yes	17 (63)
No	10 (37)
Use of Instagram	
Yes	7 (26)
No	20 (74)
Use of online search engines	
Yes	25 (93)
No	2 (7)
Use of online shopping	
Yes	19 (70)
No	8 (30)
Use of health trackers	

Participant characteristics	Participants (N=27), n (%)
Yes	10 (37)
No	17 (63)
Use of Twitter	
Yes	10 (37)
No	17 (63)

^aGCSE: General Certificate of Secondary Education.

^bO Level: Ordinary Level.

^cCSE: Certificate of Secondary Education.

^dA Level: Advanced Level.

Conditional Acceptance of Commercial- and Health-Data Linkage and Symptom Surveillance

In general, the concept of linking commercial and health data for early detection of cancer was perceived to be interesting and people were conditionally willing to share their data. The key conditions were having safeguards, transparency, and an option to opt out or withdraw from the study. Safeguards included not just data security, but also ensuring that the data would not be used for purposes outside of the details provided in the initial consent, as illustrated in the following quote:

If somebody checked the data on my phone, because we had a cancer scare, it would be quite interesting because I had gone on symptom checkers quite a lot, so I think they'd have got quite a lot of data probably from that, which might have been useful. So, I wouldn't disagree with that, it's always this thing of safeguards isn't it? [Focus Group 4, Participant 27, female, age 66]

The conditions also included transparency about the data management and data sharing policies. Participants wanted clear and concise information about the purpose and usage of their data during the consent process. These were all related to concerns about the misuse of the data by commercial gain.

I wouldn't be averse to that for research purposes, people being able to link things, as long as only certain people had access to that and that it was well-controlled and [with] data protection. [Focus Group 2, Participant 10, female, age 34]

They do loads of these terms and conditions because they know you'll get bored before the end of it or they'll confuse you before you get to the end of it. They should make that very clear at the box that it's only for their [researchers'] use. [Focus Group 3, Participant 12, female, age 55]

Beliefs About Accuracy of the Data

While participants were intrigued by the potential to detect cancer early through data linkages between commercial datasets and health records, there was skepticism about the accuracy of the data as well as the potential outcomes of misinterpretation. This concern was toward the predictive utility of understanding illness development, the presence of symptoms, and behavior change, using data other than individual health records.

Do we understand yet a cure for cancer as a result of some really good researchers and all our data? I think that kind of story would be really convincing. [Focus Group 3, Participant 17, male, age 53]

Relating to the predictive utility, participants questioned whether the commercial data will be representative of the individuals' actions and the symptoms they could be experiencing. The reliability of data entered into the social media websites and search engines were questioned by most focus groups. In particular, concerns were raised about data entry on behalf of someone else or for interest (eg, looking up someone else's symptoms on search engines). Participants also felt that people are not open and honest about their actual behaviors on social media websites and agreed that outcomes of social media data analysis will have a "self-presentation bias." In most focus groups, participants proposed a preference and trust in objective data (eg, tracker data and phone apps).

People start having the symptoms and they change their eating habits, get more yoghurts or cut down on the bread and things; could that not just be that our taste buds change and we like bread for a while and then go, "I'm fed up of bread." And there's actually nothing wrong with us, it's just... [Focus Group 3, Participant 12, female, age 55]

Perceived Benefits

Participants agreed that if cancer symptom surveillance is found to be effective, there may be a positive impact on research, an increase in early diagnosis, and ultimately reduction in costs to the National Health Service. A few mentioned that this could reduce the pressure on emergency services and could support general practitioners' (GPs) decision-making processes if they had a clear idea of the symptoms timeline. One participant, however, perceived the impact to be more direct on his life and expressed the potential impact that this research would have on his partner and himself if her online data and consumer behavior were researched before she was diagnosed with cancer.

So she started to feel tired, so she's Googling tiredness, but privately; then she's got this pain in her shoulders, so she started having physio on her shoulders—this is from September to February. She's buying some painkillers or whatever and eventually a lump appears under her arm and she went to the doctor and it's late-stage lung cancer; but she's a

very fit woman, so in those six months beforehand, you look back now in time on reflection, it's pretty obvious that pain she was having was the tumor. So that makes sense doesn't it? It might give her a heads up, "you've got a tumor here," or "get checked out for a tumor:"...So that early diagnosis makes complete sense, however, is it for us as human beings to discover stuff? I don't know. I'm really interested to hear. [Focus Group 3, Participant 17, male, age 53]

Considerations for Communication Strategies

Furthermore, the discussions included how people would like to be informed about the outcomes if such analysis existed in the future. Some participants preferred being directly informed from a trusted source (eg, their GP). They felt direct letters with a GP's recommendation to themselves would prompt an action toward early detection or prevention. Others preferred to be informed by receiving a generalized public health message where the outcome could be more informative rather than used to highlight specific risk.

If someone found out something might be a pointer towards a problem, I'd like it to go through the proper channels and come from my GP rather than anyone else really. [Focus Group 4, Participant 23, male, age 60]

I like to think if it was a very good advert, maybe some compelling way of communicating with people, then I would. I also feel like doing something in a community that feels nicer to me than getting a horrible email. [Focus Group 3, Participant 16, female, age 26]

All participants felt that feedback from either of the options would have to be communicated clearly to ensure that it does not create any unwarranted anxiety among those who are not actually having symptoms of cancer.

I'm just thinking that it might be too vague and that you might give people an idea that they could have cancer who are actually not at risk at all. I'm just thinking that it might actually cause more anxiety in people than it would do good. [Focus Group 2, Participant 8, female, age 25]

Discussion

Principal Findings

This study demonstrates the potential to investigate patient appraisal before someone starts having any symptoms and signs related to cancer using real-time data collected by commercial organizations. Our study showed that real-time data collected by a commercial organization could offer insights to patients before presentation at primary care. Furthermore, if this data are used fairly and if the processes are transparent, the public are willing to give consent to commercial- and health-data linkages. It is also important to note that although it is feasible to investigate commercial- and health-data linkages, there needs to be further developments toward public trust in data accuracy and communication strategies.

As stated, screening for ovarian cancer is not being recommended [10] and the early detection of ovarian cancer still remains a major public health problem. Although our study had a limited sample size to detect differences between the cases and the control group, we did observe purchases of pain and indigestion medication in the ovarian cancer patients leading up to diagnosis. Our findings are encouraging to pursue the monitoring of self-care behaviors of ovarian cancer patients with a large-scale, retrospective, case-control study. Although the focus groups agreed that this data linkage was acceptable, only 26% of the ovarian cancer patients approached for this study consented to participate. One of the reasons for not consenting may have been that they did not hold any requisite loyalty cards, but this will need to be explored in future research. We believe that past literature on self-care behaviors before diagnosis and the emerging evidence supports this research agenda. For instance, a recent study on the nature and the frequency of abdominal symptoms suggest that patients with persistent bloating and distention waited a minimum of two months before presenting to primary care [27]. The identification of self-care behaviors using commercial data could be an effective approach to probe earlier engagement in primary care. For ovarian cancer patients, specifically, this might mean an increase in purchase of antacids to alleviate the feeling of indigestion associated with bloating symptoms. It might also mean a prolonged chronic use of pain medication to alleviate stomach pain or back pain associated with ovarian cancer.

Furthermore, access to real-life data through high-street retailers, trackers, and mobile phone apps will also open up other opportunities for future research. For example, the link between diet and cancer risk has been extensively studied in epidemiological cohort studies, such as the European Prospective Investigation into Cancer and Nutrition [28]. These studies have traditionally used food frequency questionnaires to estimate links between individuals' diets and cancer incidence, which have considerable recall bias and often only measure at very few time points. Many other cancer types also have specific symptoms that might be alleviated by over-the-counter medications or monitored using loyalty card data. For example, symptomatic esophageal cancer is often mistaken for indigestion and gastroesophageal reflux [29], lung cancer is often mistaken for persistent coughing [30], and pancreatic cancer is often mistaken for abdominal pain and loss of appetite [31]. Furthermore, with a large enough cohort using an agnostic approach with machine learning, one could discover novel purchase behaviors associated with early cancer symptoms.

Strengths and Limitations

This proof-of-concept study was the first-ever research project that aimed to understand self-care behaviors of cancer patients prior to their diagnosis using commercial data. Therefore, we have learned about the limitations of our proposed methodology as we proceeded with the data collection. The limitations of our study includes the small number of subjects that were available for analysis of loyalty card data. Our data does not show evidence of distinguishing between ovarian cancer patients and control subjects given the small number of subjects. However, it does show that it is feasible to analyze loyalty card data for

purchases such as pain and indigestion medication by patients prior to their diagnoses. Furthermore, it is also important to clarify that identifying these purchases are not sufficient to diagnose ovarian cancer, but should be sufficient to *nudge* the patient to visit their GPs and discuss these symptoms as a potential cancer-related symptom. Larger studies will be needed to assess any statistical evidence to support our hypothesis that purchase behavior may indicate cancer symptoms prior to diagnosis and to assess the sensitivity and specificity of detecting a cancer diagnosis. In retrospect, hair care products were not an ideal comparator, particularly for the postdiagnosis period, as there is a period during chemotherapy when hair care is not particularly relevant to ovarian cancer patients, although it is still relevant for the prediagnostic period. Other product categories may be needed as control purchases for future studies. Lastly, by using individual consent to analyze purchase behaviors, we have also identified the most secure pathway to analyze commercial data, which also fulfilled the criteria for the commercial organization and the participants.

As the participants recruited for the focus groups were self-selected, this may have introduced bias into the sample. Although the focus groups were relatively diverse, with a broad age range and a mixture of socioeconomic groups, the sample was unbalanced for gender (70% female). This gender imbalance is also observed with loyalty card usage, with the majority of card holders from most high-street retailers being female, which offers an insight about the target population for using loyalty card data. The use of loyalty cards as a data source, in general, has other limitations that need to be explored further. These include the fact that people often buy for other family members, not just themselves; they do not always use the card for every purchase; they may often shop at other stores; or they may not even hold any loyalty cards. Based on our data, approximately half of the women held multiple loyalty cards from several retailers and for these individuals the use of loyalty card data will be of most value when combining data from several sources. When conducting future studies, we will require the collaboration of data analysts at multiple commercial organizations to understand the variation in household data (eg, the proportion of individuals who buy products on behalf of

others and a way to combine loyalty card data from multiple retailers to understand an individual's purchasing behavior more clearly). With the new General Data Protection Regulation by the European Union and support by our focus group outcomes on transparency and accountability, any other use of loyalty card data and data linkage needs to be conducted with individual consent and in a secure environment. Although this may be perceived as a barrier to conducting large-scale projects or big data analyses, we were able to fulfill focus group participants' and supporting retailers' criteria with our proposed methodology using the CDRC secure laboratory.

Conclusions

In summary, we have shown that the potential use of commercial- and health-data linkage for cancer symptom surveillance was generally acceptable, with assurances for transparency, security, and confidentiality. Our use of individual purchase data, from loyalty card data from a high-street retailer, was an appropriate source of this data to explore this novel method for earlier diagnosis of ovarian cancer. There are a number of exciting opportunities to use this data to investigate novel methods of cancer surveillance and symptom recognition. For example, unbiased machine learning-based approaches may be used to discover novel purchase behaviors or interactions between variables in these datasets to develop new hypotheses that can be tested. Lastly, understanding when ovarian cancer patients begin to self-medicate symptoms may provide more direct empirical evidence for when symptoms occur prior to diagnosis and improve our understanding of the natural progression of this disease.

