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Original Paper

Evaluation of a Web-Based App Demonstrating an Exclusionary Algorithmic Approach to TNM Cancer Staging

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Abstract

Background: TNM staging plays a critical role in the evaluation and management of a range of different types of cancers. The conventional combinatorial approach to the determination of an anatomic stage relies on the identification of distinct tumor (T), node (N), and metastasis (M) classifications to generate a TNM grouping. This process is inherently inefficient due to the need for scrupulous review of the criteria specified for each classification to ensure accurate assignment. An exclusionary approach to TNM staging based on sequential constraint of options may serve to minimize the number of classifications that need to be reviewed to accurately determine an anatomic stage.

Objective: Our aim was to evaluate the usability and utility of a Web-based app configured to demonstrate an exclusionary approach to TNM staging.

Methods: Internal medicine residents, surgery residents, and oncology fellows engaged in clinical training were asked to evaluate a Web-based app developed as an instructional aid incorporating (1) an exclusionary algorithm that polls tabulated classifications and sorts them into ranked order based on frequency counts, (2) reconfiguration of classification criteria to generate disambiguated yes/no questions that function as selection and exclusion prompts, and (3) a selectable grid of TNM groupings that provides dynamic graphic demonstration of the effects of sequentially selecting or excluding specific classifications. Subjects were asked to evaluate the performance of this app after completing exercises simulating the staging of different types of cancers encountered during training.

Results: Survey responses indicated high levels of agreement with statements supporting the usability and utility of this app. Subjects reported that its user interface provided a clear display with intuitive controls and that the exclusionary approach to TNM staging it demonstrated represented an efficient process of assignment that helped to clarify distinctions between tumor, node, and metastasis classifications. High overall usefulness ratings were bolstered by supplementary comments suggesting that this app might be readily adopted for use in clinical practice.

Conclusions: A Web-based app that utilizes an exclusionary algorithm to prompt the assignment of tumor, node, and metastasis classifications may serve as an effective instructional aid demonstrating an efficient and informative approach to TNM staging.

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KEYWORDS

TNM staging; neoplasms; medical oncology; instructional technology

Introduction

The tumor/node/metastasis (TNM) staging system collaboratively developed and maintained by the American Joint Committee on Cancer and the International Union for Cancer Control plays a critical role in the evaluation and management of patients diagnosed with a range of different types of cancers [1]. Accurate staging based on assessment of the extent of anatomic spread of cancer at the time of diagnosis helps to determine prognosis based on correlated survival rates. Staging also helps to guide the planning of treatment, facilitates communication between providers working in different disciplines, and serves as the basis for identifying patients who may be eligible for enrollment in clinical trials [2].

Criteria for stage assignments have been established for 47 different types of cancers. Determination of a patient's stage is based on the classification of three principal components that

may be assessed at the point of diagnosis to determine a clinical stage, or after definitive surgery to determine a pathologic stage. Assignment of a tumor (T) classification ranging from T0-T4(a-d) is based on assessment of the size and extent of contiguous spread of the primary tumor. Assignment of a node (N) classification ranging from N0-N3(a-c) is based on assessment of the extent of spread of tumor to regional draining lymph nodes. Assignment of a metastasis (M) classification ranging from M0-M1(a-b) is based on assessment of the presence or absence of distant metastases (Table 1).

Additional prognostic factors that have proven to be significant in the staging of specific types of cancers include tumor grade, tumor location, mitotic rate, risk factors, histologic scores, and biochemical tumor marker levels. Compiled groupings of T, N, M, and prognostic factor classifications are sorted into tabular arrays that are stratified to define stages characterized as anatomic stages or prognostic groups ranging from 0-IV(A-C) in order of declining prognosis (Table 2).

Table 1. T, N, and M classifications for cancer of the lung.

Classification	Definition
Primary tumor (T)	
TX	Primary tumor cannot be assessed
T0	No evidence of primary tumor
Tis	Carcinoma in situ
T1	Tumor 3 cm or less in greatest dimension, surrounded by lung or visceral pleura, without bronchoscopic evidence of invasion more proximal than the lobar bronchus (ie, not in the main bronchus)
T1a	Tumor 2 cm or less in greatest dimension
T1b	Tumor more than 2 cm but 3 cm or less in greatest dimension
T2	Tumor more than 3 cm but 7 cm or less or tumor with any of the following features (T2 tumors with these features are classified T2a if 5 cm or less): involves main bronchus, 2 cm or more distal to the carina; invades visceral pleura (PL1 or PL2); associated with atelectasis or obstructive pneumonitis that extends to the hilar region but does not involve the entire lung
T2a	Tumor more than 3 cm but 5 cm or less in greatest dimension
T2b	Tumor more than 5 cm but 7 cm or less in greatest dimension
T3	Tumor more than 7 cm or one that directly invades any of the following: parietal pleural (PL3) chest wall (including superior sulcus tumors), diaphragm, phrenic nerve, mediastinal pleura, parietal pericardium; or tumor in the main bronchus less than 2 cm distal to the carina but without involvement of the carina; or associated atelectasis or obstructive pneumonitis of the entire lung or separate tumor nodule(s) in the same lobe
T4	Tumor of any size that invades any of the following: mediastinum, heart, great vessels, trachea, recurrent laryngeal nerve, esophagus, vertebral body, carina, separate tumor nodule(s) in a different ipsilateral lobe
Regional lymph nodes (N)	
NX	Regional nodes cannot be assessed
N0	No regional lymph node metastasis
N1	Metastasis in ipsilateral peribronchial and/or ipsilateral hilar lymph nodes and intrapulmonary nodes, including involvement by direct extension
N2	Metastasis in ipsilateral mediastinal and/or subcarinal lymph node(s)
N3	Metastasis in contralateral mediastinal, contralateral hilar, ipsilateral or contralateral scalene, or supraclavicular lymph node(s)
Distant metastasis (M)	
M0	No distant metastasis
M1	Distant metastasis
M1a	Separate tumor nodule(s) in a contralateral lobe; tumor with pleural nodules or malignant pleural (or pericardial) effusion
M1b	Distant metastasis

Table 2. Anatomic stage/prognostic groups for cancer of the lung.

Stage	T	N	M
Occult	Tx	N0	M0
0	Tis	N0	M0
IA	T1a	N0	M0
	T1b	N0	M0
IB	T2a	N0	M0
IIA	T2b	N0	M0
	T1a	N1	M0
	T1b	N1	M0
IIB	T2a	N1	M0
	T2b	N1	M0
	T3	N0	M0
IIIA	T1a	N2	M0
	T1b	N2	M0
	T2a	N2	M0
	T2b	N2	M0
	T3	N1	M0
	T3	N2	M0
	T4	N0	M0
	T4	N1	M0
IIIB	T1a	N3	M0
	T1b	N3	M0
	T2a	N3	M0
	T2b	N3	M0
	T3	N3	M0
	T4	N2	M0
	T4	N3	M0
IV	Any T	Any N	M1a
	Any T	Any N	M1b

The conventional approach to staging involves (1) selecting appropriate T, N, M, and prognostic factor classifications, (2) combining these classifications to generate a TNM grouping, and (3) locating this TNM grouping in the array of possible combinations to determine a corresponding stage. This combinatorial approach is inherently inefficient due to the fact that successive tumor and node classifications for different types of cancers are not always graded or mutually exclusive. Assignment of a T1 classification may be based on measurement of the diameter of the primary tumor, while assignment of a T2 classification may be based on identification of a pattern of local invasion. Assignment of an N2 classification may be based on confirmation of spread of tumor to a specific group of regional draining lymph nodes, while assignment of an N3 classification may be based on tabulation of the number of involved lymph nodes. As a result, accurate staging relies on scrupulous review of the criteria for each T, N, and prognostic factor classification to ensure that correct assignments are made.

An alternative approach to staging that seeks to optimize the efficiency of the process is predicated on the notion that unambiguous selection or exclusion of a T, N, M, or prognostic factor classification may serve to constrain the number of subsequent classifications that need to be reviewed to identify a correct TNM grouping. If a specific T, N, M, or prognostic factor classification can be selected based on review of its criteria, then any TNM groupings that do not include that classification can be excluded from further consideration. Alternatively, if a specific classification can be excluded without reservation, then any TNM groupings that include that classification can be excluded from further consideration. The set of TNM groupings that remain as viable options after a specific classification has been selected or excluded will most often encompass a restricted subset of classifications. In its elaboration, this exclusionary approach may effectively serve to minimize the number of classifications that need to be reviewed to accurately determine a patient's stage.

Methods

A Web-based app configured to demonstrate this approach to staging was developed as an instructional aid for trainees. A version coded in ActionScript 3.0 was iteratively adapted to incorporate the following key features [3]:

- an exclusionary algorithm that cycles through a sequence of (1) polling the set of TNM groupings listed for each anatomic stage to tabulate the number of times that each T, N, M, or prognostic factor classification is listed, (2) sorting the tabulated classifications in ascending order of frequency prioritized based on the extent of spread ($M > N > T$) and level of classification ($N3 > N2 > N1 > N0$), (3) prompting selection or exclusion of the first ranked classification, and (4) excluding nullified TNM groupings from the set based on the response
- a grid of anatomic stage listings with corresponding TNM groupings incorporating selectable T, N, M, and prognostic factor classifications
- reconfiguration of the criteria specified for T, N, M, and prognostic factor classifications to generate yes/no questions phrased to (1) itemize the components of complex definitions, (2) disambiguate definitions that incorporate combined Boolean AND + OR conditions, and (3) minimize negative definitions (Table 3)

Table 3. Reconfiguration of classification criteria for cancer of the lung.

Classification	Definition	Yes/No question
T3: Complex definition	Tumor more than 7 cm or one that directly invades any of the following: parietal pleural (PL3) chest wall (including superior sulcus tumors), diaphragm, phrenic nerve, mediastinal pleura, parietal pericardium; or tumor in the main bronchus less than 2 cm distal to the carina but without involvement of the carina; or associated atelectasis or obstructive pneumonitis of the entire lung or separate tumor nodule(s) in the same lobe	Is the primary tumor >7 cm in greatest dimension? OR Does it invade any of these structures: Parietal pleura; Chest wall (including the superior sulcus); Diaphragm; Phrenic nerve; Mediastinal pleura; Parietal pericardium OR Does it involve the main bronchus at a site that is >2 cm distal to the carina without involvement of the carina? OR Is it associated with atelectasis or obstructive pneumonitis of the entire lung? OR Is there a separate tumor nodule in the same lobe?
T2: Combined Boolean AND + OR conditions	Tumor more than 3 cm but 7 cm or less or tumor with any of the following features (T2 tumors with these features are classified T2a if 5 cm or less): involves main bronchus, 2 cm or more distal to the carina; invades visceral pleura (PL1 or PL2); associated with atelectasis or obstructive pneumonitis that extends to the hilar region but does not involve the entire lung	Is the primary tumor >3 cm and ≤7 cm in greatest dimension? OR Is it associated with any of these findings: <ul style="list-style-type: none"> • Involvement of the main bronchus at a site that is ≥2 cm distal to the carina; • Invasion of the visceral pleura; • Atelectasis or obstructive pneumonitis that extends to the hilar region but does not involve the entire lung
M0: Negative definition	No distant metastasis	Is there evidence of distant metastasis?

Users are prompted to select a tumor type to begin a staging exercise. Some tumor types require selection of secondary options which may include identification of a tumor subtype, anatomic location, age limit, or phase of staging (clinical vs pathologic). Selection of a tumor type shifts to a display that includes a grid of anatomic stage listings and a prompted yes/no question corresponding to the first ranked T, N, M, or prognostic factor classification (Figure 1).

Clicking a Yes or No button to answer the question will select or exclude the classification. If a specific classification is known at the point of entry, it can be directly selected by clicking on a corresponding entry in the grid of anatomic stage listings. Selection or exclusion of a classification triggers fading of

nullified TNM groupings and cycling of the exclusionary algorithm. Subsequent prompted yes/no questions will appear in sequence until the set of TNM groupings has been narrowed to delimit a single TNM grouping and/or a specific anatomic stage. If a specific anatomic stage has been delimited with multiple TNM groupings that persist as viable options, a “Complete” button can be clicked to prompt further selection and exclusion. When a single TNM grouping has been identified, a terminal display lists the anatomic stage and T, N, M, and prognostic factor classifications with their corresponding criteria. Forward and back arrows can be clicked to scroll through the sequence of classifications with highlighting of selected answers

and concordant enhancement and fading of associated TNM groupings.

Figure 1. Clicking a response to the prompted question triggers fading of nullified TNM groupings. Forward and back arrows can be clicked to scroll through the sequence of selected and excluded classifications.

	T	N	M
Occult	TX	N0	M0
0	Tis	N0	M0
IA	T1a	N0	M0
	T1b	N0	M0
IB	T2a	N0	M0
IIA	T2b	N0	M0
	T1a	N1	M0
	T1b	N1	M0
	T2a	N1	M0
IIB	T2b	N1	M0
	T3	N0	M0
IIIA	T1a	N2	M0
	T1b	N2	M0
	T2a	N2	M0
	T2b	N2	M0
	T3	N1	M0
	T3	N2	M0
	T4	N0	M0
	T4	N1	M0
IIIB	T1a	N3	M0
	T1b	N3	M0
	T2a	N3	M0
	T2b	N3	M0
	T3	N3	M0
	T4	N2	M0
	T4	N3	M0
IV	Any T	Any N	M1a
	Any T	Any N	M1b

Lung

T4

Does the primary tumor invade any of these structures?

- Mediastinum
- Heart
- Great vessels
- Trachea
- Recurrent laryngeal nerve
- Esophagus
- Vertebral body
- Carina

or

Is there a separate tumor nodule in a different ipsilateral lobe?

◀

Yes

No

Recruitment

An evaluation study was conducted to assess the usability and utility of this app. Participating subjects recruited from regional clinical training programs by email solicitation included 14 internal medicine residents, 9 surgery residents, and 7 oncology fellows. Institutional review board approval was obtained prior to recruitment and enrollment. Subjects were provided with open access to a fully functional version of the app along with a set of basic operating instructions. They were asked to evaluate its performance during staging exercises that included assessment of a newly diagnosed cancer, restating of recurrent cancer, and review of an incorrectly staged cancer. Subjects were asked to complete these exercises with an eye towards assessment of how they might use this app to (1) simulate the staging of different types of cancers encountered during training and (2) study for board exams that test knowledge of TNM staging criteria. After completing the staging exercises, subjects were asked to complete a Web-based survey about the app focused on rating its ease of use, clarity of presentation, perceived accuracy, and potential for adoption in different clinical and educational settings. The survey consisted of 12

statements phrased to support the usability and utility of the app. Selectable responses were arrayed on a 5-point scale with options labeled “Strongly disagree”, “Disagree”, “Undecided”, “Agree”, and “Strongly agree”.

Statistical Analysis

Median Likert scores and 25th and 75th quartiles were calculated for each survey item assigning a value of 1 to responses scored as “Strongly disagree”, 3 to items scored as “Undecided”, and 5 to items scored as “Strongly agree”. Subjects were also asked to rate the overall usefulness of the app on a scale ranging from 1 (“Not at all useful”) to 10 (“Essential”) and were provided with the option of entering free text comments about what they did or did not like about the app.

Results

All 30 of the enrolled subjects completed the entire survey. Subjects expressed a high level of agreement with each of the 12 statements. No “Strongly disagree” responses were registered. The median level of agreement was “Agree” for 7 of 12 statements and “Strongly agree” for the remainder with minimal dispersion (Table 4).

Table 4. Survey responses.

Statement	Median	25-75 interquartile range
It was easy to learn how to use this app.	5	4-5
It is easy to navigate between different sections.	4	4-5
The information presented is clearly organized.	5	4-5
Presenting definitions in the form of Yes/No questions helps to clarify distinctions between different T, N, M, and prognostic factor classifications.	4	4-5
Breaking down complex definitions into sets of questions linked by and/or statements helps to clarify distinctions between different T, N, M, and prognostic factor classifications.	4	4-5
The graphic display helps to clarify distinctions between different anatomic stages.	4	4-5
The ability to review prior answers in sequence helps to clarify distinctions between different anatomic stages.	4	4-5
The approach to staging promoted by this app is efficient.	4.5	4-5
The anatomic stages assigned through use of this app are accurate and reliable.	4	4-5
This app would be a useful instructional aid to help prepare for board certification and re-certification exams.	4	3-5
This app would be a useful resource in clinical practice.	5	4-5
Providers who do not stage patients on a regular basis would be able to use this app without difficulty.	5	4-5

The median overall usefulness rating was 9 (25-75 interquartile range 8-9.75). Eighteen subjects elected to enter free text comments that ranged from general impressions of the app to specific criticisms of its navigability and functionality. While most of the general impressions were favorable (“Great application”, “Very useful clinically”), a few subjects expressed reservations about the limited scope of the app (eg, “It would be nice to have links to the appropriate staging guidelines or references”, “It would be great to see some of the hematologic malignancies like myeloma and lymphoma added”). The majority of the specific criticisms focused on problems that subjects experienced when trying to use the browser back button to navigate between screens. This problem is commonly encountered with the first use of platform-independent apps that run in browser plug-ins [4]. Internal navigation controls were moved to more intuitive locations in subsequent iterations as a result. A few of the subjects found staging exercises that began with prompted questions about the presence of distant metastases to be disconcerting at first, but on reflection they expressed an understanding of the logic of this approach.

Discussion

Principal Findings

Studies conducted to assess the validity of TNM staging after the most recent revision of specified criteria have demonstrated high levels of correlation between accurately assigned anatomic stages and overall survival for a range of different cancer types [5-14]. In light of the critical role that TNM staging has come to play in the treatment of cancer, it is curious that there do not appear to have been any published studies investigating the approaches that providers adopt to assign anatomic stages. Most of the studies evaluating TNM staging have focused on assessing rates of completion and accuracy of assignment without any examination of the process itself. Inventories of tumor registries have revealed that providers treating patients with specific types of cancers do not always assign anatomic stages or track the

information needed to retrospectively confirm accurate assignments [15-17]. Studies that have compared assigned anatomic stages to adjudicated anatomic stages have shown that the accuracy of assignment may vary based on the expertise levels of providers and the specific types of cancers under consideration [18-21].

Resources that have been developed to assist providers engaged in the task of assigning anatomic stages include printed worksheets, encoded spreadsheets, wizards incorporated in electronic medical records, and an array of apps developed to run on smartphones and tablets [1,22-28]. While the controls and interfaces that they present vary to an extent, these resources universally implement combinatorial approaches to staging that rely on the selection of discrete T, N, M, and prognostic factor classifications to determine an anatomic stage. While the automated linkage of TNM groupings to anatomic stages provided by coded apps may ensure greater accuracy of assignment that obviates the need to refer to tabular arrays, users still need to review the criteria for each T, N, and prognostic group classification to ensure that correct groupings have been identified.

Conclusion

This evaluation study demonstrated the perceived utility of a Web-based app configured to demonstrate an exclusionary approach to TNM staging. Subjects recruited from a pool of target users found that it was easy to use, and they deemed the approach to assignment that it employed to be informative, efficient, accurate, and reliable. It was interesting to note that while this app was originally developed as an educational resource, the statement that elicited the greatest number of “Disagree” responses focused on its potential use as an instructional aid to help prepare for board certification and re-certification exams. By way of contrast, statements suggesting that it could be used in clinical practice by providers with varying degrees of expertise elicited greater numbers of

“Strongly agree” responses. This feedback may guide further development and investigation that may focus on evaluating the performance and acceptance of this app when it is deployed for use in simulated cancer staging exercises and real-time clinical practice.

Conflicts of Interest

None declared.

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Abbreviations

TNM: tumour/node/metastasis

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Short Paper

YouTube Videos Related to Skin Cancer: A Missed Opportunity for Cancer Prevention and Control

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Abstract

Background: Early detection and treatment influence the mortality risk of skin cancer.

Objective: The objective of this study was to analyze the content of the most viewed professional and consumer videos uploaded to YouTube related to skin cancer.

Methods: A total of 140 professional and consumer videos uploaded between 2007 and 2014 were identified and coded. Coding involved identifying and sorting followed by gathering descriptive information, including length of the video, number of views, and year uploaded. A dichotomous coding scheme (ie, yes or no) was used in coding specific aspects of video content, including provision of information, type of skin cancer, age group, family history, risk reduction, risk factors, fear, and home remedies for skin cancer treatment.

Results: The majority of videos provided information related to screening. Many consumer videos conveyed information related to the use of a black salve as a home remedy for skin cancer, despite the fact that there is no evidence that it is an effective treatment.

Conclusions: Research is needed to identify characteristics of videos that are most likely to be viewed to inform the development of credible communications.

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KEYWORDS

skin cancer; social media; YouTube

Introduction

In the United States, skin cancer is the most common cancer affecting both men and women, and incidence rates have recently been rising [1,2]. Early detection and treatment influences mortality risk, particularly with melanoma [3]. Public understanding about the causes, consequences, and treatment of skin cancer may influence individuals' motivation and ability to make informed decisions regarding prevention, early detection, and treatment. The public has increasingly used the Internet in general and social media in particular as a source of information [4].

YouTube is a popular social media website with approximately one billion unique worldwide users per month [5]. With this extent of reach, there is great potential for both improving understanding or, conversely, creating confusion and disseminating inaccurate and potentially dangerous information. There is limited research on the content of YouTube videos related to public health. In this study, we assessed selected aspects of the most widely viewed YouTube videos related to skin cancer.

Methods

Using the keywords “skin cancer”, all videos in English were sorted by number of views. Those with 5000 or more views were included in the sample. Each video was classified as being posted from a professional source or consumer. Professional videos were defined as those derived from a health or non-profit organization, or featuring one or more professionals with clinical credentials. Consumer videos featured people with no clinical credentials and the originator was not affiliated with any organization.

A total of 140 professional and consumer videos uploaded between 2007 and 2014 were identified and coded by 1 researcher (RR); 10 were re-coded by 2 researchers (CHB and RR) to demonstrate that the coding was completed in a consistent way. Coding involved an identifying and sorting process followed by gathering descriptive information, including length of the video, number of views, and year uploaded. A dichotomous coding scheme (ie, yes or no) was used in coding specific aspects of video content, including provision of information, type of skin cancer, age group, family history, risk reduction, risk factors, fear, and home remedies for skin cancer treatment.

Descriptive statistics, including frequencies, percentages, means, and standard deviations, were calculated to describe the year each video was uploaded, number of views (since the date of upload), duration (in minutes), and number of views. Chi-square analysis for categorical variables and Student's *t* test for continuous variables were used to assess if there were differences between videos posted by consumers versus professionals concerning characteristics and content. Interrater reliability was assessed using Cohen's kappa and was found to

be excellent ($\kappa=0.99$). *P* values <0.05 were considered statistically significant. All analyses were performed using IBM SPSS (version 22).

Results

Collectively, the 140 videos were viewed more than 33 million times (range 5131-9,049,986 views) (Table 1). Consumers created the majority of videos (60.0%; 84/140). The mean length of the videos was 5 minutes (range: 28 seconds to 86 minutes). There were no statistically significant differences between videos posted by consumers versus professionals with respect to number of videos represented, length, or number of views. There were, however, differences in other respects.

The majority of videos (61.4%, 86/140) provided information related to skin cancer screening and tended to discuss skin cancer in general (32.1%, 45/140) or melanoma (26.4%, 37/140) (Table 2). Overall, content was not directed at any specific age group (88.6%, 124/140). Risk reduction was commonly discussed covering signs and symptoms of skin cancer (32.9%, 46/140), importance of screening (28.6%, 40/140), use of sun block (27.9%, 39/140), and dangers of tanning (27.1%, 38/140). Compared with consumer-created videos, those created by professionals more often provided information ($P<0.001$), mentioned squamous cell skin cancer ($P=0.02$), focused on importance of screening ($P<0.001$), and on signs and symptoms ($P<0.001$). These videos were also more likely to discuss the ABCDE method of skin cancer self-examination ($P=0.026$). Videos created by consumers conveyed information related to the use of black salve as a home remedy cure of skin cancer (consumer 27.7%, 23/83 vs professional 0.0%, 0/57, $P<0.001$) (Figure 1-3).

Table 1. Characteristics of 140 popular skin cancer screening videos posted on YouTube.

Characteristics	Total (N=140), n (%)	Consumer (N=84, 60.0%), n (%)	Professional (N=56, 40.0%), n (%)	<i>P</i> value
Year video uploaded				.29
2007	18 (12.9)	9 (10.7)	9 (16.1)	
2008	18 (12.5)	8 (9.5)	10 (17.9)	
2009	15 (10.7)	7 (8.3)	8 (14.3)	
2010	13 (9.3)	10 (11.9)	3 (5.4)	
2011	23 (16.4)	18 (21.4)	5 (8.9)	
2012	26 (18.6)	16 (19.0)	10 (17.9)	
2013	20 (14.3)	12 (14.3)	8 (14.3)	
Jan.-Oct. 2014	7 (5.0)	4 (4.8)	3 (5.4)	
Length of video, minutes				.16
Mean (SD)	5.14 (8.75)	4.63 (4.73)	5.92 (12.60)	
Range	0.28-86.44	0.28-32.23	0.45-86.44	
Length of video, minutes				.28
0.0-1.50	34 (24.3)	22 (26.2)	12 (21.4)	
1.51-3.20	36 (25.7)	17 (20.2)	19 (33.9)	
3.21-5.40	35 (25.0)	21 (25.0)	14 (25.0)	
>5.40	35 (25.0)	24 (28.6)	11 (19.6)	
Number of video views				.43
Total	33,722,068	17,685,501 (52.44)	15,631,764 (46.35)	
Mean (SD)	237,980 (1,053,305)	210,541 (994,412)	279,138 (1,144,002)	
Range	5131-9,049,986	5329-9,049,986	5131-7,131,624	

Table 2. Content of 140 popular skin cancer screening videos posted on YouTube.

Content	Total (N=140), n (%)	Consumer (N=83), n (%)	Professional (N=57), n (%)	P value
Provide information	86 (61.4)	33 (39.8)	53 (93.0)	<.001
Type of skin cancer				
Brief mention or irrelevant	11 (7.9)	10 (12.0)	1 (1.8)	.026
Melanoma	37 (26.4)	19 (22.9)	18 (31.6)	.25
Basal cell carcinoma	25 (17.9)	17 (20.5)	8 (14.0)	.33
Skin cancer in general	45 (32.1)	30 (36.1)	15 (26.3)	.22
Squamous cell carcinoma	13 (9.3)	4 (4.8)	9 (15.8)	.03
Multiple types	16 (11.4)	7 (8.4)	9 (15.8)	.18
Age group discussed				
Age not discussed	124 (88.6)	79 (95.2)	45 (78.9)	.016
<40	4 (2.9)	1 (1.2)	3 (5.3)	
≥40	4 (2.9)	0 (0.0)	4 (7.0)	
All ages	8 (5.7)	3 (3.6)	5 (8.8)	
Family history	16 (11.4)	6 (7.2)	10 (17.5)	.06
Risk reduction				
Importance of screening	40 (28.6)	12 (14.5)	28 (49.1)	<.001
Signs and symptoms	46 (32.9)	16 (19.3)	30 (52.6)	<.001
Use of sunblock	39 (27.9)	24 (28.9)	15 (26.3)	.74
Danger of tanning	38 (27.1)	20 (24.1)	18 (31.6)	.33
Wearing a hat	13 (9.3)	8 (9.6)	5 (8.8)	.86
Prevention in youth	12 (8.6)	6 (7.2)	6 (10.5)	.49
ABCDE method	15 (10.7)	5 (6.0)	10 (17.5)	.03
Fear	19 (13.6)	14 (16.9)	5 (8.8)	.17
Home remedies for skin cancer treatment				
Black salve	23 (16.4)	23 (27.7)	0 (0.0)	<.001

Figure 1. Screenshot for black salve success.



Figure 2. Screenshot of tumor removed.

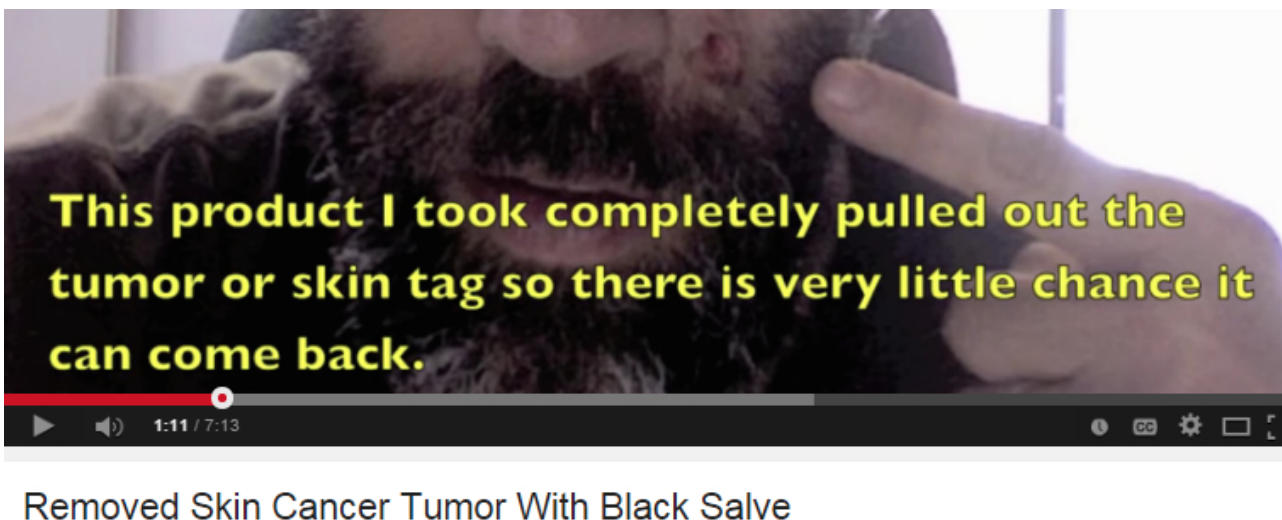


Figure 3. Screenshot of info for the black salve.