Availability of the Data and Material

The case study data for this research have been provided by the CDRC, an ESRC Data Investment, under project ID CDRC 0018, ES/L011840/1; ES/L011891/1. Under CDRC license agreement, the data included in the ovarian cancer case study was limited to the purposes of this project and cannot be shared with others. The anonymized focus group transcripts can be made available from the corresponding author upon reasonable request and will be assessed on a case-by-case basis. Users will be required to complete a data-sharing agreement.

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Authors' Contributions

JMF, XS, and YH conceived of the study. YH designed both studies and participated in their implementation. YH and HS designed the focus groups. HS conducted the focus groups and analyzed the data. JMF performed the loyalty card data analysis. JMF, YH, and HS drafted the manuscript. All authors read and approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Patient pathway recruitment survey.

[[PDF File \(Adobe PDF File\), 99KB - cancer_v5i1e10447_app1.pdf](#)]

Multimedia Appendix 2

Focus group discussion guide.

[[PDF File \(Adobe PDF File\), 49KB - cancer_v5i1e10447_app2.pdf](#)]

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Abbreviations

- A Level:** Advanced Level
- CA 125:** cancer antigen 125
- CDRC:** Consumer Data Research Centre
- CSE:** Certificate of Secondary Education
- ESRC:** Economic and Social Research Centre
- GCSE:** General Certificate of Secondary Education
- GP:** general practitioner
- O Level:** Ordinary Level
- SURE:** Safe User of Research Data Environments
- UCL:** University College London

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Original Paper

Impact of a Mobilized Stress Management Program (Pep-Pal) for Caregivers of Oncology Patients: Mixed-Methods Study

Alaina L Carr¹, MA; Jacqueline Jones², RN, PhD; Susan Mikulich Gilbertson³, PhD; Mark L Laudenslager³, PhD; Jean S Kutner⁴, MSPH, MD; Kristin Kilbourn¹, MPH, PhD; Timothy S Sannes³, PhD; Benjamin W Brewer⁵, PsyD; Elissa Kolva⁶, PhD; Tanisha Joshi⁵, PhD; Nicole Amoyal Pensak^{7,8}, PhD

¹Department of Psychology, University of Colorado-Denver, Denver, CO, United States

²College of Nursing, University of Colorado Anschutz Medical Campus, Aurora, CO, United States

³Department of Psychiatry, University of Colorado Anschutz Medical Campus, Aurora, CO, United States

⁴Division of General Internal Medicine, Department of Medicine, University of Colorado School of Medicine, Aurora, CO, United States

⁵Division of Hematology, Department of Medicine, University of Colorado Anschutz Medical Campus, Aurora, CO, United States

⁶Division of Medical Oncology, Department of Medicine, University of Colorado Anschutz Medical Campus, Aurora, CO, United States

⁷Jersey Shore University Medical Center, Hackensack Meridian Health, Neptune, NJ, United States

⁸Georgetown University Medical Center, Washington, DC, United States

Corresponding Author:

Nicole Amoyal Pensak, PhD

Jersey Shore University Medical Center

Hackensack Meridian Health

19 Davis Avenue

9th Floor, Hope Tower

Neptune, NJ, 07753

United States

Phone: 1 5519964267

Email: nicolepensak1@gmail.com

Abstract

Background: Caregivers of patients with advanced diseases are known to have high levels of distress, including depression and anxiety. Recent research has focused on recognizing caregivers in need of psychosocial support to help them manage their distress. Evidenced-based technological interventions have the potential to aid caregivers in managing distress.

Objective: The objective of our study was to describe caregiver perceptions of the usability and acceptability, and their suggestions for future adaptations, of a mobilized psychoeducation and skills-based intervention.

Methods: This study was a part of a larger trial of a mobilized psychoeducation and skills-based intervention (Psychoeducation and Skills-Based Mobilized Intervention [Pep-Pal]) for caregivers of patients with advanced illness. This substudy used a mixed-methods analysis of quantitative data from all 26 intervention participants and qualitative data from 14 intervention caregivers who completed the Pep-Pal intervention. The qualitative semistructured individual interviews, which we conducted within the first 4 weeks after participants completed the intervention, assessed the acceptability and usability of Pep-Pal. Additionally, the qualitative interviews provided contextual evidence of how the intervention was helpful to interviewees in unanticipated ways. We conducted applied thematic analysis via independent review of transcripts to extract salient themes.

Results: Overall, caregivers of patients with advanced cancer deemed Pep-Pal to be acceptable in all Web-based sessions except for Improving Intimacy. Caregivers perceived the program to be of use across the areas they needed and in others that they had not anticipated. Caregiver recommendations of key changes for the program were to include more variety in caregiver actors in sessions, change the title of Improving Intimacy to Improving Relationships, provide an audio-only option in addition to video, and change the format of the mobilized website program to a stand-alone mobile app.

Conclusions: The valuable feedback in key areas from individual interviews will be integrated into the final version of Pep-Pal that will be tested in a fully powered randomized clinical trial.

Trial Registration: ClinicalTrials.gov NCT03002896; <https://clinicaltrials.gov/ct2/show/NCT03002896> (Archived by WebCite at <http://www.webcitation.org/76eThwaei>)

KEYWORDS

advanced cancer caregivers; psychoeducation; mHealth; cancer; bone marrow transplantation; qualitative research; internet; randomized controlled trial; caregivers; neoplasms; telemedicine; clinical trial, phase I

Introduction

Background

There are over 40 million caregivers in the United States [1], and this number will only increase over time [2]. Caregivers provide uncompensated support for loved ones at a value of over US \$450 billion per year [2] and lost income equivalent to over US \$300,000 per lifetime [3]. Over half of caregivers report feeling overwhelmed by their responsibilities [2,4]. Caregivers have been termed “silent patients,” neglecting to seek treatment for themselves while taking care of their loved ones. For this study, we defined primary caregiver as the person in the patient’s life who was primarily responsible for care decisions, was emotionally invested in the patient’s care, and provided instrumental care, such as transportation. Caregivers of patients receiving hematopoietic stem cell transplant (HSCT), of patients enrolled in phase 1 oncology clinical trials, and of patients with advanced cancer experience significant distress [5-7]. Besides the transplant process, patients who undergo HSCT commonly have sexual dysfunction [8-10], which can also contribute to caregiver distress.

Caregivers have been found to be reluctant to participate in in-person support services because of the extra burden of time constraints [11]. There are barriers to accessing treatment, and consequently there is strong support for developing novel and *convenient* behavioral health interventions to support caregivers in coping with caretaking responsibilities and reducing depression and anxiety [5]. Use of technology to deliver innovative and convenient behavioral health interventions to support cancer caregivers can improve coping and reduce depression and anxiety without the added burden of having to attend a face-to-face session [5,12]. According to the US National Alliance for Caregiving, a large majority of family caregivers believed that using technologies such as video phone systems and a caregiving coordination system would be personally beneficial, save them time, make caregiving easier logistically, increase self-efficacy, and reduce stress [13]. In particular, mobile technologies (eg, telehealth) have been effectively implemented in family caregiver populations without face-to-face interactions and may help to overcome some logistical and geographical barriers to obtaining support [14,15].

Telehealth is a mode of delivering health care services through telecommunication and is commonly used to deliver educational interventions, consultation services, and behavioral interventions [16]. It can be used as a means of improving social support, collecting care management data, monitoring symptoms, and delivering clinical care [15]. In a review assessing telehealth tools and support to family caregivers, more than 95% of the 65 studies reported significant improvement in psychosocial outcomes [15]. Telehealth studies involving rural family caregivers, as well as telehealth studies conducted in a home setting, found significant improvements in psychological health

and quality of life of family caregivers. Additionally, family caregivers reported high levels of satisfaction and comfort with using telehealth [14,15]. These findings suggest that family caregivers who provide around-the-clock care and symptom monitoring can use telehealth interventions for efficient care while reducing the burden of traveling to medical clinics.

While evidence on the effects of telehealth interventions on family caregivers is encouraging, further attention is needed to identify the most effective technologies for family caregivers of cancer patients. Furthermore, because rates of mobile phone use are high among socioeconomically disadvantaged populations [17], mobile technologies present an optimal intervention strategy for targeting caregivers with financial limitations and other barriers to accessing in-person care. As technologies continue to emerge, engaging caregivers still remains a significant challenge [18-21]. To our knowledge, there are no evidence-based interventions to help caregivers manage their distress using technological platforms that can be disseminated widely.

Evidence-Based Intervention

Recent studies have shown that brief interventions can be effective in reducing distress among caregivers of allogeneic HSCT (allo-HSCT) patients [22]. Allo-HSCT patients have certain cancers of the blood or bone marrow and receive an infusion of a human leukocyte antigen-matched donor stem cell. Providing strategies to improve communication with their loved ones and intimacy after transplant may help caregivers better adjust to relationship changes. To advance knowledge in this area and overcome limitations of available caregiver resources, we completed a randomized controlled trial (RCT) of an in-person skills-based intervention with caregivers of allo-HSCT patients [5]. The brief intervention, Psychoeducation, Paced Respiration and Relaxation (PEPRR), was shown to reduce perceived stress in caregivers (primary outcome) with reductions in depression and anxiety as secondary outcomes [5]. We adapted PEPRR and enhanced it for a mobile-based platform (Psychoeducation and Skills-Based Mobilized Intervention [Pep-Pal]). Based on focus groups and feedback in our preliminary formative mobile health evaluation work, we found that Pep-Pal was feasible and usable among caregivers of patients receiving autologous HSCT (auto-HSCT) [6]. This substudy built upon the formative feasibility and usability study and tested the mobilized intervention, Pep-Pal, in a pilot RCT with caregivers of auto-HSCT patients, caregivers of patients enrolled in phase 1 oncology trials, and caregivers of patients with advanced cancer.

Objective

The purpose of this study was to continue to establish Pep-Pal as an evidence-based intervention for reducing distress in caregivers of patients with advanced illness by further assessing acceptability and usability of Pep-Pal through qualitative

interviews and self-report assessments. The aims of this study were to assess acceptability of Pep-Pal by caregivers based on mean self-reported helpfulness scores, and usability based on the majority of caregivers' ratings as above average on the usability questionnaire. We evaluated acceptability and usability of Pep-Pal through semistructured qualitative interviews. In addition, we explored ways to improve Pep-Pal based on caregiver feedback via postintervention questionnaires administered to all intervention participants and through qualitative interviews. Feedback about improvements to Pep-Pal will be integrated into a final version to be tested in a fully powered RCT.

Methods

Setting

This study was conducted at the University of Colorado Comprehensive Cancer Center, Aurora, CO, USA, a large urban academic medical center with a diverse range of patients with socioeconomic statuses seen from across the state.

Participants

Participants were eligible to enroll if they identified as a primary caregiver of a patient who was either receiving an HSCT, enrolled in a phase 1 oncology clinical trial, or with a diagnosis of advanced cancer (stage IV, solid tumor). For this study, we defined primary caregiver as the person in the patient's life who was primarily responsible for care decisions, was emotionally invested in the patient's care, and provided instrumental care such as transportation. Additional inclusion criteria for participants were (1) age over 18 years, (2) ability to read and speak English, (3) absence of cognitive or psychiatric conditions prohibiting participation (eg, significant developmental or intellectual disability), (4) endorsement of a moderate level of anxiety (eg, ≥ 8 on the Hospital Anxiety and Depression Scale subscale for Anxiety [HADS-A] [23,24]), and (5) access to a computer, laptop, smartphone, or tablet with internet access. We based the rationale for the screening cutoff score of 8 or above on the HADS-A on clinically significant anxiety symptoms in medical populations [23,24]. There were no other inclusion or exclusion criteria.

Procedure

We recruited participants over an 11-month period in the HSCT clinic, the Phase 1 Oncology Trials Clinic, and the gastrointestinal, lung, glioblastoma, and genitourinary medical oncology clinics in the study setting. We obtained informed consent alongside a treatment visit or provider appointment. We deemed potential participants to be eligible if they endorsed a total score of 8 or above (moderate level of anxiety) on the HADS-A. Study staff reviewed study procedures, the consent form, and data collection procedures with eligible participants. After participants provided consent, we administered baseline questionnaires. Randomization by permuted block design, set by the study statistician (SMG), was completed after baseline assessment. Participants were randomly assigned to receive either Pep-Pal in addition to treatment as usual or treatment as usual only. Treatment as usual was any support or resources caregivers sought out themselves. Study staff provided access

to Pep-Pal (passcode) through email. Caregivers were instructed to watch each session at least once, watch 1 to 2 new sessions per week, and practice skills between sessions. Participants were informed that they could go back and watch sessions as many times as they liked. Study participants filled out postassessment questionnaires delivered via an automated REDCap (REDCap Consortium) email at 12 weeks after enrollment. After postassessment completion, we contacted a subgroup of participants by purposeful selection of 14 intervention completers to conduct a semistructured qualitative interview. This study examined responses to semistructured interviews conducted with 14 intervention completers within 4 weeks after they had completed the Pep-Pal intervention. The trial was approved by the Colorado Multiple Institutional Review Board and registered with ClinicalTrials.gov (NCT03002896).

Pep-Pal Intervention

Pep-Pal was delivered via a mobilized website that was conveniently accessible anytime by smartphone, computer, tablet, or laptop. Pep-Pal consisted of 9 full-length sessions that were each less than 20 minutes. The 9 sessions were (1) Introduction to Stress Management, (2) Stress and the Mind-Body Connection, (3) How Our Thoughts Can Lead to Stress, (4) Coping With Stress, (5) Strategies for Maintaining Energy and Stamina, (6) Coping With Uncertainty, (7) Managing Relationships, (8) Getting the Support You Need, and (9) Improving Intimacy ([Multimedia Appendix 1](#)). Additionally, the website included "Mini-Peps," brief (<3 minutes each) video guided activities including relaxation exercise modules (eg, body scan, deep breathing, and mindfulness meditation), mood exercises (eg, gratitude exercises), and relationship enhancement activities (eg, communication exercises) ([Multimedia Appendix 2](#)).

Measures

Demographic Questionnaire

Each participant completed a demographic questionnaire at baseline that requested information on age, sex, race, ethnicity, marital status, religion, relation to patient, education level, living context (eg, number of children in the household and their ages), duration of caregiving specific to this illness, and patient's diagnosis.

Pep-Pal Usability Questionnaire

The Pep-Pal Usability Questionnaire delivered at postassessment posed 9 questions regarding the experience of using Pep-Pal on a 5-point Likert scale. Higher total scores indicated greater usability (Cronbach alpha=.88).

Helpfulness of Intervention Sessions Questionnaire

The Helpfulness of Intervention Sessions Questionnaire, delivered at postassessment, asked 10 questions regarding the helpfulness of each intervention session on a 10-point Likert scale. Higher total scores indicate greater helpfulness (Cronbach alpha=.96).

Semistructured Interview

We used a semistructured interview guide ([Multimedia Appendix 3](#)) to conduct qualitative interviews.

Data Analysis

This mixed-methods substudy included analyses of both quantitative and qualitative data. We conducted descriptive statistics on 14 intervention completers' baseline demographic questionnaires using IBM SPSS version 24 (IBM Corporation). We assessed the usability and acceptability of Pep-Pal using descriptive data that reported means and proportions. We analyzed the qualitative data from interviews, which were audiorecorded and transcribed, using an inductive approach to thematic analysis to draw out broad themes and subthemes within the data [25]. Data analysis involved systematic organization of data through open coding in ATLAS.ti version 8.2.1 (ATLAS.ti Scientific Software Development GmbH). Data analysis also involved repeated continuous comparisons across coded data to identify salient themes. We used a team approach to synthesize and contextualize the data. Team members (ALC, NAP, and JJ) independently reviewed the transcripts and met biweekly to discuss emerging themes, discrepancies, and alternative explanations. Ongoing modification of the conceptual framework of themes was a fundamental part of the analytic process. Informational saturation was reached when no new themes emerged regarding key outcomes [26].

Results

Participant Characteristics

We approached 189 caregivers for study screening across all clinics. A total of 56 caregivers were enrolled and completed assessments, of whom 14 participated in semistructured interviews. All participants were recruited through medical clinics or referred by their medical team. Figure 1 shows the flow of participants through the study.

Table 1 lists demographic characteristics. Characteristics of caregivers who participated in semistructured interviews were representative of characteristics of those in the larger trial and were not statistically significantly different from the remainder of participants in the trial regarding age, education, relationship status, and race/ethnicity. Most participants were female, at least college educated, married, employed full-time or part-time, and white.

Acceptability of Pep-Pal

We determined acceptability of Pep-Pal using the Helpfulness of Intervention Sessions Questionnaire and semistructured exit interviews with 14 completers. Participants rated intervention sessions as acceptable as measured by mean helpfulness scores at or above a rating of 5 out of 10 (1=not at all helpful, 5=neutral, 10=very helpful) for all intervention sessions except for the Improving Intimacy session (mean 4.19, SD 3.80; see Figure 2). A qualitative analysis of the interviews indicated that acceptability of the Improving Intimacy session was less about the video content but more about the topic itself, and other participants alluded to intimacy not being a priority when the partner is terminally ill.

When asked about an appropriate session length, 64% (9/14) of the qualitative participants indicated that they were satisfied with the 10- to 20-minute session length, while 28% (4/14) of qualitative participants indicated that full sessions could be 10 minutes or less. Participants were satisfied with the delivery method of Pep-Pal. Despite support for the delivery method of the intervention, 21% (3/14) of caregivers indicated that they would have preferred a more accessible mobile app instead of a Web-based format. These caregivers reported a preference for a mobile app format instead of a Web-based format due to internet connectivity issues during their commute to work.

Usability of Pep-Pal

Participants overall felt that Pep-Pal was well organized and easy to navigate (see Figure 3). In terms of the modality used to access Pep-Pal, 64% (9/14) used a computer or laptop, 42% (6/14) used an iPad or tablet, and 21% (3/14) used their smartphone. Several participants reported that they used more than one modality to access Pep-Pal (eg, computer, laptop, tablet, smartphone).

Thematic Analyses Results

A total of 4 major themes emerged in regard to usability of Pep-Pal for issues related to the caregiver experience: (1) putting the caregiver first, (2) guilt, (3) isolation and loneliness, and (4) latent traumatizing effects. Table 2 shows narrative examples that highlight exit interviewee language, context, and interpretation of usability.

Putting the Caregiver First

The overarching perspective described was that Pep-Pal was helpful in shifting caregiver focus toward putting the caregiver first. During the program, caregivers described how Pep-Pal helped them shift their focus and remind themselves to prioritize their own mental, physical, and emotional needs. One caregiver described this as "I count as somebody that I need to take care of." Additionally, caregivers described that the program helped them to balance caregiving with their other daily roles (eg, mother, spouse, friend). Some caregivers indicated that Pep-Pal was helpful in prioritizing time for a spousal or partner role in their relationship with the patient.

Guilt

The second theme that emerged was that working caregivers felt guilty in falling short of their obligations (eg, because of needing to take time off work). Caregivers described this sense of guilt when taking time off to care for their loved ones or needing to ask coworkers for help. Guilt was also evident when caregivers had to renegotiate caregiving time with family time. Much of the reported caregiver guilt was self-induced and was an internal perception of not living up to their own standards of how they should behave. One caregiver indicated that Pep-Pal helped reframe this sense of guilt by identifying with the term *caregiver* as a way to validate the need to attend the patient's hospital visits instead of going to work.

Figure 1. Study flow. BMT: bone marrow transplantation; HADS-A: Hospital Anxiety and Depression Scale subscale for Anxiety.

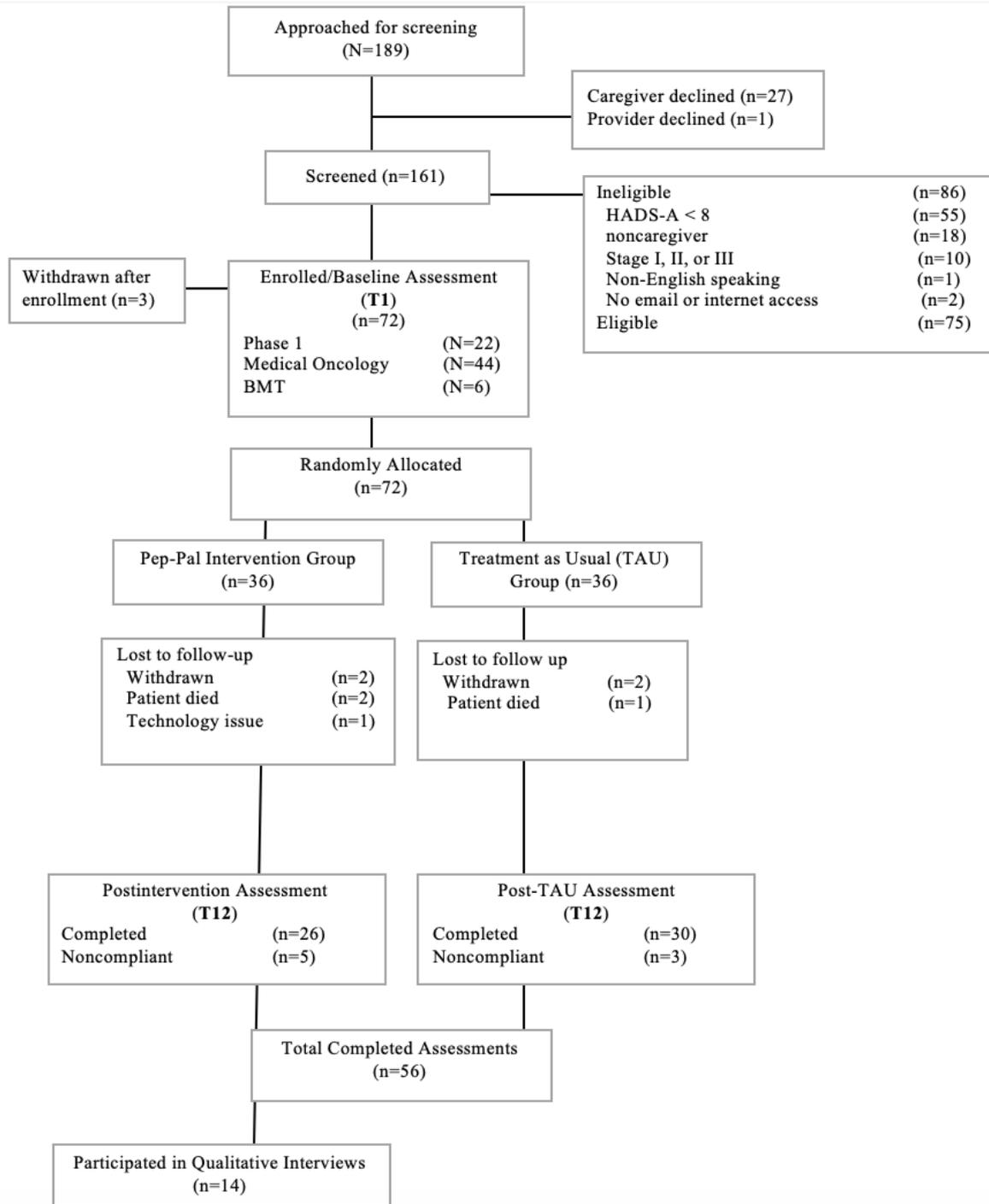


Table 1. Demographics and key characteristics of caregivers at baseline by group.