Discussion

Principal Findings

This is the first study to examine the content of videos pertaining to skin cancer on the popular social media site, YouTube. It is important for health professionals to recognize that a great deal of information accessed by the public is from material posted by consumers. Indeed, consumers posted the majority of the most widely viewed videos related to skin cancer prevention and treatment. Perhaps the most important finding from this study is the focus of consumer videos on home remedies for skin cancer, namely the use of black salve for treatment or removal of cancers on the skin.

Black salve varies in composition but typically contains zinc chloride and/or powdered bloodroot from *Sanguinaria canadensis* [6]. There is no evidence that black salve is effective in treating skin cancer. Two case studies were identified in which patients attempted to use black salve for treatment of skin cancer, but patients' melanoma in these studies persisted [7,8]. More than one in four consumer videos (27.7%, 23/83) focused on black salve, and these videos were viewed over 3 million times. Videos can be particularly deceiving as they tend

to show before and after imagery and messages tend to be delivered from a person claiming to have used the product with success.

Additionally, none of these popular videos were posted by a US governmental health agency. Given that prevention and control of skin cancer is a goal of multiple agencies of the US Public Health Service as well as non-profit agencies, the lack of widely viewed communications on this topic represents a missed opportunity for disease prevention and health promotion. The number of views was sizeable, though it is not distinguishable whether the views represent unique users.

YouTube has proven to be a valuable tool for health information in the digital age. The medium has been used for a wide range of purposes, including the creation of educational materials for health care professionals [9], the generation of a patient community where discussion about experiences and treatment can occur [10], the documentation of patient experiences for side-by-side health communication messages [11], and personal barriers to accessing care [12]. The platform provides a unique mix of social media and visual representation that can create confusion in regard to the quality of health information available. One study reported on the unreliability and misleading

nature of the information presented on the website [13], while another has shown that the majority of condition specific videos are generally consistent with medical recommendations [11].

Conclusion

Additional research is needed to identify the characteristics of videos that are most likely to be viewed and to develop credible communications through YouTube and other social media to help the public make informed decisions about cancer prevention and control.

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Conflicts of Interest

None declared.

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Original Paper

Age-Related Use and Perceptions of eHealth in Men With Prostate Cancer: A Web-Based Survey

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Abstract

Background: Men with prostate cancer require ample information and support along the continuum of care, and eHealth is one way to meet such critical information and support needs. Currently, evidence about how age influences use and perceptions about prostate cancer eHealth information and support is lacking.

Objective: The aim of this paper is to explore use and perceptions about eHealth among men living with prostate cancer. Specifically, we aimed to analyze men with prostate cancer by age-specific cohorts to identify potential age-related differences in use and perceptions about prostate cancer eHealth information.

Methods: We used survey methodology to examine how men under 65 years old with prostate cancer differ from those aged 65 years old or older in use and perceptions about prostate cancer eHealth information and support (n=289).

Results: We found that men in the younger cohort used the Internet more often to be informed about treatment options ($P=.04$) and to learn more about staging/grading ($P=.01$) than men in the older cohort. Results also showed comparatively greater use of online prostate cancer information for emotional support and encouragement by the younger as compared to the older cohort ($P=.001$). Furthermore, the older cohort reported more negative psychosocial effects of eHealth (eg, more anxious, depressed) than younger men ($P=.002$). We also found that as a result of more frequent Internet use, younger men experienced more positive psychosocial effects (eg, more informed, in control) from accessing information about prostate cancer through eHealth channels ($b=-0.10$, 95% CI -0.28 to 0).

Conclusions: Men with prostate cancer have different information and support needs; our findings suggest that these needs might vary by age. Future research is needed to unravel age-related factors underlying these differences to be better able to tailor prostate cancer eHealth information to men's information and support needs.

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KEYWORDS

consumer health information; prostate cancer; age groups; information-seeking behavior; social support; psychosocial aspects

Introduction

Overview

Men with prostate cancer often turn to the Internet to fulfill their information and support needs [1,2]. Research has shown that the Internet helps some individuals with prostate cancer gain

and share knowledge and experiences to cope with their illness [3,4]. For these reasons, the Internet has become an important eHealth communication channel for men with prostate cancer [1,2]. eHealth is defined as "health services and information delivered or enhanced through the Internet and related technologies" [5].

Although diagnosed more often in older adulthood, or at the median age of 66 years old [6], diagnosis of prostate cancer among younger men has more than doubled over the past two decades [7,8]. Age at the time of diagnosis of prostate cancer is a meaningful factor to consider given the fact that younger men typically live with the consequences of the disease and treatment for a longer amount of time [9]. On the other hand, older men may experience prostate cancer complicated by age-related comorbidities, such as vascular diseases, other cancers, and infections [10]. Ensuring that appropriate and useful prostate cancer eHealth information is available for audiences of diverse ages and life stages is important, given these considerations.

To deepen the understanding of the reasons for using eHealth information and the perceived psychosocial effects of its use, this paper aims to explore use and perceptions about eHealth among younger and older men living with prostate cancer. We refer to younger and older individuals as men under 65 years old and men 65 years and older, respectively. These two age groups have been found worthy of separate analysis in several studies on adulthood development [11] and disease in adulthood [12]. Moreover, dividing individuals into these two cohorts is justified by the median age at diagnosis of prostate cancer, which is 66 years old [6].

Use and Experience of Prostate Cancer eHealth

In 2013, nearly 80% of adults aged 45 to 64 years had Internet access compared to a little less than 60% of adults aged 65 and over [13]. Although the gap in use between younger and older adults is narrowing, older adults also use eHealth for cancer information less frequently than their younger counterparts [14,15].

When evaluating prostate cancer eHealth and age, it is important to consider that using the Internet does not necessarily mean that individuals find what they seek online or that they perceive the information in the same way. This is often referred to as eHealth literacy, the ability to seek, find, understand, and act on health information from electronic sources to solve a health problem [16], and eHealth literacy is considered lower among older adults [17]. Moreover, older adults often suffer from a decline in basic abilities, such as cognitive (eg, decreased working memory) and sensory (eg, decreased visual acuity) impairments [18], which makes their user experience online different from adults under 65 years of age.

Considering these age-related differences with respect to Internet use and experience, we expect that when compared to younger men with prostate cancer, older men in our study will use the Internet less frequently in general, as well as less frequently specifically for prostate cancer information and/or support (Hypothesis 1a [H1a]). We also expect that older men will have a more negative experience using the Internet in general and in relationship to prostate cancer information and/or support when compared to their younger counterparts (Hypothesis 1b [H1b]).

Reasons for Using Prostate Cancer eHealth

Prostate cancer eHealth is as varied as the challenges men with prostate cancer face. Examples include information about cancer staging and grading (Gleason score), available treatments,

treatment decision-making tools (nomograms) [19], and more complex eHealth tools that address a variety of information and support needs [20,21]. Such tools may appeal to men's desire for autonomy and security in their treatment decisions [1].

Other manifestations of prostate cancer eHealth focus on opportunities to find support from others through online tools, such as online support groups [1-3]. Online support groups may be a particularly attractive means of communication about sensitive prostate cancer topics [3]. They offer the opportunity to maintain anonymity, lurk, cast aside social constraints associated with face-to-face interactions, and interact regardless of location, which some men may find beneficial [3,22].

Although eHealth resources for prostate cancer are abundantly available online, issues concerning the applicability of these eHealth resources across diverse audiences needs further investigation. Given the scarcity of prior work on the specific age-related differences in reasons for using prostate cancer eHealth, we propose the first research question (RQ1): Are there differences between younger and older men living with prostate cancer in reasons for using prostate cancer eHealth for information and support?

Effects of Using Prostate Cancer eHealth

To date, there are few studies that have focused on the perceived psychosocial effects of using prostate cancer eHealth. Some researchers, such as Dickerson et al [2], report that use of the Internet for prostate cancer information and support enhances the ability to cope with prostate cancer because it helps men feel more informed, in control, and connected with others. Other researchers have begun to evaluate the psychosocial effects of using specific Web-based support tools. For example, Ruland et al [20] found that participants who used the multi-featured illness management tool, WebChoice, had significantly less symptom distress than control group participants. These authors also found within-group improvements in depression within the experimental group.

Not all aspects of prostate cancer eHealth are perceived as having positive effects on psychosocial health. Broom [3] discovered that some men with prostate cancer perceive the anonymity and secrecy of online social support groups, for example, as problematic because unknown, "faceless" individuals may try to deceive them. Men with this perspective generally considered use of this type of eHealth as maladaptive. Expressions of distrust in prostate cancer information found on the Internet has also been found in other studies [2]. Such distrust may be antithetical to the coping process.

Given the lack of a body of research about a range of psychosocial effects of prostate cancer eHealth, consideration of the rigorous literature review of Bjørnes et al [1] about accessibility of prostate cancer information from health care providers and the Internet may be meaningful. Their literature review highlighted words and phrases from the literature that represent "the positive process" of receiving individualized information through dialogue-based contacts with health care providers (ie, the "gold standard"), including words and phrases that reflect positive experiences and feelings, words and phrases that connect these experiences and feelings to the coping

process, and how these words and phrases are related to theory (eg, certainty-, security-, and/or empowerment-based theories). These authors also developed a schema of “the negative process” that occurs when information and support are lacking. Words and phrases in the positive dimension included, for example, “being prepared for,” “a sense of confidence and control,” and “coping.” In the negative dimension of the schema, words and phrases included, for example, “suffered in silence and anxiety,” “all alone,” and “fears of the unknown” [1].

Since there is not currently a large body of research to support the effect of prostate cancer eHealth on psychosocial outcomes, investigating men’s perceptions may enhance understanding of the relationship between eHealth and coping. Since perceptions of prostate cancer eHealth might vary by age, the second research question (RQ2) is posed: Are there differences between younger and older men living with prostate cancer in how prostate cancer eHealth affects positive and negative psychosocial outcomes?

Methods

Instrumentation

To evaluate use and perceptions of prostate cancer eHealth, survey methodology was used. An online questionnaire was designed using multiple types of response scales for closed-ended questions. For bounded continuous scales, Likert-type scale response anchors as described by Vagias [23] were used with some modifications. The survey was divided into three primary domains of interest in order to address the hypotheses and research questions: (1) Internet behavior and experiences, (2) reasons for using prostate cancer eHealth for information and support needs, and (3) effect on psychosocial indicators. Furthermore, information about personal history and prostate cancer history were assessed to determine the background of the study participants.

To address the third domain, the work of Bjørnes et al [1] was used to develop a measure of how prostate cancer eHealth influences a broad set of psychosocial outcomes. These positive and negative schema were used to inform the development of our measure since the ways in which eHealth influences psychosocial health have not been widely studied. Using their schema, we conceptualized the positive psychosocial dimension to include the following indicators: feeling informed, in control, able to cope, confident about treatment decision, and connected with others. For the negative psychosocial dimension, we conceptualized the indicators as feeling anxious, depressed, lonely, and scared. By using their schema, we hoped to determine whether we could produce a brief yet reliable measure of psychosocial health [1].

Sampling Strategy and Procedure

Institutional Review Board (IRB) approval for this study was obtained from George Mason University and Inova Health System. Survey participants were recruited using nonprobability sampling methods, including voluntary and snowball sampling. After obtaining permission from website administrators, recruitment occurred through four online prostate cancer social networks—the “New” Prostate Cancer InfoLink Social Network,

His Prostate Cancer, the Association of Cancer Online Forums Prostate Problems Mailing List, and a prostate cancer-related email list of Life with Cancer, Inova Health System. All respondents provided informed consent through the questionnaire before the study questions were displayed.

Measures

Sociodemographic and Prostate Cancer Characteristics

Sociodemographic characteristics included questions about age, race/ethnicity, and education level. Race/ethnicity included the answer options “African American/Black,” “Asian/Pacific Islander,” “Hispanic,” “Native American/Alaska Native,” “White,” and “Other”; multiple responses were allowed. Education level was measured using the answer options “high school or less,” “some college,” “college graduate (Bachelor’s degree),” and “graduate degree (Master’s degree or above).” Prostate cancer characteristics were assessed by asking about the amount of time since diagnosis and types of treatment. Time since diagnosis was assessed through the answer options “less than 1 year ago,” “1-2 years ago,” “3-4 years ago,” and “5 years ago or more.” For type of treatment, participants were asked to select all treatments they had received. They could select “prostatectomy,” “radiation (external beam),” “radiation (brachytherapy),” “proton beam therapy,” “hormone therapy,” “testicle removal,” “cryotherapy,” “chemotherapy,” and “watchful waiting.” Other types of treatment not provided as options could be typed in an “other (please specify)” comment field.

Internet Behavior and Experiences

Internet measures included questions about men’s Internet behavior and experiences. *Internet use* was measured with the question “how often do you use the Internet?” (1 = never, 2 = almost never, 3 = occasionally, 4 = a moderate amount, 5 = a great deal). *Internet access* was assessed through the following item selections: “I have easy access to the Internet” (1 = strongly disagree, 2 = disagree, 3 = neither agree nor disagree, 4 = agree, 5 = strongly agree). *Level of comfort with the Internet* was measured by “what is your level of comfort when you use the Internet?” (1 = not at all comfortable, 2 = slightly comfortable, 3 = somewhat comfortable, 4 = very comfortable). *Internet use for prostate cancer information* was assessed with “[...] how often have you used the Internet to find information about prostate cancer?” (1 = never, 2 = about once every few months, 3 = about once a month, 4 = about once a week, 5 = about once a day). *Level of difficulty finding information online* was measured by “[...] was it difficult to find the specific information you were looking for?” (1 = never, 2 = almost never, 3 = occasionally, 4 = usually, 5 = always). *Level of applicability of the information* was questioned by “[...] did you think that the prostate cancer information on the Internet applied to your personal situation?” (1 = never, 2 = almost never, 3 = occasionally, 4 = usually, 5 = always). *Trust in online information* was measured by “[...] how much do you trust information about prostate cancer that you get from the Internet?” (1 = never trust, 2 = almost never trust, 3 = occasionally trust, 4 = usually trust, 5 = trust a great deal).

Reasons to Use eHealth for Information and Support

Participants were asked why they used eHealth for information and support. They were provided with 13 information categories to select from, such as “to learn more about staging and/or grading,” and five support categories, such as “to read/listen to other men’s personal prostate cancer stories.” Participants could select as many options as applied.

Psychosocial Indicators

How the Internet influences psychosocial health was measured with 10 items, such as “I feel informed,” “I feel in control,” and “I feel lonely.” All items were provided with the answer options “more,” “less,” and “no effect.” Scores were assigned to each item by giving a +1 when the Internet had affected men with prostate cancer more, a 0 when the Internet had no effect, and a -1 when the Internet had affected them less. Principle Component Analysis (PCA) with varimax rotation distinguished two reliable components: one for the “positive” effects of eHealth (Eigenvalue [EV] = 1.62, explained variance = 24.23%, $\alpha = .70$) and one for the “negative” effects of eHealth (EV = 3.59, explained variance = 27.92%, $\alpha = .83$). Two sum scales were computed, one representing the positive effects of eHealth and one representing the negative effects of eHealth.

Statistical Analysis

We used descriptives and chi-square statistics to present the sociodemographic and prostate cancer characteristics. To address the first research domain, we tested whether there were differences between men under 65 years old and men 65 years old and older in Internet behavior (H1a) and experiences (H1b). Analysis of variance (ANOVA) tests were conducted with age group as the independent variable and the seven Internet measures as dependent variables. For the purpose of investigating the second domain, we used chi-square statistics to examine the differences between men under 65 years old and men 65 years old and older in reasons for using eHealth

information to address information and support needs (RQ1). To investigate the third and final domain, differences between men under 65 years old and men 65 years old and older in how prostate cancer eHealth impacts psychosocial indicators (RQ2) were examined using Kendall’s tau-b correlation coefficients. The relationships between age, Internet measures, and psychosocial indicators were further explored using the conditional process modeling program PROCESS, Model 4 [24]. All indirect effects were subjected to bootstrap analyses with 5000 bootstrap samples and a 95% CI.

Results

Sociodemographic and Prostate Cancer Characteristics

A total of 402 respondents started the online survey, of which 382 completed the survey (completion rate = 95.0%). Another 93 participants out of 382 (24.3%) chose not to fill out their age, and therefore were excluded from the data as we were not able to analyze age differences in use and perceptions of eHealth information for this group. This resulted in 289 valid cases for data analysis. Our sample of men with prostate cancer were on average 64.91 years old (SD 8.34, range 40-89). Most participants were white (277/289, 95.8%), and almost half of them had a graduate degree (134/289, 46.4%). For analysis, the sample was divided into a cohort of younger men (40-64 years old, 144/289, 49.8%) and older men (≥ 65 years old, 145/289, 50.2%). Older men were more likely to be diagnosed five years ago or more ($\chi^2_1 = 13.3, P < .001$), whereas younger men were more likely to be diagnosed less than one year ago ($\chi^2_1 = 8.5, P = .004$). In terms of treatments men had undergone, younger men were more likely to have had a prostatectomy than older men ($\chi^2_1 = 13.9, P < .001$) and older men were more likely to have had hormone therapy than younger men ($\chi^2_1 = 3.8, P = .05$). [Table 1](#) shows an overview of results related to personal and prostate cancer characteristics.

Table 1. Personal and prostate cancer characteristics (n=289)^a.

Characteristics	Younger men (< 65 years), n (%), mean (SD), or range	Older men (≥ 65 years), n (%), mean (SD), or range
Number of men per age group, n (%)	144 (49.8)	145 (50.2)
Age in years, mean (SD)	58.28 (4.62)	71.49 (5.51) ^b
Age in years, range	40-64	65-89
Ethnicity, n (%)		
White	135 (93.8)	142 (97.9)
African American/Black	4 (2.8)	2 (1.4)
Asian/Pacific Islander	2 (1.4)	3 (2.1)
Hispanic	2 (1.4)	2 (1.4)
Native American/Alaska Native	2 (1.4)	0 (0)
Education level, n (%)		
High school or less	8 (5.6)	7 (4.8)
Some college	28 (19.4)	35 (24.1)
College graduate (Bachelor's degree)	43 (29.9)	33 (22.8)
Graduate degree (Master's degree or above)	65 (45.1)	69 (47.6)
Time since diagnosis, n (%)		
Less than 1 year ago	36 (25.0)	16 (11.0) ^c
1-2 years ago	40 (27.8)	32 (22.1)
3-4 years ago	36 (25.0)	34 (23.4)
5 years ago or more	32 (22.2)	62 (42.8) ^b
Type of treatment, n (%)		
Prostatectomy	79 (54.9)	47 (32.4) ^b
Hormone therapy	41 (28.5)	58 (40.0) ^d
Radiation—external beam	39 (27.1)	54 (37.2)
Watchful waiting/active surveillance	25 (17.4)	36 (24.8)
Chemotherapy	11 (7.6)	10 (6.9)
Radiation—brachytherapy (implants)	10 (6.9)	19 (13.1)
Proton beam therapy	3 (2.1)	7 (4.8)
Cryotherapy	1 (0.7)	4 (2.8)
Testicle removal	0 (0)	0 (0)

^aSome numbers do not add up to 100% due to missing data.

^bDiffers significantly from younger men ($P < .001$).

^cDiffers significantly from younger men ($P = .004$).

^dDiffers significantly from younger men ($P = .05$).

Domain 1: Internet Behavior and Experiences

To describe our findings regarding the first research domain, we found that the two age groups significantly differed on the frequency of Internet use (H1a) ($F_{1,285} = 3.80$, $P = .05$, $\eta_p^2 = .01$)

and Internet experiences (H1b), such as level of comfort with the Internet ($F_{1,286} = 6.31$, $P = .01$, $\eta_p^2 = .02$). The means show that men in the older cohort used the Internet less frequently than men in the younger cohort and also felt less comfortable using the Internet, confirming our hypothesis (see Table 2).

Table 2. Internet behavior and experiences among younger (< 65 years) and older (≥ 65 years) men with prostate cancer.

Internet behavior and experiences ^a	Younger men (< 65 years), mean (SD)	Older men (≥ 65 years), mean (SD)
Internet use	4.84 (0.39)	4.74 (0.47) ^b
Internet access	4.60 (1.00)	4.54 (0.88)
Internet comfort ^c	3.85 (0.39)	3.72 (0.49) ^d
Internet use for prostate cancer information	3.78 (1.10)	3.81 (1.09)
Information-seeking difficulty	2.57 (0.96)	2.58 (0.88)
Internet personal applicability	3.67 (0.67)	3.59 (0.66)
Internet trust	3.76 (0.66)	3.68 (0.66)

^aAll measures were assessed using a 5-point Likert-type scale.

^bDiffers significantly compared to younger men ($P=.05$).

^cLevel of comfort with the Internet was measured on a 4-point Likert scale.

^dDiffers significantly compared to younger men ($P=.01$).

Domain 2: Reasons to Use eHealth for Information and Support Needs

The second domain investigated (RQ1) showed that the most frequently selected reasons to address information needs were to learn more about available treatments (255/289, 88.2%), to learn more about the effects of treatment (245/289, 84.8%), and to keep up to date with prostate cancer research (237/289, 82.0%). We found that men in the younger cohort used the Internet more often to be informed about treatment options ($\chi^2_1=4.4$, $P=.04$) and to learn more about staging/grading ($\chi^2_1=7.7$,

$P=.01$) than men in the older cohort. Our results showed that the most common reasons to use eHealth to address support needs were to read and/or listen to other men's prostate cancer stories (192/289, 66.4%), to offer their own personal prostate cancer stories (136/289, 47.1%), and to get personal opinions to help make a treatment decision (135/289, 46.7%). Our results revealed that men in the younger cohort used the Internet significantly more often than older men to get emotional support and encouragement online ($\chi^2_1=12.0$, $P=.001$). Table 3 provides an overview of the information and support needs.

Table 3. Reasons to use eHealth for information and support needs among younger (< 65 years) and older (≥ 65 years) men with prostate cancer.

Reasons to use eHealth ^a	Younger men (<65 years) (n=144), n (%)	Older men (≥65 years) (n=145), n (%)
To learn more about available treatments	129 (89.6)	126 (86.9)
To learn more about the effects of treatment	122 (84.7)	123 (84.8)
To keep up to date with prostate cancer research	115 (79.9)	122 (84.1)
To learn more about recurrence of prostate cancer	101 (70.1)	98 (67.6)
To be informed about treatment options	114 (79.2)	98 (67.6) ^b
To know what questions to ask my doctor	112 (77.8)	101 (69.7)
To learn more about staging and/or grading	113 (78.5)	93 (64.1) ^c
To learn more about self-management	79 (54.9)	87 (60.0)
To make sure what the doctor told me is correct	66 (45.8)	66 (45.5)
To make a treatment decision using a website tool	54 (37.5)	53 (36.6)
To check out my doctor's reputation	52 (36.1)	44 (30.3)
To get a second opinion	39 (27.1)	55 (37.9)
To learn more about and/or enroll in a clinical trial	41 (28.5)	41 (28.3)
To read/listen to other men's prostate cancer stories	96 (66.7)	96 (66.2)
To offer my personal prostate cancer story	64 (44.4)	72 (49.7)
To get personal opinions to help decision making	64 (44.4)	71 (49.0)
To get personal opinions to help address treatment effects	58 (40.3)	69 (47.6)
To get emotional support and encouragement	48 (33.3)	22 (15.2) ^d

^aMore than one reason to use eHealth for information needs could be selected. Reasons are presented from most frequently selected reasons to least frequently selected reasons.

^bPercentage differs significantly compared to younger men ($P=.04$).

^cPercentage differs significantly compared to younger men ($P=.01$).

^dPercentage differs significantly compared to younger men ($P=.001$).

Domain 3: Impact on Psychosocial Indicators

Examining the third and final domain (RQ2), we found that increasing age was positively related to negative psychosocial indicators, indicating that older men with prostate cancer were more likely to feel lonely, depressed, anxious, and scared as a result of using the Internet for prostate cancer eHealth than men in the younger cohort ($\tau\text{-}b=.17$, $P=.002$). We found that positive psychosocial indicators were positively related to Internet use ($\tau\text{-}b=.16$, $P=.004$), Internet use for prostate cancer ($\tau\text{-}b=.14$, $P=.005$), personal applicability of the Internet ($\tau\text{-}b=.15$, $P=.004$), and Internet trust ($\tau\text{-}b=.21$, $P<.001$). This indicates that more frequent use of the Internet, personally

relevant information on the Internet, and higher trust in the Internet might result in a more positive experience of using the Internet. Furthermore, positive psychosocial indicators were negatively related to the level of difficulty in use of the Internet ($\tau\text{-}b=-.12$, $P=.02$), indicating that the easier it is to use the Internet, the more positive experience men have with the Internet. In addition, negative psychosocial indicators were significantly and negatively related to Internet trust ($\tau\text{-}b=-.11$, $P=.04$), suggesting that less trust in Internet information may lead to a more negative experience of the Internet. Factor loadings for psychosocial indicators are displayed in Table 4 and correlation coefficients in Table 5.

Table 4. Factor loadings for psychosocial indicators.

Psychosocial indicators ^a	Component 1, <i>r</i>	Component 2, <i>r</i>
I feel in control	.68 ^b	-.19
I feel like I can cope	.63	-.33
I feel connected with others living with prostate cancer	.63	-.02
I feel connected with my spouse/partner	.60	.01
I feel confident about my treatment decision	.60	-.23
I feel informed	.59	-.09
I feel scared	-.08	.85
I feel depressed	-.13	.84
I feel lonely	-.10	.83
I feel anxious/stressed	-.26	.69

^aNegatively phrased items were not reversely recoded as Principle Component Analysis (PCA) distinguished the same two scales and same factor loadings when using the negatively phrased items.

^bItalic numbers indicate which items load onto which components.

Table 5. Correlations between age, Internet measures, and psychosocial indicators.

Age, Internet measures, and psychosocial indicators	Correlations between age, Internet measures, and psychosocial indicators, Kendall's tau-b ^a									
	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.
1. Age ^b	-									
2. Positive dimensions	-.08	-								
3. Negative dimensions	.17 ^c	-.31 ^d	-							
4. Internet use	-.12 ^e	.16 ^f	.04	-						
5. Internet access	-.12 ^g	.07	0	.33 ^d	-					
6. Internet comfort	-.16 ^h	.10	-.01	.44 ^d	.37 ⁱ	-				
7. Internet use for prostate cancer information	.01	.14 ^h	-.05	.14 ^h	.09	.07	-			
8. Information-seeking difficulty ^j	0	-.12 ^k	-.02	-.05	-.08	-.13 ^k	0	-		
9. Internet personal applicability	-.04	.15 ^f	-.07	.06	.15 ^h	.06	.04	-.32 ^d	-	
10. Internet trust	-.05	.21 ^d	-.11 ^g	.03	.13 ^l	.09	0	-.18 ⁱ	.42 ^d	-

^aCorrelation coefficients are Kendall's tau-b coefficients for ordinal level variables.

^bAge as dichotomous variable. Using the continuous variable of age resulted in the same results.

^cThe correlation was significant ($P=.002$).

^dThe correlation was significant ($P<.001$).

^eThe correlation was significant ($P=.05$).

^fThe correlation was significant ($P=.004$).

^gThe correlation was significant ($P=.04$).

^hThe correlation was significant ($P=.01$).

ⁱThe correlation was significant ($P=.001$).

^jThe higher the score, the more difficult information seeking was perceived.

^kThe correlation was significant ($P=.02$).

^lThe correlation was significant ($P=.03$).

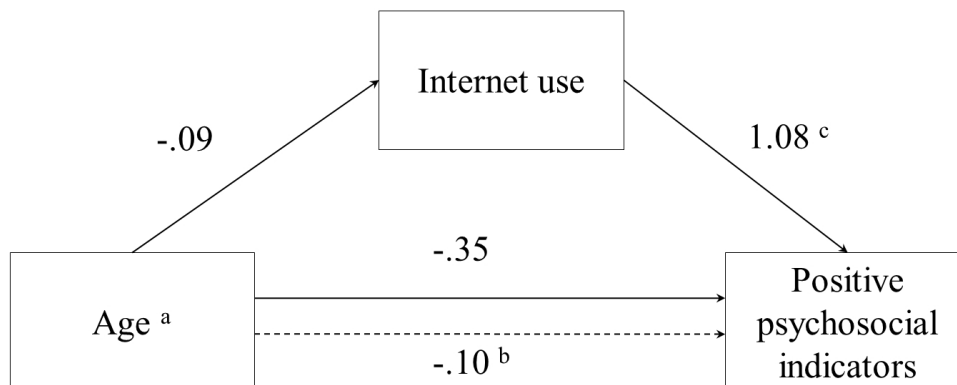
When further exploring the relationships between age, Internet measures, and psychosocial indicators, we found a significant negative mediated effect of age on the positive psychosocial

dimension through Internet use. The model showed an insignificant direct effect of age on positive psychosocial indicators ($b=-0.35$, $P=.17$), but a significant indirect effect of

age on the positive psychosocial dimension via Internet use ($b=-0.10$, 95% CI -0.28 to 0). This suggests that older men use the Internet less than their younger counterparts, which causes

them to have a less positive experience when using the Internet (see Figure 1).

Figure 1. Mediation model: The effect of age on positive psychosocial indicators through Internet use. Unstandardized regression coefficients are presented. (a) Age as dichotomous variable. Using the continuous variable of age resulted in the mediation effect. (b) Significant at 95% CI -0.28 to 0. (c) $P=.001$.



Discussion

Principal Findings

Our findings show that there may be age-related differences in use and perceptions about prostate cancer eHealth information and support among men with prostate cancer. Perhaps most provocative, when men were asked how prostate cancer information and/or support found on the Internet affected them, men in the older cohort were more likely to report that it made them feel lonely, depressed, anxious/stressed, and scared, for example (negative psychosocial indicators). We also found significant positive associations between measures of Internet use and, for instance, feeling informed, in control, and confident about treatment decision (positive psychosocial indicators). Moreover, we found that Internet use mediated the association between age and the positive dimension of psychosocial indicators, which shows that greater use of the Internet among men in the younger cohort, in particular, appears to lead to a more positive psychosocial response to prostate cancer eHealth. That men in our younger cohort were significantly more likely to use the Internet and feel comfortable with using the Internet is consistent with findings from past investigations [13,25].