Characteristics	Postintervention assessment participants (n=26)	Qualitative interviewees (n=14)
Caregiver age (years), mean (SD)	53.3 (17.7)	52.5 (17.9)
Patient disease category, n (%)		
Enrollment in phase 1 trial	7 (26)	5 (35)
Lung	14 (53)	5 (35)
Genitourinary	1 (3)	1 (7)
Gastrointestinal	1 (3)	1 (7)
Bone marrow transplantation	3 (11)	2 (14)
Glioblastoma	N/A ^a	N/A
Female caregiver, n (%)	19 (73)	10 (71)
Married or in a civil union, n (%)	20 (76)	9 (64)
Spouse or civil partner or patient, n (%)	20 (76)	10 (71)
College degree or higher, n (%)	16 (61)	10 (71)
Total annual income ≥US \$75,000, n (%)	18 (69)	8 (57)
Living with the patient, n (%)	22 (84)	11 (78)
No. of dependent children, n (%)	17 (30)	6 (42)
Employment status as a caregiver, n (%)		
Full-time	12 (46)	7 (50)
Part-time	6 (23)	4 (28)
On leave	N/A	N/A
Unemployed	2 (7)	1 (7)
Retired	6 (23)	2 (14)
Patient felt ill prior to diagnosis, n (%)	17 (65)	9 (64)
Chronic health issues prior to diagnosis, n (%)	7 (26)	3 (21)
Caregiving responsibilities began, n (%)		
When patient became ill	20 (35)	5 (35)
When patient was diagnosed	28 (50)	7 (50)
Before patient was diagnosed	3 (5)	1 (7)
Other	5 (8)	1 (7)

^aN/A: not applicable.

Figure 2. Mean scores on the Helpfulness of Intervention Sessions Questionnaire by group. A score of 10 indicates a “very helpful” session and 1 indicates a “not at all helpful” session. Error bars are standard deviation.

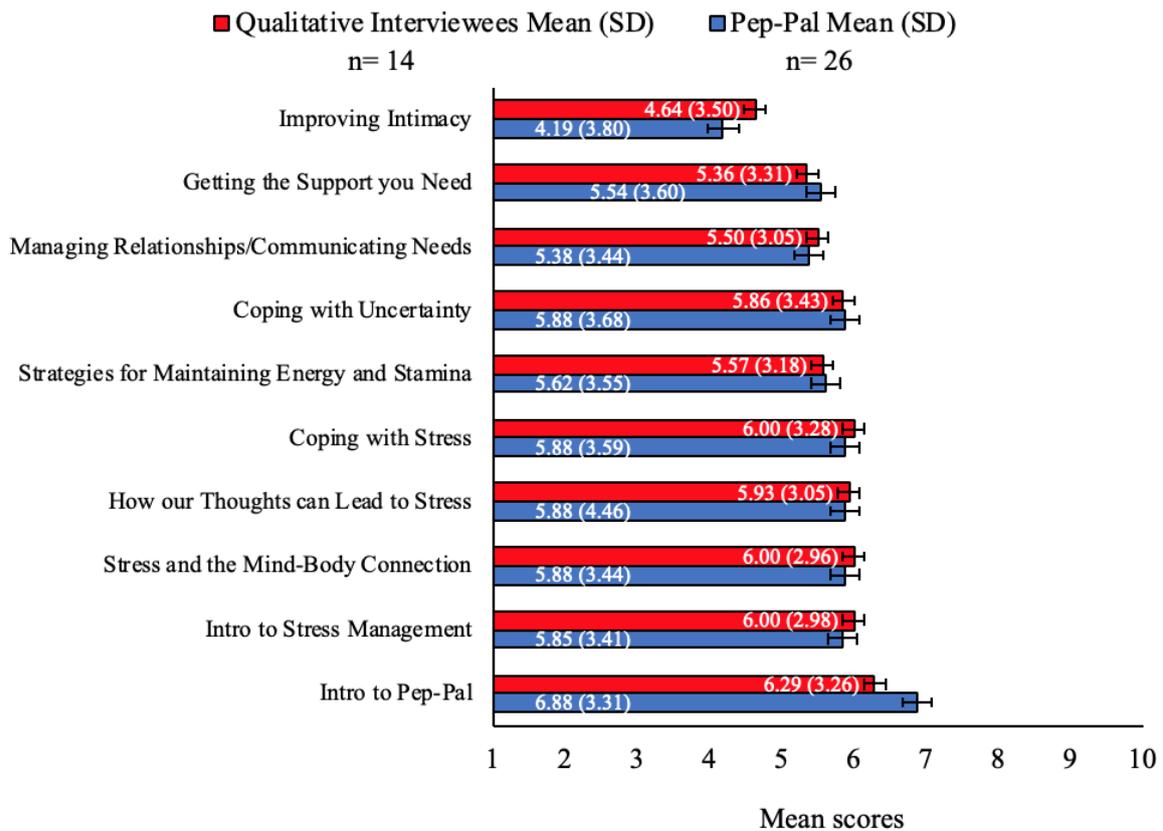


Figure 3. Mean scores on the Pep-Pal Usability Questionnaire by group. A score of 5 indicates “very strongly agree” and 1 indicates “very strongly disagree”. Error bars are standard deviation.

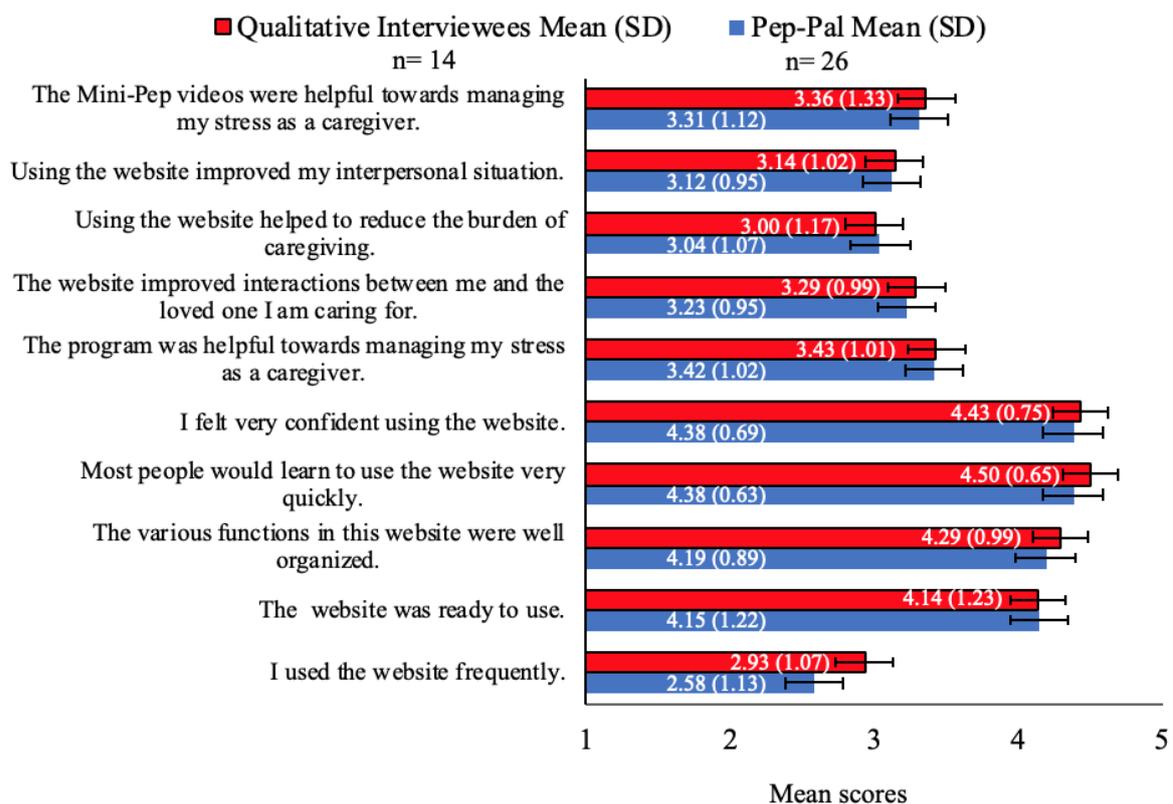


Table 2. Summary of qualitative interview results on the usability of Pep-Pal.

Theme and participant ID	Participant type	Quotation
Putting the caregiver first		
1064	Working caregiver, caregiver with a family	She would say, “Stop and write down some things that you think you could do”....I didn’t have time to do that but I did like listening to them and having that time to reflect kind of on my own needs and...mental health.
1065	Working caregiver, caregiver with a family	Mostly keeping in mind I count as somebody that I need to take care of.
1071	New caregiver	It’s talking about you need to get out and do things for yourself those things were great reminders.
1026	Long-term caregiver	It’s very, very difficult to figure out how to basically getting any of my needs met....It’s really difficult because I feel like all of his energy is directed towards fighting his cancer.
Guilt		
1060	Working caregiver, caregiver with a family	I feel guilty you know. And I think to myself, “Man, all of my paid time off has been sucked up from when my husband was in the hospital.”
1065	Working caregiver, caregiver with a family	If I had to take work off, that’s...really difficult....I could say, “Well, I’m my brother’s primary caregiver so I need to do this” I could feel okay with that. It lessened the guilt.
1009	Working caregiver	I am working full-time, so I guess so there is a little bit of guilt with that.
Isolation and loneliness		
1075	Working caregiver	During the beginning of my wife’s care it felt very lonely and very isolated and you feel like no one understands.
1021	Long-term caregiver	The thing that probably most affected me, and still...is the isolation the disease causes.
1065	Working caregiver, caregiver with a family	That feeling that you’re not alone...that there are people who are dealing with similar things and then if somebody else is dealing...
1034	Caregiver with a family, new caregiver	It’s just not you...everyone is having some...situation going on and...you’re not alone.
1060	Working caregiver, caregiver with a family	I just felt really alone in that whole process.
1026	Long-term caregiver	I just feel sort of lonely in terms of him because he’s not there for me in a way he used to be.
Latent traumatizing effects		
1060	Working caregiver, caregiver with a family	When he first got diagnosed I thought my life was ending....There were emotions at the very beginning...very overwhelming and maybe if I had known about this then, it would have been more helpful for me then.
1071	New caregiver	It [Pep-Pal] helped with feelings of a little bit of panic every time you get really bad news [laughter]. Like, “Uh-oh” but helped calm me down.
1075	Working caregiver	The illness in general...you get new information that might not be positive. And then trying to reframe it....“Okay, this is the new normal” and many times when something challenges the new normal...and you have to reset.
1026	Long-term caregiver	It’s not...easy...to deal with initially....You see people walking around traumatized....Initially, you think, oh, we’ll just do this...and then we’ll go back to our life....But going from shock to...start caregiving immediately.