We also explored whether our two cohorts would differ in reasons for using prostate cancer eHealth. We found that, when compared to older men, men in the younger cohort used eHealth information significantly more to be informed about treatment options and to learn more about staging and/or grading. Additionally, younger men reported using communication for emotional support and encouragement significantly more often than older men. Although a significant difference in time since diagnosis between the cohorts might partially explain this finding—older men had a longer time since diagnosis—it is still worthy of attention. Dickerson et al [2] describe online social support as an “online friendship.” It is possible that such friendships can provide emotional support and encouragement, and in a format that younger men are comfortable with navigating as experienced Internet users. Because men under 65 years old make up a relatively smaller proportion of the

prostate cancer population, it is possible that they have a more difficult time finding support in their own social circles when compared to older aged men. Online social networks may offer a way to generate new social circles that would not have been possible prior to the existence of nonstatic Web technologies [26]. Our study may have uncovered an important distinction in the eHealth needs of men with prostate cancer who are diagnosed at younger ages, a rapidly growing segment of the prostate cancer population [8], however, further investigation is needed.

Study Limitations

Although our findings shed light on the fact that there may be age-related differences in the use of prostate cancer eHealth and perceptions about how it affects one’s psychosocial health, these results should be interpreted with caution. Since there was a significant difference between cohorts in time since diagnosis (longer time since diagnosis for the older cohort) and types of treatment regimens (greater frequency of hormone therapy over prostatectomy for the older cohort), our findings might have detected differences in use and perceptions based on time since diagnosis or treatment regimen. For example, men diagnosed longer ago may use certain features of eHealth less or more frequently, which was not measured in this study. Furthermore, treatment effects on psychosocial health, such as depression or anxiety, as well as baseline predispositions related to depression, anxiety, and coping ability may have influenced participants’ responses about the specific effect of eHealth on their psychosocial health. Finally, certain treatment effects, such as cognitive effects associated with hormone therapy, could have influenced findings related to use and perceptions of prostate cancer eHealth [27].

Other limitations of this study included those related to selection bias. While the sample was fairly representative of the prostate cancer population based on age distribution [6], the findings are not generalizable to the entire prostate cancer population since the survey sample was predominantly non-Hispanic white, well-educated men, with easy access to the Internet. Because

our sampling strategy involved voluntary recruitment of men from prostate cancer social networks, it is not surprising that both cohorts were relatively frequent and comfortable Internet users. It may also explain why we did not detect significant differences between cohorts for several measures of Internet behavior or experiences, such as ease of access to the Internet, frequency of use of the Internet to seek prostate cancer eHealth, and level of trust in prostate cancer eHealth. Furthermore, as we dealt with cross-sectional data, we can only suggest that Internet behavior and experience may lead to positive or negative psychosocial experiences as a result of using eHealth. It could also be the case that, for instance, due to negative psychosocial experiences with prostate cancer eHealth, men trust the Internet less, and therefore use the Internet less as a source of information and support.

Implications and Directions for Future Research and Practice

There are several implications of this study for future research and practice. As described by Harden et al [28] and reiterated by Bjørnes et al [1], men with prostate cancer have a great deal of information and support needs, but each man needs different information or needs the information to be presented differently. Our study findings show that eHealth information and support needs for prostate cancer may vary by age, in particular. With respect to tailoring of future eHealth interventions, men under 65 years old may benefit from nonstatic Web technologies so that they can receive ample emotional support and

encouragement in addition to informational support. In turn, men 65 years and older may benefit from assistance with using the Internet in more advanced ways, since increased Internet experience and comfort with use may promote positive psychosocial effects, such as feeling more in control and informed about prostate cancer. Nevertheless, future research is needed to unravel age-related factors underlying age-related differences to be better able to tailor prostate cancer eHealth information to men's information and support needs.

Kreps [29] describes the importance of audience analysis to better meet audience needs related to Internet information technologies. With this recommendation in mind, future prostate cancer eHealth studies that build on these study findings should not only analyze men by age, but also by ethnicity. Whether or not men who were underrepresented in this study use and perceive prostate cancer eHealth in the same way as their non-Hispanic, white counterparts remains in question. We particularly recommend that future studies include a representative sample of men from different racial backgrounds, particularly African-American/black men given their two-fold increased risk for prostate cancer when compared to white men. We also suggest inclusion of other population segments that may be impacted by the "digital divide," such as men with different levels of education and income, and those who live in urban versus rural areas [30]. Most importantly, the understanding and appreciation of diverse audience segments gleaned from research should be used to inform translation of evidence to practice.

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Conflicts of Interest

None declared.

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Abbreviations

ANOVA: analysis of variance
EV: Eigenvalue
H1a: Hypothesis 1a
H1b: Hypothesis 1b
IRB: Institutional Review Board
PCA: Principle Component Analysis
RQ1: research question 1
RQ2: research question 2

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Viewpoint

Defining the Role of the Online Therapeutic Facilitator: Principles and Guidelines Developed for Couplelinks, an Online Support Program for Couples Affected by Breast Cancer

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Abstract

Development of psychological interventions delivered via the Internet is a rapidly growing field with the potential to make vital services more accessible. However, there is a corresponding need for careful examination of factors that contribute to effectiveness of Internet-delivered interventions, especially given the observed high dropout rates relative to traditional in-person (IP) interventions. Research has found that the involvement of an online therapist in a Web-based intervention reduces treatment dropout. However, the role of such online therapists is seldom well articulated and varies considerably across programs making it difficult to discern processes that are important for online therapist involvement. In this paper, we introduce the concept of “therapeutic facilitation” to describe the role of the online therapist that was developed and further refined in the context of a Web-based, asynchronous psychosocial intervention for couples affected by breast cancer called Couplelinks. Couplelinks is structured into 6 dyadic learning modules designed to be completed on a weekly basis in consultation with a facilitator through regular, asynchronous, online text-based communication. Principles of therapeutic facilitation derived from a combination of theory underlying the intervention and pilot-testing of the first iteration of the program are described. Case examples to illustrate these principles as well as commonly encountered challenges to online facilitation are presented. Guidelines and principles for therapeutic facilitation hold relevance for professionally delivered online programs more broadly, beyond interventions for couples and cancer.

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KEYWORDS

couples; cancer; Internet; online therapist; psychosocial support; therapeutic alliance

Introduction

There has been a steady increase in the number of Internet-delivered psychological interventions addressing a

range of different issues that include chronic medical conditions (see [1,2]), eating disorders [3-5], substance use (see [6] for review), depression and anxiety [7-9], and cancer (eg, [10,11]). Although research suggests that such online programs are quite

effective (eg, [12]), few studies have examined the components of an online intervention that contribute to program adherence and positive outcomes. Such lack of knowledge is problematic given that online programs demonstrate higher attrition rates relative to traditional in-person (IP) therapy, rendering the significant outcomes achieved applicable to only a subsample of participants [13,14]. Specifically, self-help Web programs that are entirely self-guided (ie, have no contact with or guidance from an online expert or professional incorporated into the program) demonstrate much higher attrition rates with program completion ranging anywhere from 1% [15,12] to 53% [16]. There is compelling evidence that involvement of an online clinician is associated with better outcomes for Internet-delivered interventions (see [9,17] for reviews). A recent qualitative study with individuals that participated in online interventions without an online therapist found that the most commonly cited reasons for program dissatisfaction and disengagement included the lack of personalized support, feedback, and guidance [18,19].

Despite its potentially critical role in program adherence and outcome, there has been minimal discussion and guidelines in the literature on how best to provide therapeutic support within the context of an online, primarily self-guided, psychosocial intervention. Online interventions are different from IP therapy in that much of the intervention is delivered by way of the Web program and an individual's interaction with the program (eg, reviewing content, logging behavior). The online clinician, when included, may have differing tasks depending on the program, but generally is there to provide support with the objective of ensuring compliance with the intervention. In contrast, the IP therapist provides the intervention itself. Therefore, the 2 types of intervention differ in their format and hence the role of the clinician. Still, as trained clinicians, online therapists/facilitators are likely to draw on their general psychotherapy skills, such as empathy and validation in the provision of support. Compared to IP therapists, online clinicians are not privy to the nonverbal communication and paralinguistic cues of their clients [20]. Not surprisingly, relative to IP clinicians, online clinicians express a lack of clarity around how to fulfill similar objectives as the IP therapist using text-based formats for interaction [21].

This paper takes a step toward addressing this gap by defining the role of the online clinician, referred to in this paper as the online facilitator, and by presenting principles and guidelines for online therapeutic facilitation that were developed and refined in the context of a novel Web-based intervention for couples coping with breast cancer. The program, called Couplelinks, was previously developed and tested in a Phase I pilot trial [22] and is presently being evaluated in a multisite randomized controlled trial (RCT) [23]. The observations of the facilitation process in the pilot trial led to greater elaboration and precision of the facilitation guidelines and were formally described in the Couplelinks Program Facilitation Manual [24] for the RCT. The principles and strategies discussed are based on what was learned from the pilot trial.

Interaction with the online facilitator in this program is primarily via text-based asynchronous online communication. The online facilitator role was developed with the vision that it need not

entirely mirror the IP therapist role given the obvious differences between a self-guided Web-based intervention program and IP therapy, but instead be defined differently bearing in mind the potential for unique advantages specific to the technological medium.

In this paper, we review the modest literature on the various ways professionally offered support in online interventions has been defined and provided. This review is followed by a proposed definition of the online facilitator and guiding principles for online facilitation in the context of Couplelinks. Challenges for couple participation and engagement using the online modality are discussed and highlighted with use of case examples from the Couplelinks pilot study.

Research on the Utility of an Online Clinician for Web-Based Interventions

Inclusion of a professionally trained support person in a Web-based intervention varies considerably across programs in terms of the role and the nature of his or her interaction with participants. Methods of online support that have been used and found to increase program adherence include online, telephone, or mailed reminders and brief written descriptions on how to use the program [25-27]; online feedback aimed to emphasize new learning and encourage ongoing engagement [28,29]; and/or telephone contact [7,30]. With respect to program effectiveness, 2 meta-analyses of studies comparing Internet-based interventions for depression and anxiety disorders to a no-treatment control group found that Web-based interventions with therapist support revealed larger effect sizes than Web-based interventions without therapist support [7,9]. Palmqvist et al's [17] quantitative synthesis of several Internet-based interventions found that the amount of online therapist support provided in an intervention was positively correlated with outcome, such that more support related to greater benefits derived from the program.

Few studies have compared the same online intervention with and without therapist guidance and for the few that have been done, the results are equivocal with some finding superior outcomes for an online therapist-guided program over a non-therapist-guided version [31,32] and others finding no significant difference [33,34]. However, the design of the programs themselves, the populations served, and the function and nature of therapist involvement in these programs varied considerably making comparisons difficult. For a number of online self-help programs, "support" was operationalized as automated reminder messages or program instruction (eg, [25,27,28,35]). In other studies, the therapist provided more tailored "feedback" to clients; for instance, specific strategies or access to additional relevant resources [36] or a discussion regarding the interpretation of assessment outcomes and the client's reaction to this information [37]. Berger and colleagues [34] found no difference between therapist-supported and unsupported versions of an online depression intervention. However, therapist support in their study involved weekly generic email responses meant to motivate participants but not necessarily provide any tailored feedback on process or progress. In contrast, Lancee and colleagues' [31] online intervention for

insomnia found significantly greater outcomes for the therapist-guided group compared to the unsupported group. Participants in their therapist-supported group received emails that included tailored feedback on their progress and support and encouragement to complete modules, including suggestions on how to continue with the program. Therapists had the ability to log in and review participants' progress on assigned exercises and integrate participants' own words into the therapist's feedback. In contrast, the unsupported group received prescribed automated email reminders to complete the program and had someone available to contact for questions regarding procedural or technical issues. Taken together, the research suggests that therapist involvement entailing a more individualized approach to online facilitation rather than mere generic responses is critical to outcomes.

Todkill and Powell [19] assessed experience of participants in a RCT of a self-help cognitive behavioral therapy program that included automated email reminders to log in and complete the program. Participants reported that the absence of a message tailored specifically to them as individuals was a major drawback of the program. Similarly, Mathieu et al [18] found that although most participants of an Internet-based psychological program liked if not preferred Internet-based delivery of an intervention because it was flexible, easy to use, and not burdensome, they also reported feeling restricted, disconnected, and unmotivated to continue because of the lack of an online support person to provide personalized feedback and understanding, and the lack of someone who was available to respond to questions and take into consideration their individual circumstances. Finally, Berger and colleagues [34] found that 73% of participants in a non-therapist-supported group desired contact with an online therapist.

Reconceptualizing the Therapist-Client Relationship in Web-Based Interventions

The association between therapeutic alliance and outcomes in IP settings is well established [38,39]. When comparing working alliance client ratings online versus IP therapies, no significant difference in ratings were found, suggesting that a strong therapeutic alliance can be established equally in IP and online mediums (see [40] for review). Different from IP therapy, however, alliance ratings for online interventions have reportedly had a small to no significant effect on outcome despite the high level of therapeutic alliance achieved in them [41-43].

How can we reconcile the findings that the therapeutic alliance is a major factor that explains outcomes of IP therapy but not Web-based interventions, yet both forms of intervention demonstrate comparable efficacy? One possible explanation for this seeming paradox is that the alliance with an online therapist is qualitatively different from that of the alliance formed with an IP therapist because it emerges from the synergistic effect of the website components and the online clinicians' responses [44]. Peck [45] addresses this paradox by reinterpreting the well-established finding that the therapy relationship contributes to outcomes by suggesting that it is not the relationship itself but the processes it activates within a client that impacts

outcomes. As he writes, "In contemplating this conundrum, it may be advantageous to construe the therapeutic relationship not as one of the common factors, but as the vehicle or channel that facilitates (or hinders) the activation of the remaining 'true' common (and specific) factors" [45]. Peck [45] further elaborates by suggesting that in IP therapy, the therapist is typically the only source of delivering the common and specific therapeutic factors, thus components of interpersonal skill in-person will largely determine how well and if therapeutic change processes will be activated. On the other hand, in Web-based interventions, various evidence-based components of therapy are delivered in a structured way via the website itself. Cavanagh and Millings [44] suggest that the significance of other factors, such as support and accountability to the program, will be more salient for the online therapist relationship.

In what ways does the online therapist provide this support and encourage such engagement? Despite recommendations that online interventions require the development of specific skills [46], little work has been done to date to articulate the type of specialized skills required to provide the most effective online facilitation. The way in which the therapist provides "support," "guidance," "assistance," or "feedback" is not well defined for the majority of Web-based interventions [17]. Furthermore, the amount of time and level of engagement of the online therapist is not consistently defined, measured, and reported alongside empirical findings.

Mohr et al [47] propose that the online therapist's role is that of "supportive accountability" and interventions are meant to support progress through and completion of the program using various technological components such as email or phone calls. They further elaborate on the role by suggesting that the online coach is seen as a trustworthy and benevolent person with expertise in the intervention and demonstrates presence and accountability to the program objectives through their interventions. Part of supporting accountability includes clarifying expectations regarding how various aspects of the intervention relate to the benefits clients would experience, making the intervention meaningful and hence increasing compliance. Similarly, Warmerdam and colleagues [29] suggest that the primary role of the online facilitator is to offer feedback with the aim of helping the client work through the program rather than to provide advice or foster a therapeutic relationship per se. In their study, the feedback content consisted of "showing empathy by letting participants know that the coach had read the assignments, being positive by giving compliments on what the participant had done, and giving suggestions on how to continue with the course" [29].