Isolation and Loneliness

The third theme emerging was a negative sense of isolation and loneliness from taking on the primary caregiver role. Most caregivers reported feelings of social isolation and feeling that “no one understands the emotional and physical demands in the progress of being a caregiver.” One caregiver alluded to her “loneliness” as related to the changes in her relationship with her husband and how he could no longer fulfill a supportive

role given his disease prognosis. Caregivers indicated that Pep-Pal was helpful in normalizing many isolating aspects of the caregiving experience, such as the unpredictability of daily caregiving responsibilities. Caregivers also described Pep-Pal as being helpful in providing a sense of social cohesion with other caregivers’ experiences, notably without connecting them to other caregivers. Many caregivers expressed a desire for a chatroom feature within Pep-Pal as an additional means of social support.

Latent Traumatizing Effects

The fourth theme emerging from caregivers' comments was a sense of latent trauma or assault with the patient's terminal illness trajectory. ALC and JJ extracted the lay terms "assault," "trauma," and "shock" from caregiver qualitative interviews to contextualize the theme of latent traumatizing effects. Caregivers characterized their caring for a loved one with advanced cancer as heightened arousal, as negative affectivity and mood, and as a trauma itself. This was greater in caregivers' descriptions of feelings of trauma upon initially hearing about their loved one's terminal diagnosis. Anticipatory grief, defined as reduced levels of preparedness for their loved one's imminent death [27], was reported in caring for a loved one with a terminal disease and adjusting to "the new normal" of their daily routines that involved frequent medical visits. Overall, most caregivers described "making sense" of the latent traumatizing effects of caring for their loved one as the biggest mental, physical, and emotional challenge in caregiving.

Caregiver-Recommended Future Adaptations for Pep-Pal

Three main suggestions emerged (Multimedia Appendix 4). The first suggestion, to change the name of the session, resulted from a mixed response to the full-length Improve Intimacy session. Some interviewees (3/14, 21%) indicated that the intimacy session was not as helpful or relevant to their situation due to patient prognosis or identifying with a nonspousal role with their patient. Alternatively, several interviewees (4/14, 28%) indicated that the intimacy session provided a new perspective on redefining intimacy to include nonsexual activities to recapture meaning in their relationship.

The second suggestion to improve Pep-Pal was to include *different actors* to represent various caregiver demographics. One male caregiver recommended including different sex caregivers in Pep-Pal videos to better tailor the caregiver experiences. Despite the desire to have multiple caregivers featured in Pep-Pal videos, interviewees felt that the "caregiver" featured in the videos normalized and validated *isolating and lonely elements* of the caregiving experience. For example, one caregiver expressed frustration around meal planning with her loved one:

It's just these are common things that happen...I didn't know that anybody else has had that very same thing where you'll go "here's your dinner" [laughter] or just a wide variety of things...You know you can't take care of your own health needs sometimes because you can't get out.

The third suggestion to improve Pep-Pal was contingent on the full-time employment of caregivers. Employed caregivers indicated they would have preferred a mobile app with audio features as an additional way to navigate through the videos on their commute to work. These interviewees were also the only exit interviewees to use their smartphone as their sole modality in viewing the program sessions. Caregivers recommended including an audio component as a means to further integrate the skills from Pep-Pal into their full schedules.

Discussion

Principal Findings

Results from quantitative data and individual interviews supported the acceptability and usability of Pep-Pal.

This caregiver feedback highlights the ease of use of the Web-based platform modality and convenience that prior literature recommended for evidenced-based intervention platforms [5,28,29]. Within the specific areas of improving stress management, improving relationships, and the use of the Mini-Peps, caregivers rated the usability of Pep-Pal as "neutral." Despite neutral ratings, other contextual evidence supports the notion that, overall, the study was positive. For example, user engagement in various sessions related to stress and to getting support, and at least one Mini-Pep, provided more contextual evidence of how the intervention was helpful. In particular, qualitative interviews addressing how the intervention was helpful emphasized how interviewees found Pep-Pal to be helpful in unanticipated ways. The themes of putting the caregiver first, guilt, isolation and loneliness, and latent traumatizing effects of caregiving indicate how Pep-Pal helped participants reconceptualize elements of self-care and acknowledge guilt as a stressor, which is overlooked in this population. The fourth major salient theme, latent traumatizing effects, has been reflected in prior literature as knowledge of a loved one's advanced cancer diagnosis, and their prognosis is perceived as a traumatic event that can result in anticipatory grief [30]. These overarching themes further emphasize the multidimensional supportive needs of family caregivers and support the usability of Pep-Pal as helpful in addressing psychological, social, mental, and emotional supportive needs for caregivers.

We will integrate feedback from individual interviews into the final version of Pep-Pal to further enhance the helpfulness of the program for caregivers. Based on these interviews, it will be important to include session content or resources on grief to help caregivers process their loved one's illness and prognosis. For working caregivers and caregivers with families, a full-length session on communication about their loved one's illness to children and coworkers would be helpful in framing difficult discussions. Many caregivers reported feelings of isolation and loneliness in their caregiving role and felt that Pep-Pal was helpful in normalizing these elements of the caregiver experience. An additional feature of the program such as online chatrooms for caregivers to seek social support from one another may help to further mitigate these feelings of loneliness. Lastly, working caregivers expressed a desire for a mobile app of the program in addition to audio sessions, which would enhance the convenience of Pep-Pal. Variations in types of caregivers featured in sessions (eg, male and female) would also further tailor Pep-Pal to fit individual user needs.

We used a mixed-methods approach to further assess intervention participants' reasons for their below-average ratings of the Improving Intimacy session. Feedback was less suggestive of improving the video content itself and more indicative of how variable the topic of intimacy is within the types of caregiver-patient relationships. Several interviewees indicated

that the intimacy session provided a new perspective on how intimacy can be redefined to include nonsexual activities to recapture meaning in their relationship, which was the main goal of the Improving Intimacy session. The session was not exclusively tailored to the physical act of intimacy but broadly discussed having caregivers redefine intimacy (eg, holding hands, cooking dinner together, or taking a long walk together) in their own relationship (regardless of whether the patient is their significant other, or their child or parent, for example). As a result, we will change the title of the session to Improving Relationships in the final version.

It is important to note that, despite positive perceptions of helpfulness in the program, this program is one of many forms of care and is not a “one-size-fits-all” model. Pep-Pal is geared toward caregivers who cannot physically attend in-person support or have limited time to get to the care they need. This program is one modality in addressing how evidenced-based strategies can be disseminated in a convenient, cost-effective platform.

Limitations

The study had several limitations. First, most of the intervention caregivers were white, female, spousal caregivers, which might

limit the generalizability of the results. Second, this study involved a small qualitative sample of bone marrow transplantation intervention caregivers, which might neglect to highlight the experiences of this type of advanced cancer caregiver in Pep-Pal. Third, technological interventions can yield their own disadvantages. For example, working caregivers described internet connectivity issues when using the Web-based platform on their commute to work.

Conclusion and Future Directions

We will integrate suggestions for improvement based on the results of this study into the final version of Pep-Pal. Specifically, on the basis of qualitative caregiver feedback, we will add a chatroom feature, audio sessions, content on grief, diversity in caregiver actors, and communication strategies. In addition, we will change the title of the Improving Intimacy session to Improving Relationships. The next step is to demonstrate the efficacy of a mobile app version of Pep-Pal in a fully powered RCT with advanced cancer caregivers. Ultimately, the goal will be to conduct a larger, multisite effectiveness implementation study of Pep-Pal.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Screenshot of some of the full-length Pep-Pal sessions.

[[PNG File, 464KB - cancer_v5i1e11406_app1.png](#)]

Multimedia Appendix 2

Screenshot of some of the Mini-Pep sessions.

[[PNG File, 587KB - cancer_v5i1e11406_app2.png](#)]

Multimedia Appendix 3

Semistructured interview guide.

[[PDF File \(Adobe PDF File\), 67KB - cancer_v5i1e11406_app3.pdf](#)]

Multimedia Appendix 4

Summary of caregiver-recommended future implementations for Pep-Pal.

[[PDF File \(Adobe PDF File\), 259KB - cancer_v5i1e11406_app4.pdf](#)]

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Abbreviations

- allo-HSCT:** allogenic hematopoietic stem cell transplant
auto-HSCT: autologous hematopoietic stem cell transplant
HADS-A: Hospital Anxiety and Depression Scale subscale for Anxiety
HSCT: hematopoietic stem cell transplant
Pep-Pal: Psychoeducation and Skills-Based Mobilized Intervention
PEPRR: Psychoeducation, Paced Respiration and Relaxation
RCT: randomized controlled trial

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Original Paper

Exploring the Experiences of Cancer Patients With Chemotherapy-Induced Ototoxicity: Qualitative Study Using Online Health Care Forums

Stephanie E Pearson^{1,2,3}, BSc (Bio), MSc; John Taylor^{1,2,3}, PhD; Derek J Hoare^{1,2}, PhD; Poulam Patel^{3,4}, MBBS, FRCP, PhD; David M Baguley^{1,2,3}, MBA, PhD

¹Nottingham Biomedical Research Centre, National Institute for Health Research, Nottingham, United Kingdom

²Hearing Sciences, Division of Clinical Neuroscience, School of Medicine, University of Nottingham, Nottingham, United Kingdom

³Nottingham University Hospitals NHS Trust, Nottingham, United Kingdom

⁴Academic Unit of Oncology, Division of Cancer and Stem Cells, School of Medicine, University of Nottingham, Nottingham, United Kingdom

Corresponding Author:

Stephanie E Pearson, BSc (Bio), MSc
Nottingham Biomedical Research Centre
National Institute for Health Research
Ropewalk House, 113 The Ropewalk
Nottingham, NG1 5DU
United Kingdom
Phone: 44 0115 823 2600
Email: stephanie.pearson@nottingham.ac.uk

Abstract

Background: Many cancer patients and survivors experience permanent and life-debilitating effects, such as ototoxicity, from treatment. Ototoxicity manifests as high-frequency hearing loss and tinnitus, which can have a detrimental effect on the quality of life (QoL) of those affected. Currently, there is little information and support offered to these patients who experience ototoxicity, potentially leading to many being undiagnosed and untreated.

Objective: The aim of this study was to explore the extent of ototoxic side effects, such as hearing loss and tinnitus, and their impact on cancer patients following chemotherapy treatment. Secondary objectives included detecting the time periods of onset and duration of the ototoxicity and identifying what support was available to this population.

Methods: Posts from publicly available online forums were thematically analyzed using the guidelines by Braun and Clarke. A coding manual was iteratively developed to create a framework for the analysis of the ototoxicity experience among the cancer population.

Results: A total of 9 relevant online forums were identified, consisting of 86 threads and 570 posts from 377 members. Following the *bottom-up* thematic analysis, 6 major themes were identified: *nature of ototoxicity, time of experienced ototoxicity, information on ototoxicity, quality of life, therapies, and online social support.*

Conclusions: There was a significant number of reports expressing concerns about the lack of information on the risk of ototoxicity. More support for those suffering is needed; for example, improved interdepartmental communication between oncology and audiology services could optimize patient care. Patients should also be encouraged to communicate with their health care professionals about their ototoxicity and relay how their QoL is impacted by ototoxicity when accessing support. Tinnitus was the most common concern and was associated with distress. Hearing loss was less common; however, it was associated with fear and employment issues. Those who reported preexisting conditions were fearful about worsening their condition as their QoL was already impacted.

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KEYWORDS

quality of life; neoplasms; drug-related side effects and adverse reactions; hearing loss; tinnitus; online social networking; internet; eHealth; social support

Introduction

Background Information

Although there are an estimated 17.5 million cancer cases per year worldwide, the development of screening programs and improved diagnostics have contributed to an increase in survival rates [1,2]. The current overall 5-year survival rate is 67%, this means that many more cancer survivors are now living with the late effects of cancer treatment, such as peripheral neuropathy and ototoxicity [3]. Ototoxicity is defined by American Speech-Language-Hearing Association as a decrease in hearing thresholds relative to baseline testing and indicates evidence of damage in hearing caused by medication [4]. Platinum-based chemotherapy, for example, cisplatin, although a highly effective antineoplastic agent, is known to cause peripheral neuropathy and ototoxicity (resulting in tinnitus and hearing loss) [5]. Tinnitus is defined as the manifestation of a conscious perception of an auditory sensation without a corresponding external stimulus [6,7].

These effects can potentially have a significant impact on quality of life (QoL). Tinnitus, for example, is associated with sleep difficulties, and hearing loss is associated with dementia [8,9]. A deeper understanding of the impact these long-term consequences of cancer treatments can have on QoL can improve long-term symptom management in patients living with the debilitating effects of cancer treatment [10,11].

There is a lack of information on the prevalence and effect of ototoxicity because of the underreporting of ototoxic events, and few longitudinal studies have been carried out [12,13]. The literature advising on the diagnosis, grading systems, and management of ototoxicity is heterogeneous across studies, resulting in poor-quality information being available [13-15]. Consequently, this has had a substantial effect on the quality of support offered to patients, as there is no standard protocol or guidance for clinicians to follow.

The increase in popularity of using the internet allows anyone to access health care information instantly and can potentially improve patients' knowledge and help with treatment decisions [16,17]. Technological advances have meant that this method of research is becoming increasingly used within medicine [18]. Although this methodology has not been used for ototoxicity, there have been thematic analyses carried out on Web-based group discussions in Parkinson disease and men's fertility issues [19,20]. There has also been, although inconclusive, evidence to show that Web-based support for cancer patients has a positive effect [21]. By exploring online health care forums (OHFs), the impact on QoL from ototoxicity can be analyzed. OHFs are a way in which patients can contribute to a range of personal health-related discussions openly with one another by grouping various threads on a specific topic [16,22,23]. Individuals suffering from long-term effects of treatment are significantly more likely to participate in this Web-based community to discuss health concerns [24].

Aims and Rationale

Approximately 14.2% of long-term cancer survivors live with disabilities directly caused by their cancer treatment and its toxic nature [10,25]. Clinical reports of patients may not reflect the true incidence or severity of the late effects caused by treatments, specifically ototoxicity. In many cases, patients ask medical questions or share experiences on the Web that they could not in person. Yet this potentially rich source of information has not yet been explored. Thus, the aim of this study was to explore the true demographic and the impact on QoL of ototoxic effects caused by cancer treatment via analysis of OHF discussions. The secondary objectives were to explore the time course of ototoxicity occurrence in relation to treatment, whether the adverse effects were reported as temporary or permanent, and which means of support patients had access to and used. This research has the potential to significantly inform clinical and social aftercare of those who have been treated for cancer.

Methods

Ethical Considerations

Ethical approval for the study was obtained by the University of Nottingham, School of Medicine Ethics Committee. Although informed consent was not required in this study as the information was available in the public domain, all members' personal details were kept anonymous to maintain confidentiality and protect privacy [26].

Quotes used were extracted as part of a longer original post. Details that would allow the member to be traced were excluded. Risk to forum users was deemed to be minimal.

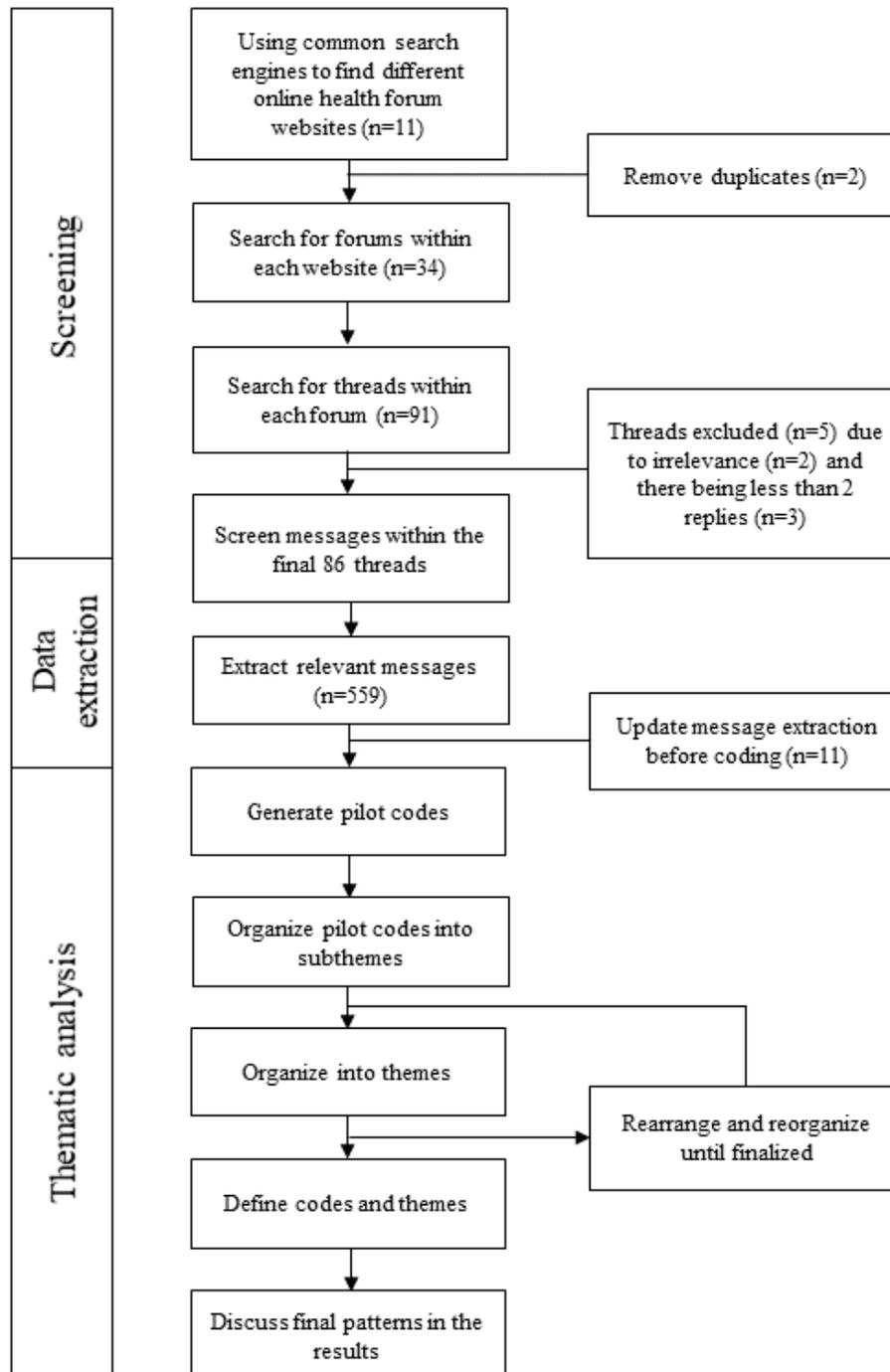
Sample and Inclusion Criteria

Relevant and representative forums were identified using the 4 most common search engines: Google, Yahoo!, AOL, and Bing [27]. Search terms included combinations of "impact," "effect," "forum," "discussion," "hearing loss," "tinnitus," "chemotherapy," and "cancer." Inclusion criteria were (1) forum did not require membership (ie, publicly available) and (2) the forum content was in the English language [28]. The first search page was screened for results, and there were no date restrictions for the searches. Relevant OHFs were manually extracted onto Excel, and the threads within these OHFs were screened. A thread was considered relevant when the post itself mentioned hearing loss or tinnitus and either cancer or chemotherapy, by asking a question or offering support. The relevant threads were extracted ready for thematic analysis.

Thematic Analysis

The data extraction and the thematic coding strategy were based on the Gao et al [16] and Braun and Clarke [26] methodologies. Whole threads were screened, and the messages deemed irrelevant or which had too few replies were excluded (Figure 1). Messages were then extracted for thematic analysis. The number of members posting on the forums was quantified and the threads were randomized using computer software.

Figure 1. Flowchart representing the methodology and strategy of the online health care forum screening and analysis.



Following the *bottom-up* strategy, open coding was performed by making initial comments on the first 100 messages, from which a pilot coding manual was produced. For example, the quote “The most worrying thing I have come across is that I may suffer changes to my hearing, I am petrified.” was described as a fear of developing ototoxicity. This was followed by grouping similar descriptions together into codes which fit into categories, and finally, arranging these into clearly defined themes [29]. Using the example quote, this was defined as a *general fear* code and grouped into the *emotions* category in the *quality of life* theme. A total of 2 researchers (SP and JT) independently coded the remaining randomized messages

against the coding manual and compared results. Every difference was discussed, and the coding manual was reorganized and developed accordingly. Following this discussion, the 2 researchers (SP and JT) agreed on a final coding manual, and the remaining messages were coded and quantified to assess which topics people discussed most frequently.

Results

Description of Included Forums

The search found 11 OHF websites varying in popularity. This was further narrowed to 9 following the elimination of duplicates (Table 1). A total of 34 OHFs were identified, and 86 threads were included in the final analysis. The number of messages within the threads varied greatly. For the larger threads, only the most relevant messages were extracted. Over 3000 messages were screened, and a total of 570 messages were manually extracted for the final analysis.

The numbers of members in each thread posting about ototoxicity ranged from 1 to 17, with 56 members seeking information and sharing their experiences in multiple threads and forums. The forums themselves varied in popularity;

however, the number of active members was not always publicly available. Overall, 377 members were responsible for the 570 messages extracted (Table 1). The geographical information of the posts was not always available though it consisted mainly of the United Kingdom and United States; however, there were also threads based in Australia, New Zealand, and South Africa.