Despite obvious limitations in the level of interaction that can be achieved with clients via a Web-based program, there are several advantages. For example, the clinician can review participant's progress via the data entered online and provide feedback accordingly [48]. Furthermore, Stephen and colleagues [49] reported that facilitators found the physical distance of the online format helped them to better manage the emotional content of the group. Online facilitators in their study found that the act of writing increased their own self-awareness and

mindfulness of the specific clinical skills and interventions being incorporated.

Couplelinks: Program Rationale and Description

Providing psychosocial support via the Internet for people dealing with serious chronic illness such as cancer is particularly compelling when considering the potential geographical, physical, or psychological barriers that may make IP therapy impossible. Serious illnesses such as cancer affect not just the person with the illness, but their family members and their intimate partner [50]. Cancer is destabilizing to the relationship system and invariably results in significant relationship reorganization and strain [51]. The rather modest collection of research examining online facilitation with cancer populations focuses predominantly on Internet-based support groups for patients (eg, [52-60]). Online interventions for couples dealing with cancer, however, are notably absent. This oversight is problematic given that cancer has a profound impact on both the individual and the relationship system.

A well-established finding is that younger, mainly premenopausal breast cancer survivors (age 50 or younger) and their partners are significantly more likely than older couples to experience relationship distress and poorer quality of life [61,62], and are more likely to continue experiencing declines in relationship functioning and quality of life 5 and 10 years after treatment completion [63,64]. Younger couples dealing with cancer experience multiple barriers to traditional counseling that limit the likelihood that these couples will seek support. Factors such as being in active cancer treatment may result in reduced inclination on the part of individuals to seek out couples counseling due to additional appointments, particularly if they are coping with the effects of treatment [65]. As well, younger couples tend to lead busier lives, as they juggle work and family commitments, and may have difficulty scheduling and obtaining professional support, particularly if they have young children [62,65-67]. Moreover, if offered in hospital settings, psychosocial support is likely limited to daily working hours, which may prove a challenge for caregiving partners based on their employment.

Such barriers were taken into consideration in the development of Couplelinks—a novel, professionally facilitated, asynchronous online intervention designed to enhance relationship adjustment and dyadic coping, and reduce individual distress of young couples affected by breast cancer. The program is based on the premise that partners in intimate relationships vary in the degree to which they feel identified with the relationship, also referred to as “couple identity” or “we-ness.” When partners experience their relationship as part of their sense of self, they are more likely to think about issues and events from each other’s perspective and view stressors as shared. Consequently, such partners engage in greater perspective-taking, empathy, and interpersonal support and therefore experience greater relationship satisfaction [68,69]. Greater levels of we-ness better equip couples to cope with various stressors related to breast cancer and therefore experience lower levels of individual and relational distress

[51,70]. Couples who construe the cancer as a shared problem are better able to engage in mutually supportive interactions that promote adjustment. Indeed, research has found that couples with higher levels of we-ness or dyadic coping in relation to breast cancer experience better adjustment (eg, [70-73]).

Couplelinks focuses on enhancing such we-ness through the use of experiential exercises designed to improve couples’ communication, perspective-taking ability, and mutual understanding and empathy in relation to breast cancer. The program is structured into 6 dyadic learning modules designed to be completed on a weekly basis in consultation with a Couplelinks facilitator through regular, asynchronous, online text-based communication at the end of every module. The Couplelinks facilitator, who is a mental health professional with experience in oncology, guides the couple throughout the program. Each weekly module assumes the following basic structure that the partners engage in on their own in the following order: (1) a theoretical component that explains a key relationship principle, (2) a dyadic, experiential exercise intended to assist the couple in grasping the principle, and (3) a feedback component that each partner is asked to complete on his or her own. The facilitator then reviews the modules and logs text-based feedback via the website. In addition to such online, asynchronous, text-based contact, the facilitator schedules phone check-ins with the couple after completion of Modules 2 and 4 to discuss any issues with the program and reinforce motivation and engagement with the program. The facilitator is also available as needed.

The weekly modules are broken down into steps, some of which are completed separately by each partner and some that are completed jointly as a couple. Typically, a module starts with activities that partners complete separately, followed by a dyadic activity that incites discussion and new learning for the couple. Such learning is consolidated in the last stage of the module when partners separately answer a series of questions assessing what the partners learned and what benefits they gained from completing the module, if any. Once both partners complete a module, an email notification is automatically generated and sent to their online facilitator who then logs in to a back-end administrative interface to review the couple’s entries to the dyadic learning module. The online facilitator provides tailored feedback on the couple’s responses to the module via the Dialogue Room, which is a 3-way virtual bulletin board embedded within the website. The partners receive an automatic email alert indicating that their online facilitator has provided them with feedback in the Dialogue Room and partners can only review the feedback by logging in to the secure Couplelinks website. The facilitator ends their feedback response with a description and explanation of the learning objectives of the upcoming module and a due date for its completion, typically a week from the date the feedback was sent. Although feedback is tailored to the couple and what they logged in their modules, a standard script of the description of the subsequent module is available to the facilitators in the facilitation manual [24] that can be tweaked to blend with the content of their feedback.

The Dialogue Room acts as a forum where participants and the facilitator can communicate with each other. For instance, the couple can raise concerns and ask questions as well as let their

facilitator know if they need more time or had something unexpected happen that will delay their progress. The facilitator can also use the Dialogue Room to check in with a couple if he/she has not heard from them and they are behind schedule. Facilitators log any interactions that occur with the couple outside the Dialogue Room in a section viewable in the administrative interface called “Contact Notes.” This section includes a summary of scheduled and unscheduled phone calls and emails. The module logs, Dialogue Room, and Contact Notes provide the basis with which to assess whether facilitators are adherent with the principles of facilitation as outlined in the treatment manual.

Online Therapeutic Facilitation of Couples

The Couplelinks facilitator’s role is to provide encouragement, safety, and a sense of structure through regular online communication with the couple. We conceived of the role of the Couplelinks facilitator as that of an expert guide who functions to support and encourage the couple’s learning process and enhances adherence to the program. The Couplelinks facilitator is a trained mental health professional with expertise in psychooncology and couple interventions.

Although not engaging in psychotherapy, the facilitator draws on his/her clinical skills and judgment when crafting customized feedback to the couple on completion of a dyadic learning module and as problems and unexpected situations occur, such as when the couple does not complete a dyadic learning module by the expected time or if one partner is less responsive than the other. We termed this style of facilitator-couple asynchronous online interaction as “therapeutic facilitation.” The term “facilitation” connotes providing assistance to move an action or process forward with greater ease. We see this term as accurately capturing the online facilitator’s role in the context of a primarily self-guided Web-based intervention, which includes assisting couples as they progress through the intervention by clarifying the objectives of each dyadic learning module, answering questions, providing psychoeducation, maintaining structure, encouraging commitment in order to maintain momentum, and validating and reinforcing the learning and insights derived by the couples from the exercises.

The underlying theoretically informed objective of Couplelinks, as described previously, is to enhance couple’s we-ness so that the couple perceives and approaches the cancer as a shared problem. Thus, the overarching goal for the online facilitator when formulating responses to validate couples’ insights and reinforce gains—whether textual or by phone—is to enhance their sense of the illness being a shared experience and accentuate their shared strengths and experiences around this stressor.

The reasoning for employing therapeutic facilitation in the Couplelinks program was based not only on the need to maintain adherence, but on the premise that couples experience the most benefit when *both* partners remain equally engaged and motivated in the program, are able to easily understand how to navigate the program, and feel they are on the right track in terms of their progress. Complex processes such as these cannot be programmed into a computer but require a skilled person on

the other end. Therefore, online facilitators play a necessary supporting role in structuring the exercises by drawing on their therapeutic skills to encourage the couple’s open discussion and commitment to the intervention and their shared progression through the program.

Given that the online facilitator is supporting the couple in proceeding through and benefiting from the exercises rather than providing couple therapy, the online facilitator does not engage in certain clinical techniques as an IP therapist would, such as directly challenging partners’ unconstructive behaviors or suggesting alternative interpretations of each other’s behaviors. Instead, emphasis is on skills such as highlighting what the couple shares, vis-à-vis the couple’s responses to the modules. For instance, the online facilitator encourages equal participation of both partners by consistently incorporating comments made by both couple members in their Dialogue Room feedback responses. Additionally, if partners provide differing opinions for dealing with a problem within their relationship and explicitly note their frustrations, like the IP therapist, the online facilitator might note the way in which partners approach problems differently by providing a response in their textual feedback, such as: “It sounds like, even though you may approach things differently, both of you are dedicated to figuring this out and resolving this issue that is causing both of you stress.” The online facilitator, however, does not engage in in-depth exploration of emotions, but frames feedback in such a way that highlights the couple’s strengths and insights gleaned from completing the exercises.

Facilitator Principles

To guide and standardize the delivery of online facilitation for the Couplelinks RCT, guiding principles and specific strategies were developed. The principles are not mutually exclusive; the facilitator often employs several of these strategies in a single response to a couple. All interactions described subsequently are asynchronous and occur via the Dialogue Room unless indicated otherwise (eg, phone call or emails). Research Ethics Boards of the institutions where the participants were being recruited approved of the Phase I and later Phase III trials. All participants enrolled in the trials were informed of the study objectives, risks, and consequences and consented to participate.

Collaboratively Developing a Timeline

During the introductory phone call, the online facilitator educates the couple on time commitments and the need to maintain a relatively weekly schedule in completing the exercises, encourages partners to come up with a tentative timeline for completing the dyadic learning modules, and to identify times during the week when they would complete the shared components of the dyadic learning modules. Although the program requires no more than 1 hour commitment per week, the added burdens associated with cancer can make even minimal obligations stressful and thus lessen the potential benefits of the program. The online facilitator encourages an open 3-way discussion that helps the couple examine all their current and upcoming obligations, and allows the facilitator to consider along with the couple how to work around any obstacles to their participation in the program, thus maximizing

the likelihood that they will complete the program and obtain the greatest degree of benefit.

Encourage Open Dialog Not Avoidance

Clearly communicating the online facilitator's willingness to hear the partner's feedback to the program, regardless of whether it is positive or negative, is key to establishing and maintaining open communication. The online facilitator cultivates an atmosphere of openness and curiosity about all aspects of the couple's experience. This means that online facilitators acknowledge and directly address couples' negative comments regarding the program. Importantly, this behavior also serves to model the concept of open dialog within the couple relationship. As well, although contact with the couple primarily occurs online via text, in order to maintain the couple's momentum and commitment to the program, we have found it essential that the online facilitator also use brief telephone consultations with couples as necessary. For instance, when there have been significant lapses in online communication, the online facilitator may call the couple to inquire as to what happened.

Create a Virtual Therapeutic Space

The online facilitator takes advantage of the convenience and accessibility of the online environment to create a safe, supportive therapeutic space in ways that are likely not possible in traditional psychotherapy, such as by responding promptly via the Dialogue Room to questions posted by couples. In contrast to IP therapists that are typically available on a weekly basis at a set time, online facilitators have the opportunity to be more accessible to couples throughout the week. Couplelinks online facilitators are expected to respond to couples' messages within 24 hours in order to demonstrate their commitment to couples' timely progress through the program as well as to model frequent engagement. The online facilitator communicates availability, presence, and commitment by responding quickly via text in the Dialogue Room as well as with phone calls, the latter being used if the couple is not responding via the Dialogue Room. Additionally, online facilitators are expected to log in to the administrative interface to review each couple's progress through the substeps of the module and whether it appears they will complete by the agreed-upon deadline, otherwise providing gentle reminders to encourage them to complete by the due date they agreed to in collaboration with their facilitator.

A common situation in which online facilitators' online communication serves the dual role of demonstrating their commitment to couples while also modeling genuineness and empathic caring occurs when couples fall silent. Online facilitators are expected to consistently check in with couples when there are unexpected lags between starting and completing an exercise, but do so in ways that are meant to be supportive and encourage accountability to the program. Such a situation provides the facilitator with the opportunity to openly acknowledge and express concern regarding the couple's silence, which often serves to strengthen the couple-facilitator relationship, reduce isolation, and foster program compliance. This also represents a critical moment when the facilitator can explore the barriers with a couple and problem-solve with the couple about ways to proceed.

Encourage Structured Flexibility

The online program allows the couple to participate in the privacy of their own home and set their own pace. Although the flexibility of an online program is an unquestionable strength, a lack of structure can also be a drawback in that partners may take the program for granted and easily delay completing the module. In this regard, the online facilitator's task is to strike the right balance between acknowledging the need for flexibility and setting agreed-upon deadlines. Couplelinks online facilitators are asked to employ a "friendly but firm" stance with couples right from the beginning of the program. For example, when online facilitators are orienting new couples to Couplelinks, they emphasize upfront how couples need to set aside time on a weekly basis to work through each module and encourage the couple's involvement in problem solving to carve out the time necessary to complete the exercises on a weekly basis. Including the couple in this discussion is meant to strengthen the couple's commitment and accountability to complete the program. Online facilitators also provide suggestions and help to problem-solve when obstacles arise (as they often do while undergoing or recovering from treatment) and solicit couple involvement in setting revised deadlines when existing ones are missed.

Engage Both Members of the Couple

In general, equally engaging both members of a couple can be difficult. When one member has initiated the process, the other member may view him- or herself on the periphery of the experience. This is a considerable risk in the context of breast cancer where many male partners, although often eager and willing to help their partners, may view themselves as sitting on the sidelines. In this sense, the online facilitator's objective during the introductory telephone call before they commence the program is to acknowledge each partner's individual experience of the disease and personal motivation for participation, highlight the impact of the disease on the couple, and articulate the invaluable and active role that a partner may play in a woman's recovery. On a weekly basis, a key aspect of the online facilitator's comments to the couple is acknowledgment and integration of *both* members' experiences as expressed in the feedback component for each module, which serves to reinforce the involvement and importance of both partners through the program.

In situations where one member of the couple initiates an email outside the Dialogue Room to the online facilitator without including the other partner, the online facilitator will include the absent partner in the reply to maintain the "3-way conversation" format. This is meant to minimize the formation of alliances with the online facilitator that excludes the other partner. Whenever possible, however, the online facilitator will utilize the Dialogue Room to respond to partner inquiries rather than resort to email communication because of the Dialogue Room's security features and because it automatically engenders the 3-way conversation format as it is always (and only) accessible to both members of the couple.

Reinforce New Learning

The online facilitator reviews module content and feedback and more clearly articulates and emphasizes emerging insights and positive experiences for the couple. This may involve the online facilitator accentuating insights that partners share about themselves, each other, their relationship, or a given module. This may also involve providing psychoeducation about the module as it pertains to the couples' reflections. Couples vary in terms of their strengths and areas of challenge. Therefore, some couples may indicate that they did not derive a shift in perspective as the module addressed an already established practice or strength in their relationship. In this case, the online facilitator demonstrates their attentiveness to what the couple is expressing by acknowledging and validating an existing relationship strength.