Thematic Analysis

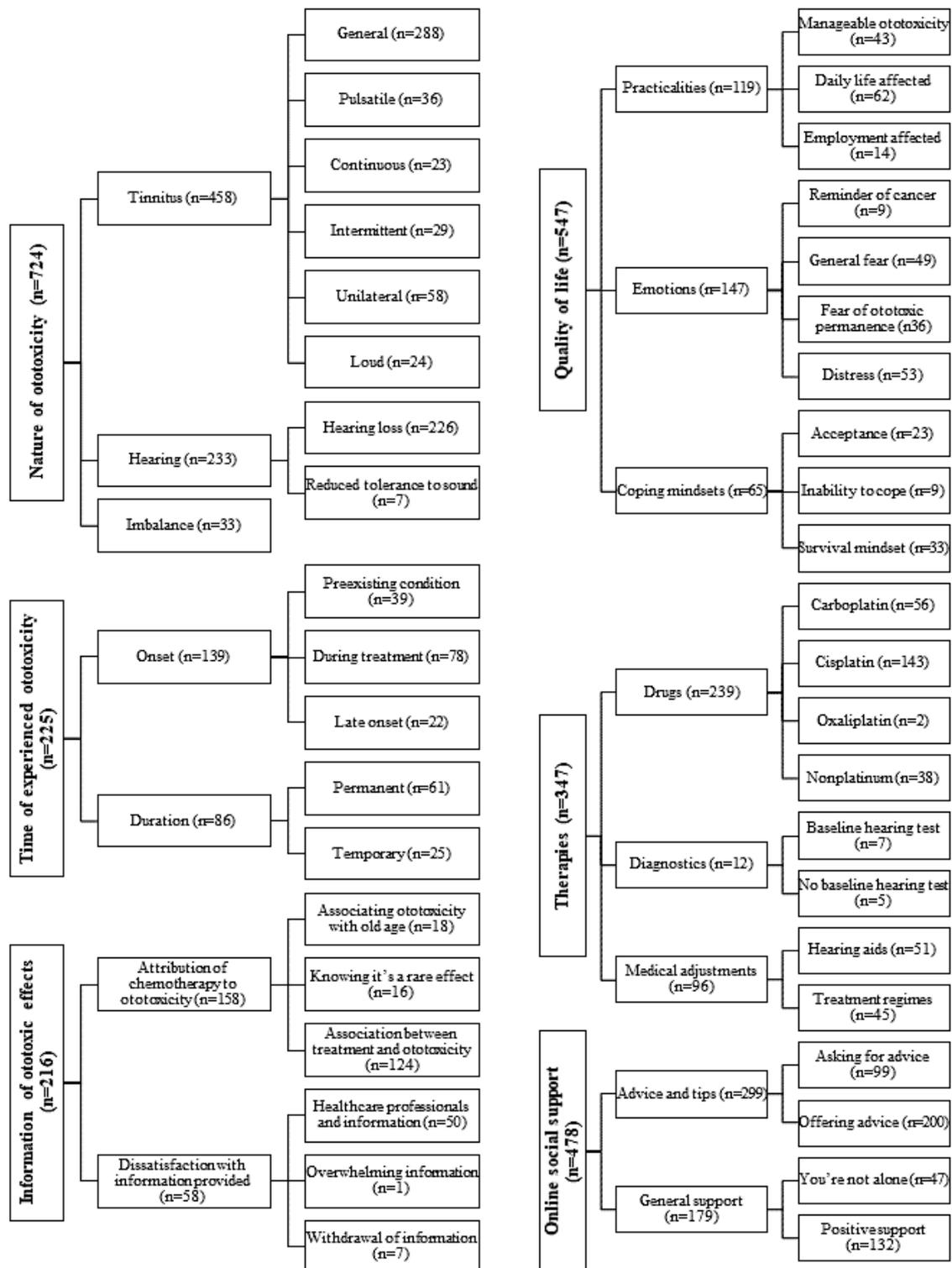
A total of 42 final codes were generated from which to interpret the forum messages by following the Braun and Clarke methodology (Figure 2). The names of each category and theme emerged through discussion of words and terms that the 2 researchers thought reflected the set of codes, which were then reviewed by all authors. The 6 overarching themes were as follows: (1) Nature of ototoxicity, (2) Time of experienced ototoxicity, (3) Information on ototoxicity, (4) Quality of life, (5) Therapies, and (6) Online social support.

Table 1. The number of threads extracted, the number of messages extracted, and the range and total of participants and members posting within the online health care forums.

Forum names	Threads analyzed (n)	Messages analyzed (n)	Participants in each thread (n)	Members posting in multiple threads (n)	Members in OHFs ^a (n)
Forum 1	8	105	1-16	6	50
Forum 2	5	41	3-10	4	32
Forum 3	18	122	2-12	14	69
Forum 4	9	68	3-17	11	49
Forum 5	19	80	1-5	7	55
Forum 6	5	14	1-8	1	14
Forum 7	8	37	2-7	6	27
Forum 8	3	21	4-12	1	20
Forum 9	11	82	3-14	6	61
Total	86	570	1-17	56	377

^aOHF: online health care forum.

Figure 2. The themes, subthemes, and codes found within the forum messages and the number of times the codes were reported (n). Themes include the nature of ototoxicity (n=724), time of experienced ototoxicity (n=225), information on ototoxicity (n=216), quality of life (n=547), therapies (n=347), and online social support (n=478).



Discussion

Nature of Ototoxicity

The *nature of ototoxicity* theme was the most discussed within the forums (n=724). It consisted of describing and categorizing the ototoxic symptoms experienced. This theme consisted of the following subthemes: *tinnitus* (n=458), *hearing* (n=233),

and *imbalance* (n=33). The *tinnitus* subtheme entailed the personal perception of tinnitus, as described by the members. Approximately 80.4% (458/570) of the messages within the forums reported some experience of tinnitus, suggesting that tinnitus is a significant occurrence within this population:

I reported to my oncologist that I experience the loudest high pitched ringing that makes me put my hands over my ears! [User X, Forum 7]

The most common aspects of tinnitus described, in addition to a ringing sensation (*general tinnitus* $n=288$), were *pulsatile tinnitus* ($n=36$) *continuous tinnitus* ($n=23$), *intermittent tinnitus* ($n=29$), *unilateral tinnitus* ($n=58$), and *loud tinnitus* ($n=24$). Users reported *pulsatile tinnitus* ($n=36$) as a *heartbeat thumping* or *whooshing sounds* in the ear. *Pulsatile tinnitus*—although no known research has been conducted on the association with cancer treatments—has been thought to be of a vascular origin and can be synchronized with the heartbeat [7,30]. *Unilateral tinnitus* seemed to occur more in the left ear ($n=34$) compared with the right ear ($n=24$). Previous research reported approximately 15% of patients treated with cisplatin had experienced unilateral tinnitus [31]. A similar total of 13% of forum messages mentioning *tinnitus* were found to be *unilateral tinnitus*, which correlates with the literature:

I just came out of the ward after my first treatment cycle, I feel okay in myself apart from this constant high ringing in my left ear. [User A, Forum 4]

Within the *hearing* subtheme, *hearing loss* ($n=226$) was commonly reported. Only 7 members reported *reduced tolerance to sound*. *Hearing loss* was mentioned by users before receiving treatment and being fearful of the deficit, in addition to complaints of already experiencing hearing loss because of chemotherapy. Furthermore, multiple users expressing hearing loss mentioned already having a form of hearing deficit that had worsened. Although there has been research carried out reporting hearing loss following chemotherapy, it is worth noting that *reduced tolerance to sound* has not previously been reported in the literature as an adverse effect, and as such, further research is warranted [32-34]:

The other day I had a hearing test which confirmed that cisplatin has damaged my hearing. I can no longer hear well [User Y, Forum 7]

Within the OHFs, there were also members reporting *imbalance*, which were mainly discussed in threads associated with breast cancer ($n=33$). *Imbalance* seemed heavily associated with Femara and Taxol treatments. Vertigo has been reported in a study investigating the etiology in 36 breast cancer survivors; however, it is rarely associated with ototoxicity within medical literature [35]:

I am currently getting weekly Taxol treatments with Carboplatin. I have had acute episodes of sudden vertigo. Both times I was reading a book and suddenly felt the room spinning. The feeling lasts about 10 seconds but is very intense! I have no previous history with vertigo. [User C, Forum 1]

Time of Experienced Ototoxicity

The *time of experienced ototoxicity* ($n=225$) was variable within the OHFs. Although members described their *onset* as *preexisting before treatment* ($n=39$), *during treatment* ($n=78$), or *late onset* ($n=22$), specific times were also noted. For example, there were reports of tinnitus and hearing loss occurring from the first cycles ($n=9$, $n=5$, $n=3$ for cycles 1, 2,

and 3, respectively) to occurring 2 years following treatment. It is thought that pre-existing hearing deficits increase the risk of experiencing ototoxicity [36]. However, only 28.1% (39/139) of those mentioning the onset of ototoxicity admitted to having prior hearing deficits [37]. Those with preexisting conditions mainly shared their concerns about further damage:

This is worrying me, I am due to start treatment but I already have congenital severe hearing loss which is corrected by the use of hearing aids. The thought that chemo could make things worse is a real issue for me. The thought of chemo is scary enough but the thought of further damage to my hearing is scarier still. [User B, Forum 2]

Many members believed tinnitus would be temporary and expressed shock when it became permanent. Furthermore, members sought validation that what they were experiencing was an adverse effect and not the reoccurrence of cancer. From those who reported their *duration* ($n=86$) of ototoxicity, 71% (61/86) reported having *permanent tinnitus*:

It's just over 10 months since I finished treatment. I had bad tinnitus during treatment but it completely disappeared for months. I've noticed that in the past few weeks my tinnitus is back intermittently maybe 2/3 times a day. Has anyone else had tinnitus reappearing after months and months of nothing? [User Z, Forum 5]

It is worth noting that many users did not share the duration of their tinnitus. Further research is needed to identify possible risk factors of permanent tinnitus, even though it is known that tinnitus caused by chemotherapy is associated with age and a higher accumulative dose [5,38-41]. Users did not commonly report their age or dose of treatment; therefore, it would be difficult to conclude if this population reflects previous studies. Overall, members appeared to remain positive, frequently sharing tips and advice to help others, despite posting how permanence of tinnitus affected their QoL:

My overall hearing loss has been profound but it's a side effect of Cisplatin I'm afraid. I'm not expecting it to go away, and I've been told it's likely to be permanent. Sorry not to be more positive. [User C, Forum 5]

Information on Ototoxicity

One of the discussion topics reported throughout the different forums was the *information on ototoxicity* ($n=216$). This theme consisted of the *attribution of chemotherapy to ototoxicity* ($n=158$) and *dissatisfaction with the information provided* ($n=58$). The *attribution of chemotherapy to ototoxicity* consisted of members who associated hearing loss with *old age* ($n=18$) or believed that because it is a fairly *rare* ($n=16$) toxic effect of chemotherapy, there must be another cause. This could be because of denial from the patients or simply a lack of knowledge on ototoxicity:

These days I have ringing in my ears. It's probably due to my old age. [User A, Forum 9]

The majority of members, however, did see an *association between chemotherapy and ototoxicity* (n=124). The members who had more knowledge on ototoxicity were vocal in sharing what they had been told by health care professionals, urging those who had not made the association to see an audiologist or their general physician. Furthermore, many members expressed some *dissatisfaction with the information provided* (n=58). Members shared their anger, disappointment, and *dissatisfaction with health care professionals and lack of information* (n=50) because they had not been warned about ototoxicity:

Straight after my first cycle, I started suffering from a ringing noise in both ears. I told my oncologist about it and she just made a note, and sent me off for the third dose without saying a word! I was not warned about this and don't get the impression that anyone cares other than me. [User C, Forum 2]

There appeared to be a lack of communication between patients and professionals, which was reported frequently throughout the forums, despite there being a significant number of studies aiming to raise awareness of ototoxicity [42]. Members expressed having felt ignored and not taken seriously during consultations:

I think they don't reveal all of these things to us because they don't want to scare us away from doing the chemo. When I first started having tinnitus all I got was "I've never seen a case from carboplatin" like I'm making it up. I looked back through all my papers they gave me at first for the side effects and there was one notation about a rare side effect: 'hearing changes'. I really feel like I didn't have all the information I needed at the time I was making my decisions. It does make you wonder what else they haven't told us. [User W, Forum 1]

In contrast, members also confessed to *withdrawal of information* (n=7) by lying or not telling their clinicians about the severity of their tinnitus and hearing loss because they feared having to compromise the dosage of their chemotherapy and feared morbidity. This could have detrimental impacts on both patients and clinicians as it reduces any reliable information reported:

I'm worried that if I tell the truth about the months of diarrhoea and headaches and tinnitus and the newer extreme tiredness, they'll say I'm too old and fragile to get any more treatment and dump me from the trial. [User Y, Forum 1]

There was only 1 message expressing how *overwhelming information* (n=1) stopped them from listening to the information provided, leading to that individual becoming fearful of undergoing treatment.

Quality of Life

Another main theme was the severity of ototoxicity and the impact this had on *quality of life* (n=547). Members discussed *practicalities* (n=119), *coping strategies* (n=65), and *emotions* (n=147) associated with how their *quality of life* was compromised. Numerous messages implied the symptoms were

mild, with many members saying they had *manageable symptoms* (n=43) that they could easily cope with or ignore, such as:

Most of the time when I am busy, I don't notice it [tinnitus], but as you probably know, when you become aware of it, it is hard to ignore. I hope you are lucky and yours goes away. [User H, Forum 5]

However, most users reported in abundance how their *day-to-day life* (n=62) was affected by ototoxic effects. Many members shared concerns over how their hearing loss affected their relationship with their partners and family members, which could be distressing and isolating:

I'm three years post chemo and now have tinnitus in my left ear which is getting worse. I don't recall being told chemo could damage ear and it drives me mad. Will it ever go? Sound sets it off so if I sit in silence its okay but it's affecting my relationship now. I don't know what to do. [User F, Forum 2]

Research has been conducted on how tinnitus and hearing loss affects QoL; however, it has not been expanded into the population facing cancer treatment and survivorship [43-45]. In addition, the few studies exploring QoL affected by tinnitus do not go in depth into what aspects of life ototoxicity affects [6,46]. Therefore, by exploring these messages from the forums, specific aspects of QoL affected by ototoxicity can be identified. This will help develop a relevant and tailored support system for these patients:

I cannot hear at all in my left ear ever since having chemotherapy. I have been fitted, aged 39, with a hearing aid but I have very short hair as a result of chemo, so they show and it affects my self-esteem. I don't sleep with the aids in so I can't hear my baby when she wakes at night which I find really distressing. I feel about 90. [User S, Forum 2]

Another concern among members was the effect ototoxicity had on *employment* (n=14). Specifically, professional musicians shared their fear over losing the ability to play music. Members spoke of the risk of losing their hearing being catastrophic for their employment and even mentioned early retirement. Most of the questionnaires used to assess QoL and ototoxicity do not mention the impact on employment. This area needs to be explored clinically, specifically in those who critically rely on hearing to be employed, such as musicians:

Better than dead? At this point, I'm wondering. I cannot work with this condition because my job requires proper hearing. Hearing loss and this constant tinnitus is life-changing, far more than having cancer is. This has me worried more than living with cancer. I'm wondering if I'll ever have another day where I can hear clearly and be a productive member of society. [User Z, Forum 4]

Of the main issues faced with ototoxicity, one was how it acted as a *reminder of cancer* (n=9). Although members mentioned successfully managing the tinnitus and hearing loss, it acted as a permanent reminder of what difficulties they had been through. There was a sense of *general fear* (n=49) experienced across

the forums, as members frequently discussed being fearful of losing their hearing and how this could affect their life. In fact, many people discussed concerns over safety and how this gave them anxiety. As mentioned previously, these aspects of life are rarely included in questionnaires, and therefore, are rarely reported in the literature:

I cannot hear the door opening, food cooking, the television or radio and comprehend what they're saying. It's dangerous. I never realized how much we rely on the sounds of cooking. No more multi-tasking in the kitchen, I have to stand and watch the stove top now. [User A, Forum 9]

Within this sense of fear, there was a specific *fear of permanence* (n=36) of the ototoxic effects. There were frequent concerns over how long the hearing loss and tinnitus would last and if they would ever recover normal hearing. Currently, there is little knowledge about the duration of ototoxicity and no predicting factors, which could further induce this fear in patients:

I completed all of my chemotherapy cycles and since then I have lost a lot of hearing and also have ringing in my ears. Has anyone experienced this and gained hearing back? I am hoping since I only finished a month ago I will improve, but no one is telling me anything. If anyone has a positive story I would love to hear about it, to give me hope. [User F, Forum 3]

Associated with fear was *distress and severe impact on QoL* (n=53). There were messages that described hearing loss and tinnitus as “unbearable, severe and extremely bothersome,” which is consistent with the current literature on how tinnitus and hearing loss affect QoL in the general population [47]. However, managing chemotherapy-induced ototoxicity in addition to coping with cancer can be extremely distressing; therefore, appropriate multidisciplinary support should be considered urgent:

Tinnitus is controlling my life right now and I don't know what to do. I am suicidal and keep thinking of the best way to end this misery once and for all. I don't know how long I can keep this up. I wish I was strong like all of you in this forum but I am so weak and fragile right now. I gave up on God ever existing cos if he did exist then none of us would be suffering like this right now and diseases such as cancer would not exist. [User E, Forum 6]

How members coped with ototoxic effects varied greatly throughout the forums. A total of 3 codes formed the *coping mindsets* subtheme: *acceptance of ototoxicity* (n=23), *survival mindset* (n=33), and the *inability to cope* (n=9). Messages on *acceptance* and *having to learn to live with tinnitus* varied from being positive to resentful:

I'm afraid I do not know how to say this without being blunt, but would you really rather die than live with some permanent tinnitus from your cancer? Most of us have a few souvenirs from cancer, I think that is better than dying. [User G, Forum 4]

I finished all my chemotherapy 6 months ago and I am still suffering from side effects. Numbness in my fingers and toes, pain in my feet and calves and hearing loss. I AM happy to be alive, but I can't shake off the dissatisfaction I have with the body treatment left me with. [User D, Forum 3]

The most frequent *coping mindset* was the *survival mindset*. People shared thoughts such as “worry about the cancer now and the side effects later” within this *survival mindset* and tended to promote this view of ignoring any side effects until after the cancer was in remission. This mindset could in fact be partially responsible for the underreporting of toxicities in clinical trials, therefore, having negative clinical implications on research. Patients should be encouraged to speak openly about their experienced toxicities:

The most important thing is that the chemotherapy worked, it just seems silly for us to be moaning about a bit of tinnitus. [User P, Forum 5]

Although not many, there were members with an *inability to cope*. These members appeared to be extremely depressed and seemed to need urgent care and advice, such as counseling:

I have had the Cisplatin dose reduced 20 percent for the second round due to the ringing and hearing loss. I can't seem to find anything positive to report. Most say it's permanent, including my oncologist and audiologist. I may be forced to stop treatment if mine gets any worse because I'd rather be dead than deaf. [User I, Forum 4]

By supporting these patients before their tinnitus and hearing loss worsens, the health service and patients alike could potentially save on mental health costs. Moreover, aspects such as sleep, employment, and relationships are all major parts of life, and when these are affected, it can have a devastating effect on a whole population. It has been reported that those with more comorbidities seem to experience a higher incidence and severity of tinnitus, which could factor in to having a lower QoL [46]. Research is needed to predict and identify patients who need more support to prevent this detrimental effect on their mental health.

Therapies

Members discussed which *drug* (n=239) treatment regimens they were on, such as *cisplatin* (n=143), *carboplatin* (n=56), *oxaliplatin* (n=2), and *nonplatinum drugs* (n=38). Some messages expressed simply their regime and their adverse effects, without mentioning how it affected their QoL. It is difficult to conclude how these members cope and are affected by ototoxicity:

I have severe hearing loss and osteoporosis from carboplatin. I am only 21. [User G, Forum 3]

There were few members discussing the *diagnostics* (n=12) they experienced, with an almost equal number of members stating they had *no baseline test* (n=5) compared with having had a *baseline test* (n=7). This correlates with studies having found that baseline tests are not as frequently carried out as suggested [48]:

I had a baseline reading before chemo. Showed mild age related hearing loss, but I could still hear compared to now! [User H, Forum 9]

I didn't have a baseline test before starting chemo because no one suggested it. [User L, Forum 4]

A subtheme that was relatively abundant within the OHFs was *medical adjustments* (n=96). This involved many of the members having to wear *hearing aids* (n=51) because of the ototoxic effects, and others *adjusting treatment regimens because of ototoxicity* (n=45), which involved anything from changing the drug and lowering the dose to stopping treatment altogether to prevent any further hearing loss or tinnitus. This code was heavily associated with *fear of permanence* and *distress*:

The hearing test I had told the audiologist it was permanent. I got hearing aids about 3 months after treatment was over. I wasn't told hearing loss was a possibility. Every time I went to a doctor, I asked the doc to look at my ears. Finally, one said, see the audiologist. I was crushed - I was only 45 at the time. I did get the hearing aids, and they help so much. [User C, Forum 3]

Online Social Support

Finally, there was a sense of *online social support* (n=478), which included support expressed by members to create a community and develop friendships. From the 570 different forum messages, only 1 message was interpreted as negative. The *advice and Tips* (n=299) subtheme involved members *asking for advice* (n=99) and *offering general advice* (n=200) from how to ignore tinnitus to which hearing aid to use. There were many messages that offered *positive support* (n=132) and used terms such as “you're not alone” (n=47):

I hadn't realised how many others have developed Tinnitus too—nice to be in good company. [User D, Forum 9]

A significant number of patients expressed concerns over not being adequately informed about the true risk of ototoxicity. Although some members expressed having been warned of the risks, they reported that the information given to them was vague and unclear. Some spoke about referrals to audiology departments and seemed satisfied with this level of support. It could be suggested that more interdepartmental communication be made to optimize patient care. Furthermore, information available to patients on ototoxicity could be improved by updating the chemotherapy leaflets. Patients may feel overwhelmed with the amount of information given to them; thus, the information should be shared on a case-by-case basis. It is noteworthy, however, that from the 570 messages analyzed,

only 1 message expressed feeling overwhelmed by the information about ototoxicity.

Members who were fearful of losing hearing were those who had preexisting conditions. This could be because their QoL has already been impacted, whereas those posting who had no previous experience with hearing loss or tinnitus would not know how exactly their QoL may be affected. For many, ototoxicity is not an immediate concern when thinking of chemotherapy. However, once the immediate adverse effects subside, ototoxicity remains as a distressing reminder of their cancer. Patients should be encouraged to communicate with their health care professionals about their ototoxicity and relay how their QoL is impacted to access the appropriate support.

There were more reported concerns over tinnitus than any other ototoxic effect. Tinnitus was also associated with distress and the inability to cope. Members posted concerns over sleep, their relationships, and their mental health. More clinical interventions, such as cognitive behavioral therapy, should be readily available to this population. Furthermore, hearing loss was common within the OHFs but was more associated with fear of losing hearing, fear over personal safety, and fear of hearing loss impacting employment.

Limitations of This Study

As this research was observational and exploratory, there was no way of quantitatively measuring QoL. The posts were subject to misinterpretation, even though 2 researchers were involved in analysis to minimize the risk of this potentially occurring. Although OHFs are popular within communities, this sample is not necessarily representative of the population, as only 2 of the forums had information on number of members and active threads; therefore, it is difficult to draw conclusions on the exact population. Only those who have internet access and are inclined to voluntarily share personal information participated. It is also possible that those who post on forums are those with the most severe worries, and those whose questions have not been answered by health care professionals, meaning they seek advice on the Web. Furthermore, gender, age, and geographical location of the members were mainly unknown. Therefore, no analysis could be undertaken on these factors.

Conclusions

In conclusion, ototoxicity has a significant burden on the QoL of those suffering from cancer. More information and support should be available to this population to help manage these long-term symptoms. Tinnitus was the most frequently reported ototoxic effect within the OHF, followed by hearing loss. The ototoxic effects were associated with lower QoL, fear, isolation, depression, and frustration that patients were not warned enough about these effects.

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Conflicts of Interest

None declared.

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Abbreviations

OHF: online health care forum

QoL: quality of life

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