Manage Emotional Content

A diagnosis of breast cancer signifies a crisis in the life of a couple. The online facilitator must attend to, manage, and, if need be, contain the emotional content that emerges throughout the course of the program. This is done by constructing Dialogue Room feedback that validates and normalizes the range of emotional responses of couples to different aspects of the program and responding to strong reactions voiced by both or either partner in a supportive way. Where the emotional content is indicative of acute distress, the online facilitator highlights his or her availability to the couple through the Dialogue Room or by phone.

The Application of Facilitator Principles to Common Challenges

This section describes 4 common challenges in relation to online couple facilitation that came to light during the pilot study. The examples presented subsequently illustrate the ways in which the online facilitator used specific strategies related to the principles of facilitation described to increase the couples' engagement and address common challenges. The examples of online facilitator responses to couples are taken from the Couplelinks Program Facilitation Manual [24].

Challenge #1: Differential Involvement of Partners

As described previously, one challenge to consistent participation and the desired outcome of a strong bond within a couple is ensuring equal engagement by both members of the couple in the program. Partners vary in terms of their levels of awareness of the impact of cancer on their relationship as well as their interest and motivation to take part in the program. For couples dealing with breast cancer, it was fairly typical for a male spouse to indicate that even though he agreed to participate in the program, his decision to participate was largely motivated by a desire to support his partner (rather than help himself too). Although differential involvement of partners may also pose a challenge for "offline" counseling, the IP therapist has the added benefit of being able to physically observe the couple dynamic and has greater opportunity to directly address any discrepancy in the moment, which may not be as apparent to the online facilitator who is working via asynchronous communication. Therefore, it was critical that the online facilitator connect with

each member of the couple in "real time" over the phone, prior to program commencement, and use this time as an opportunity to highlight the way in which cancer creates havoc in both individuals' lives and profoundly impacts them as a couple, not just as individuals. In discussions with the less keen individual, the online facilitator helps him/her to identify how helping to reduce the partner's stress is personally meaningful and relevant to their daily life together.

Throughout the program, online facilitators encouraged equal involvement between both couple members by incorporating aspects of both partners' module feedback in crafting their own response to the couple. Such communication reflected engaging the couple individually and as a unit. For example, as illustrated in the following excerpt, the online facilitator highlights the individual and shared perspectives of a couple:

It looks like you both got something out of the module and were able to really appreciate each other's finer qualities, and the way in which you complement one another. I like [the female participant's] comment about how the exercise was a "confidence builder," and [the male participant's] recognition of your "collective strengths."

At times, partners expressed having had a different experience of a particular module. In such cases, the online facilitator recognized the discrepancy, but also looked for and highlighted common ground in their responses. For instance, Module 4 is an exercise designed to assist the couple develop a sense that cancer is a common enemy by having the couple create a shared metaphor in relation to the illness using image, collage, or poetry (see [70]). In their feedback to this module, one couple indicated that they viewed their journey quite differently. The female participant described how she "was surprised to see [the image]. Very different. I have heard that art therapy helps people so it's nice to see a more creative exercise" whereas her spouse commented that he found the exercise "...kind of boring, but [my partner] likes art so it was okay." In providing feedback, the online facilitator validated both perspectives and at the same time drew their attention to the fact that they were able to work together despite it not being desirable to one of the partners:

You two had quite a different reaction to this module exercise. [Male Participant], despite finding this module "kind of boring," you were able to join in with [Female Participant] and her enjoyment with this creative exercise, and come up with a shared concept together.

Challenge #2: Responding to Heightened Relationship Distress

Women with breast cancer and their partners, particularly younger couples, are understandably more distressed [62,66]. A couple can only cope as well as they have in the past, and coping with a diagnosis of cancer is especially complicated when there is preexisting relationship discord. The online facilitator's challenge is how to simultaneously validate the couple's feelings while containing their distress so that they may benefit from the program. In Module 1, which is intended to highlight a couple's individual and collective strengths, one woman identified preexisting relationship difficulties and shared how she felt upset by the exercise as "it was very evident to me

what our weaknesses are...it just highlighted for me how hurt I am and how hurt our relationship is.” Her male partner similarly voiced how he found the exercise difficult as it served to highlight the way in which “we need to work more on communication...I need to focus more attention on our relationship.” The online facilitator can incorporate a number of strategies in responding to such a situation, as demonstrated in the next few examples starting with the following that includes normalizing and empathetically responding to their distress:

It sounds like it was beneficial to a certain degree for the two of you to think about the positive qualities that you see in each other, as well as the strengths of your relationship, which can be especially difficult to do during stressful times. On the other side, sometimes sitting down to examine even positive aspects of the relationship can draw attention to the more difficult parts. It sounds like this happened to some degree for both of you.

By providing psychoeducation about the module and the program in general, the online facilitator tried to motivate the couple to persist and assure them that the program could provide them with an opportunity to work on their communication skills. The online facilitator also tried to unite the couple by drawing their awareness to the degree that they share in the concerns about their relationship:

Looking at your relationship a little more closely, and the way you interact, is a big part of this program—and you’ll see the exercises are designed to get both of you to do this. We believe that the first step to improving the relationship is being able to take a good look at it—what is working and what can be improved. The first few exercises focus more on building that relationship awareness so that you can communicate and problem-solve better in the long run. Nevertheless, I am glad to see that you were able to identify some meaningful attributes in each other and the relationship. It seems that both of you are aware that communication is an area in your relationship that needs attention. While enhancing communication is an implicit part of each module, there is one module in particular that explicitly focuses on this and provides specific guidance.

In addition to the preceding feedback, the online facilitator reiterated her availability to the couple, both online and by telephone. Although they did not seek out greater involvement, it is important for participants to know that this is an option. In addition, the online facilitator highlighted how she viewed the couple’s willingness to engage in this process, and look at their own behavior, as positive:

Although it seems like this was a difficult exercise on a certain level, it is excellent that you, [Male Participant], were able to identify what you could be working on as a couple, and also in terms of modifying your own behavior.

Challenge #3: Reinforcing Virtual Connection and Overcoming Silence

The convenience of an online program can also be a drawback as the lack of IP contact may engender less accountability. Some couples tend to delay completion of the weekly modules and fall out of touch. In order to keep such “straggler” couples engaged and avoid disconnecting from the program, the online facilitator reinforces structure and commitment to the program by communicating his or her own commitment, presence, and availability on a regular basis. The online facilitator’s responses are meant to encourage a couple’s progress while not seeming overly demanding. For instance, when a couple did not complete their module as scheduled, the online facilitator sent the following response:

Hi [Female Participant] and [Male Participant]—I haven’t heard from you in a while so just wanted to check in and see how you are doing. Please touch base whenever you have a moment, even if it is just to let me know that you have been busy. I look forward to hearing back from you.

The goal of such a communication is to express the way in which any response is preferable to no response and to open the door to communication.

The online facilitator will also send “gentle reminders” and assume that in the case of silence the couple may be having difficulty carving out some time in their schedule to do the exercise. At times, however, the couple may require more than a gentle reminder and when a couple has not responded to online communication, telephone contact initiated by the online facilitator is necessary. Similar to IP counseling, in connecting with the couple, the online facilitator communicates from a nonjudgmental, curious, and supportive stance. This means, for example, that she is open to hearing and accepting with respect to the couple’s reasons for delays, even if it is critical of some element of the program, and tries to best support the couple in order to help them overcome any obstacles that they are facing. As well, the online facilitator can review a couple’s progress within a module and send them a message validating the steps that they have completed and highlighting what remains to be done as a way of signaling her engagement with them.

Challenge #4: Health Concerns and Changes in Health Status

Breast cancer tends to be more aggressive, more likely to recur, and more fatal in younger women [74-76]; hence, the possibility of a change in health status and ongoing worry with respect to health are very real concerns for this population. Thus, the online facilitator needs to be prepared to sensitively address such a situation by empathizing with the distress, giving the couple time to recover, and encouraging program continuance when the concerns have been resolved. This situation emerged for 2 couples during the pilot phase of the project. In one case, the male participant of one couple directly communicated his concerns to the facilitator:

Sorry for the delay but we have had a bit of a fright. [My wife] found a lump on her neck which is a swollen lymph node and had an ultrasound, at which point the doctors decided that a biopsy is best. It looks suspicious. We are very worried as you

can imagine and this is a priority right now...touch base with us in a week or two and we'll let you know how things are going. I don't think we will be doing the exercises until we know what the story is. I hope you understand.

The online facilitator addressed this email immediately with a response that reflected support and concern for the couple:

Thanks for letting me know. I am very sorry to hear that. I will be thinking of the two of you and sending warm thoughts.

Given the magnitude of the concern, rather than following up with the couple through the Dialogue Room, the online facilitator called the couple a few weeks later to check in. Thankfully, the results of the female participant's tests were clear. The couple expressed how stressed they had been and seemed grateful for the opportunity to discuss the stress they had undergone in the past few weeks. They also indicated that they were ready to resume with the program and the online facilitator sent them a message through the Dialogue Room letting them know that she set them up for the next module. This message allowed the online facilitator the opportunity to emphasize their we-ness in the very real and recent dealings with the fear of recurrence:

Whew! I am so relieved and happy to hear for the two of you that everything is okay, and the results were clear. I am sure that the two of you are very relieved. Doctor's orders—please go out and celebrate! Feel free to start the next module at any time. I hope that this will be a good creative outlet for the two of you, and it will be interesting to see the way in which the two of you represent your shared experience especially given what you've just been through. Kindest regards and thinking of you both!

Another point to note here is the online facilitator's appropriate use of humor within the framework of employing her skills as a clinician to support and empathize with the couple, while also keeping them on task with respect to their progression through the program. Also, she suggests that the next module may be a way for the couple to process their recent difficult experience in relation to cancer thereby demonstrating how preestablished

exercises may be positioned to incorporate fluidly the couples' fluctuating experiences and corresponding needs. Although health concerns may arise similarly in IP approaches, it is important to note that in an online intervention where there is no set appointment time and the online facilitator is remote, couples may find it easier to delay their involvement while facing a health crisis, making it important for the online facilitator to communicate her patience, empathy, and availability to the couple.

Conclusion

To date, there has been very little discussion in the online intervention literature on the role of the online clinician, particularly using asynchronous interaction. An online facilitator in the context of online couple interventions is particularly important to manage engagement of both partners and maximize the couple's learning. We propose that online therapeutic facilitation—a supporting role of the online clinician that (in the case of Couplelinks) focuses on encouraging the couple's bond as well as adherence to the intervention—is a useful clinical construct to guide more effective online therapist involvement with couples. Therapeutic online facilitation of couples is distinct from IP couple interventions, the latter being more intense and often entails more liberal use of interpretation and inference. However, online facilitators have several other tools at their disposal that can enhance outcomes, such as being able to review progress made by the couple as well as being available for immediate feedback and support at any time throughout the week. The clinical perspective on online facilitation presented here was derived over the course of developing and applying an online intervention for couples affected by breast cancer. Research on whether adherence to such principles contributes to outcomes has yet to be evaluated. Nonetheless, the principles presented here may offer guideposts for clinicians in the process of developing an online support program entailing asynchronous interaction between client and facilitator, stimulate discussion with respect to the theoretically necessary components of online facilitation, and identify research questions for future studies.

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Conflicts of Interest

None declared.

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Abbreviations**IP:** in-person**RCT:** randomized controlled trial

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Original Paper

Blog Posting After Lung Cancer Notification: Content Analysis of Blogs Written by Patients or Their Families

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Abstract

Background: The advent and spread of the Internet has changed the way societies communicate. A portion of information on the Internet may constitute an important source of information concerning the experiences and thoughts of patients and their families. Patients and their families use blogs to obtain updated information, search for alternative treatments, facilitate communication with other patients, and receive emotional support. However, much of this information has yet to be actively utilized by health care professionals.

Objective: We analyzed health-related information in blogs from Japan, focusing on the feelings and satisfaction levels of lung cancer patients or their family members after being notified of their disease.

Methods: We collected 100 blogs written in Japanese by patients (or their families) who had been diagnosed with lung cancer by a physician. These 100 blog posts were searchable between June 1 and June 30, 2013. We focused on blog posts that addressed the lung cancer notification event. We analyzed the data using two different approaches (Analysis A and Analysis B). Analysis A was blog content analysis in which we analyzed the content addressing the disease notification event in each blog. Analysis B was patient's dissatisfaction and anxiety analysis. Detailed blog content regarding patient's dissatisfaction and anxiety at the individual sentence level was coded and analyzed.

Results: The 100 blog posts were written by 48 men, 46 women, and 6 persons whose sex was undisclosed. The average age of the blog authors was 52.4 years. With regard to cancer staging, there were 5 patients at Stage I, 3 patients at Stage II, 14 patients at Stage III, 21 patients at Stage IV, and 57 patients without a disclosed cancer stage. The results of Analysis A showed that the proportion of patients who were dissatisfied with the level of health care exceeded that of satisfied patients (22% vs 8%). From the 2499 sentences in the 100 blog posts analyzed, we identified expressions of dissatisfaction and anxiety in 495 sentences. Our results showed that there were substantially more posts concerning "Way of living, reasons for living, set of values" and "Relationships with medical staff (own hospital)" than in previous studies (Analysis B).

Conclusions: This study provides insight into the feelings of dissatisfaction and anxieties held by lung cancer patients and their families, including those regarding the "Way of living, reasons for living, set of values" and "Relationship with medical staff (own hospital)," which were inaccessible in previous survey analyses. When comparing information obtained from patients' voluntary records and those from previous surveys conducted by health care institutions, it is likely that the former would be more indicative of patients' actual opinions and feelings. Therefore, it is important to utilize such records as an information resource.

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KEYWORDS

blog; lung cancer; notification; content analysis; communication; Internet

Introduction

The advent and spread of the Internet has fundamentally changed the way societies communicate in recent years. In an analysis of websites, blogs, and social networking sites [1], Japan's Ministry of Internal Affairs and Communications reported a surge in the number of online blogs published in Japan between 2004 and 2005. The number of blogs passed the 10 million mark in January 2006, and has since continued to increase steadily. In 2007, blog search engine company Technorati revealed that blog posts written in Japanese were the most prevalent throughout the world, accounting for 37% of the world's total (approximately 70 million blog posts) and surpassing the number of English-language posts (36%) [2]. A portion of these blog posts may constitute an important source of information concerning the experiences and thoughts of patients and their families. Looking into personal articles on social networking sites may indicate particular and specific problems. However, the collection of such particular claims from individuals may be able to provide a broader view of patients' experience. At the same time, the rumors spreading through social networking sites are very effective [3], and it is reasonable to prevent the negative reputation of the hospital by paying attention to such social networking sites' articles.

Approximately 40% of people in the United States have been reported to obtain health-related information through the Internet and email [4]. A similar proportion (39%) was reported in a survey conducted in Japan [5]. According to that survey, many frequent users of the Internet are women, are in good health, are aged in their 20s and 30s, earn annual salaries of US \$30,000 or more, and possess at least a high-school education. Among these Internet users, approximately 68% responded that the information acquired online helped to improve their understanding of symptoms, conditions, and treatments. In addition, more than 60% of Internet users reported an increased sense of assurance after acquiring health-related information. However, almost 84% of respondents reported no attempts to inform health care professionals about their online acquisition of information [5].

An analysis of daily posts regarding common cancers on blogs and discussion forums showed that posts concerning breast cancer were the most frequent, followed by prostate cancer, colon cancer, and lung cancer [6]. Most of these posts (65.8%) were published on media sites, whereas blog posts accounted for approximately 15%. These studies underline the growing trends in acquiring health-related information online, and the Internet is expected to fulfill an increasingly important role as an information source in the future.

The Internet is also garnering attention for its potential applications in accessing and applying information posted by patients or their families as a means of gaining insight into their experiences and thoughts. According to a study by Kim and Chung [7], patients and their families use blogs to obtain updated information, search for alternative treatments, facilitate

communication with other patients, and receive emotional support. However, much of this information has yet to be actively utilized by health care professionals. Recently, there has been an increase in the number of patients who, after receiving treatment, publish their experiences and sentiments online through blogs. This trend represents an important opportunity for health care professionals to become more aware of patients' complaints. Although health-related information acquired online is not a viable replacement for direct communication with a health care professional, this information may fulfill a supplementary role in facilitating patient understanding.

In 2011, a total of 357,305 patients (213,190 men and 144,115 women) in Japan died due to malignant neoplasms, with the prevailing cancers being those of the trachea, bronchi, and lungs (70,293 deaths) [8]. It is no longer unusual for people in Japan to know or to have lost close relatives with cancer. A previous study [9] has shown that diagnosing and notifying patients with cancer did not increase patient pain or feelings of anxiety. However, many cases of lung cancer are already at advanced stages upon detection, and notifying patients of their condition can have an immense effect on their psychological well-being. Therefore, health care professionals should notify their patients about their health status after careful consideration, while also being aware of the sensitivity of the issue. According to a Patient's Behavior Survey conducted by the Japanese Ministry of Health, Labour and Welfare (MHLW) in 2011 [10], 86.1% of outpatient respondents and 92.3% of inpatient respondents reported that they had been briefed by physicians about the medical care and treatment strategies for their disease. In addition, 96.6% of outpatient respondents and 93.7% of inpatient respondents stated that they had understood these briefings. By contrast, the proportions of respondents who felt that they were sufficiently able to communicate their inquiries and opinions about these briefings to their physicians were substantially lower, at 68.7% and 62.8% in outpatients and inpatients, respectively. It is therefore difficult to state that the current level of physician-patient communication in Japan is adequate.

Although numerous papers on doctor-patient relationship or interaction have been published [11], these have mainly focused on their conversation [12], and several studies have pointed out that the authority of the medical staff might have kept the patient rather quiet [13]. This suggests that the patients cannot express their true feelings in front of their medical staff, and thus, their anxiety remains under the surface.

Whereas the positive nature of health care systems makes it difficult to incorporate patient complaints and opinions, clinical trials that include patient-reported outcomes have begun to sporadically appear, such as in cancer chemotherapy trials [14]. This shift reaffirms the necessity of understanding patients' complaints [15], and it is important to provide a channel for patient opinions to be heard in various settings where physicians and patients would otherwise have limited direct communication.

Although online blog posts are likely to encompass various biases, such as the bias that exaggerates the negative impression of medical care provided, it is important to focus on the fact that there are so many anxieties that patients have to face, but unable to express in front of their medical staff or any other people they deal with. Therefore, it is necessary to reduce as much anxiety of patients as possible for their better quality of life. These blog posts may contain important information such as the preferences, misgivings, and satisfaction levels of patients and their families. This allows health care providers to gain greater insight into previously inaccessible information. In this study, we analyze health-related information in blogs from Japan, focusing on the feelings and satisfaction levels of lung cancer patients or their family members after being notified of their disease.

Methods

Sample Selection

In this study, we focused on blog posts written in Japanese and published by patients (or their families) who had been diagnosed with lung cancer by a physician. The study protocol was approved by the Kyoto University Graduate School and Faculty of Medicine Ethics Committee (No 1070) on January 10, 2014.

Selection Criteria

We analyzed blogs written by lung cancer patients or their families whose blog posts were searchable between June 1 and June 30, 2013. We focused on blog posts that addressed the lung cancer notification event. *Families* were defined as patients' relatives living together with the patient or those within three degrees of kinship.

Exclusion Criteria

Blogs without posts that addressed the lung cancer notification event were excluded from analysis. Determining whether a blog had included a post about disease notification was analyzed by two investigators working independently and blinded to each other's results. Blogs were also excluded if the post addressing disease notification had been published 3 years or more after the notification event.

The *notification event* in this study was regarded as the moment when the patient or his/her family (or both in some cases) was revealed that the patient had malignant tumor. We did *not* consider the notifications by comedical staff and/or those after re-examination.

Data Collection

Overview

Data were collected using two methods, namely, by Internet search and via link-collection website. These methods are described in the following sections.

Method 1: Internet Search

We searched for various permutations of the following terms in Japanese using the Google search engine: "lung cancer," "record of struggle against disease," "blog," and "journal." We

collected information from blogs addressing people's struggles with lung cancer within the top 500 search results. However, we excluded sites containing duplicate identical entries with different dates and sites that were not blogs.

Method 2: Link-Collection Website

The TOBYO website [16] hosts a collection of links for Japanese blogs documenting people's struggles with disease. Using this website, we collected information in the order of newest blog entries first. The TOBYO website collects and posts links to blogs that fulfill the following criteria:

- Blogs that contain an adequate amount of information addressing a person's struggle with disease (including 10 screen pages or more of such information).
- Blogs that do not sell health foods or supplements, attempt religious proselytization, or solicit readers to join political/patient advocacy organizations or health care institutions.
- Blog sites that are appropriately constructed (ie, websites do not include excessive advertisements or Web animations).

The number of blogs that we could use in this research filtering by applying Methods 1 and 2 was 150 blogs written by 150 lung cancer patients and/or their family members.

Detection of Notification Event

We extracted the blog entries that indicated the moment of notification. The entries were handpicked, and of the 150 blogs, we obtained 100 articles that contained notification event.

Data Formatting

We broke down the 100 blog articles into multiple sentences, based on punctuation and some specific expressions, such as smiley, which Japanese people considered as the end of the sentence. The average number of sentences per one blog article was 25.

Study Items

Overview

We analyzed the data using the following two approaches: Analysis A, which was conducted using individual blogs as the unit for study; and Analysis B, which was conducted using individual sentences within blog posts as the unit for study.

Analysis A: Blog Content

We analyzed the content addressing the disease notification event in each blog. Qualitative data items (sex, age, date of disease notification) were coded by allocation to a category or assignment of a numerical value. For cases where patient age was ambiguous, age was estimated using the available information. For example, patients who stated that they were in their "mid-30s" were included in analysis as being 35 years of age. Because only the author's information is provided within the posted articles, we completely reviewed the articles and extracted the necessary information, such as age, gender, stage. The information extracted is presented in [Table 1](#).

Table 1. Results of coding of the blog content (n=100 blogs).

Coding items	Sex			Total
	Men	Women	Undisclosed	
Date of blog post relative to disease notification date				
Not indicated	4	4	2	10
Identical to notification date	10	7	1	18
After notification date	34	35	3	72
Blog author				
Patient	30	24	3	57
Family member	18	22	3	43
Person who received notification				
Not indicated	14	16	3	33
Patient only	20	12	2	34
Family member(s) only	4	4	0	8
Both patient and family member(s)	10	14	1	25
Person who requested notification				
Not indicated	33	33	3	69
Patient only	0	1	0	1
Family member(s) only	0	0	0	0
Both patient and family member(s)	2	3	1	6
Based solely on physician discretion	13	9	2	24
Family history of cancer				
Not indicated	47	44	6	97
Yes	1	2	0	3
No	0	0	0	0
Cancer stage at notification				
Not indicated	26	29	2	57
Stage I	2	3	0	5
Stage II	3	0	0	3
Stage III	6	6	2	14
Stage IV	11	8	2	21
Type of medical treatment				
Not indicated	21	21	4	46
Surgery	5	10	1	16
Radiotherapy	2	2	0	4
Combination of radiotherapy and chemotherapy	4	4	0	8
Chemotherapy	14	9	1	24
Alternative therapies	1	0	0	1
Combination of radiotherapy and alternative therapies	1	0	0	1
Patient actions after notification				
Not indicated	32	33	5	70
Retrieved information from the Internet and books	6	5	0	11
Arranged their personal affairs	1	0	0	1
Informed family members	1	2	0	3

Coding items	Sex			
	Men	Women	Undisclosed	Total
Informed nonfamily members (eg, employer)	0	1	0	1
Started their blog	6	1	0	7
Closed down their blog	1	0	0	1
Commenced treatment approaches different to their physician's recommendation	0	2	0	2
Combination of several of the above actions	1	2	1	4
Satisfaction toward health care				
Not indicated	30	34	5	69
Dissatisfied with physician's treatment	6	7	0	13
Dissatisfied with provided care	4	0	1	5
Dissatisfied with both physician's treatment and provided care	2	2	0	4
Satisfied with physician's treatment	4	1	0	5
Satisfied with provided care	1	0	0	1
Satisfied with both physician's treatment and provided care	1	1	0	2
Dissatisfied with physician's treatment but satisfied with provided care	0	1	0	1

The two coders coded each sentence by hand, and they did not use lexical items. They used the Shizuoka Classification System categories as a reference and labeled every sentence with the category. The Shizuoka Classification System has been built based on the 7885 cancer patients' complaints (made via phone calls) received by the Shizuoka Cancer Center. All complaints were sorted by hand, and were summarized into 20,000 descriptions of the patients' anxieties and burdens. These were then divided into 15 primary categories, 35 secondary categories, 129 tertiary categories, and 623 micro categories.

- First, the coders estimated whether the sentence contained any content regarding dissatisfaction and anxiety (binary classification).
- Second, they classified the sentences with dissatisfaction and anxiety information according to the Shizuoka Classification System (multilabel classification).

The two coders first worked on the material independently using a small dataset (120 sentences) to see how much agreement they could obtain. They obtained a high percentage of agreement (98/120, approximately 82%), and the conflicts were finally resolved by discussion. As mentioned earlier, the coding procedure was performed independently by two individuals, and discrepancies in coding were resolved after obtaining consensus through discussions. In addition, several codes, such as the coding for "satisfaction toward health care," were anticipated to be relatively subjective. We therefore examined the inter-rater agreement before obtaining consensus using the kappa coefficient. Kappa coefficient values were interpreted as follows: <0, No Agreement; .01-.20, Slight Agreement; .21-.40, Fair Agreement; .41-.60, Moderate Agreement; .61-.80, Substantial Agreement; and .81-.99, Almost Perfect Agreement [17].

Analysis B: Patient's Dissatisfaction and Anxiety

Detailed blog content regarding patient's dissatisfaction and anxiety at the individual sentence level was coded and analyzed. First, an analysis was conducted to identify whether dissatisfaction or anxiety was addressed in each of the sentences in the targeted blog posts (2499 sentences in the 100 blog posts). Next, sentences addressing dissatisfaction and anxiety were categorized according to the type of misgiving described. The sentences were categorized according to the Shizuoka Classification System, which was developed by the Shizuoka Cancer Center, Japan. The Shizuoka Classification System is based on the results of a national survey conducted by the Joint Study Group on the Sociology of Cancer. In that survey, the various dissatisfactions and anxieties of 7855 patients were organized and grouped into a structured hierarchy of indicators beginning with 15 primary categories that were further subcategorized [18]. In this study, we only used the 15 primary categories. This coding procedure was performed by a single individual. However, the following five items from the Shizuoka Classification System were expected to include content that could be interpreted in several ways: "Diagnosis/treatment," "Notification, informed consent, second opinion," "Anxiety and other mental problems," "Way of living, reasons for living, sense of values," and "Relationships with family and other people." For these categories, coding was performed by two individuals, and the kappa coefficient was used to analyze inter-rater agreement in 250 sentences among the 2499 sentences (approximately 10% of the data). Discrepancies in coding were resolved after obtaining consensus through discussions by the authors. Because the inter-rater agreement was high (kappa coefficient=.67), the remaining 2259 sentences among the 2499 sentences (approximately 90% of the data) were coded by a single individual.

Results

Overview

Using Method 1, we identified 58 eligible blogs; using Method 2, we identified 92 eligible blogs. However, we excluded 50 blogs that did not have entries addressing disease notification, and thus, a total of 100 blogs were used in the final analysis.

Analysis A: Blog Content

Table 1 shows the results of the final coding, in which nine coding items were used. The 100 blog posts were written by 48 men, 46 women, and 6 persons whose sex was undisclosed. The average age of the blog authors was 52.4 years. A higher proportion of the blogs (57%, 57/100) were written by the patients themselves, with 43% (43/100) written by family members. With regard to cancer staging, there were 5 patients at Stage I, 3 patients at Stage II, 14 patients at Stage III, 21 patients at Stage IV, and 57 patients without a disclosed cancer stage. There was a moderate level of inter-rater agreement in the coding for “satisfaction toward health care” ($\kappa=.58$). The results showed that the proportion of patients who were

dissatisfied with the level of health care exceeded that of satisfied patients (Unclear, 69/100, 69%; Satisfied, 8/100, 8%; Dissatisfied, 22/100, 22%; and Elements of both satisfaction and dissatisfaction, 1/100, 1%).

Analysis B: Patient’s Dissatisfaction and Anxiety

From the 2499 sentences in the 100 blog posts analyzed, we identified expressions of dissatisfaction and anxiety in 495 sentences. The results of this classification are presented in Table 2. In addition, the detailed points of patient’s dissatisfaction and anxiety are presented in Table 3. There was substantial inter-rater agreement for the five possibly ambiguous categories, with an average kappa coefficient of .67 (Table 4). The following expressions of dissatisfaction and anxiety were commonly noted in these 495 sentences: “Way of living, reasons for living, sense of values” (28.1%, 139/495), “Notification, informed consent, second opinion” (25.9%, 128/495), and “Diagnosis/treatment” (17.0%, 84/495). Our results showed that there were substantially more posts concerning “Way of living, reasons for living, sense of values” and “Relationships with medical staff (own hospital)” than in previous studies (Figure 1).

Table 2. Results of classification of patient’s dissatisfaction and anxiety in 495 sentences (n=100 blogs).

Category	Categories and their description	n (%)
1	Outpatient	9 (1.8)
2	Hospitalization/discharge/hospital change	18 (3.6)
3	Diagnosis/treatment ^a	84 (17.0)
4	Palliative care	12 (2.4)
5	Notification, informed consent, second opinion ^a	128 (25.9)
6	Medical coordination	1 (0.2)
7	Home care	3 (0.6)
8	Facility and equipment/access	1 (0.2)
9	Relationships with medical staff (own hospital)	27 (5.5)
10	Relationships with medical staff (other hospitals)	1 (0.2)
11	Symptoms, side-effects, after-effects	26 (5.3)
12	Anxiety and other mental problems	33 (6.7)
13	Way of living, reasons for living, sense of values ^a	139 (28.1)
14	Work, economic burdens	0 (0)
15	Relationships with family and other people	13 (2.6)

^aTop three classifications used in this research

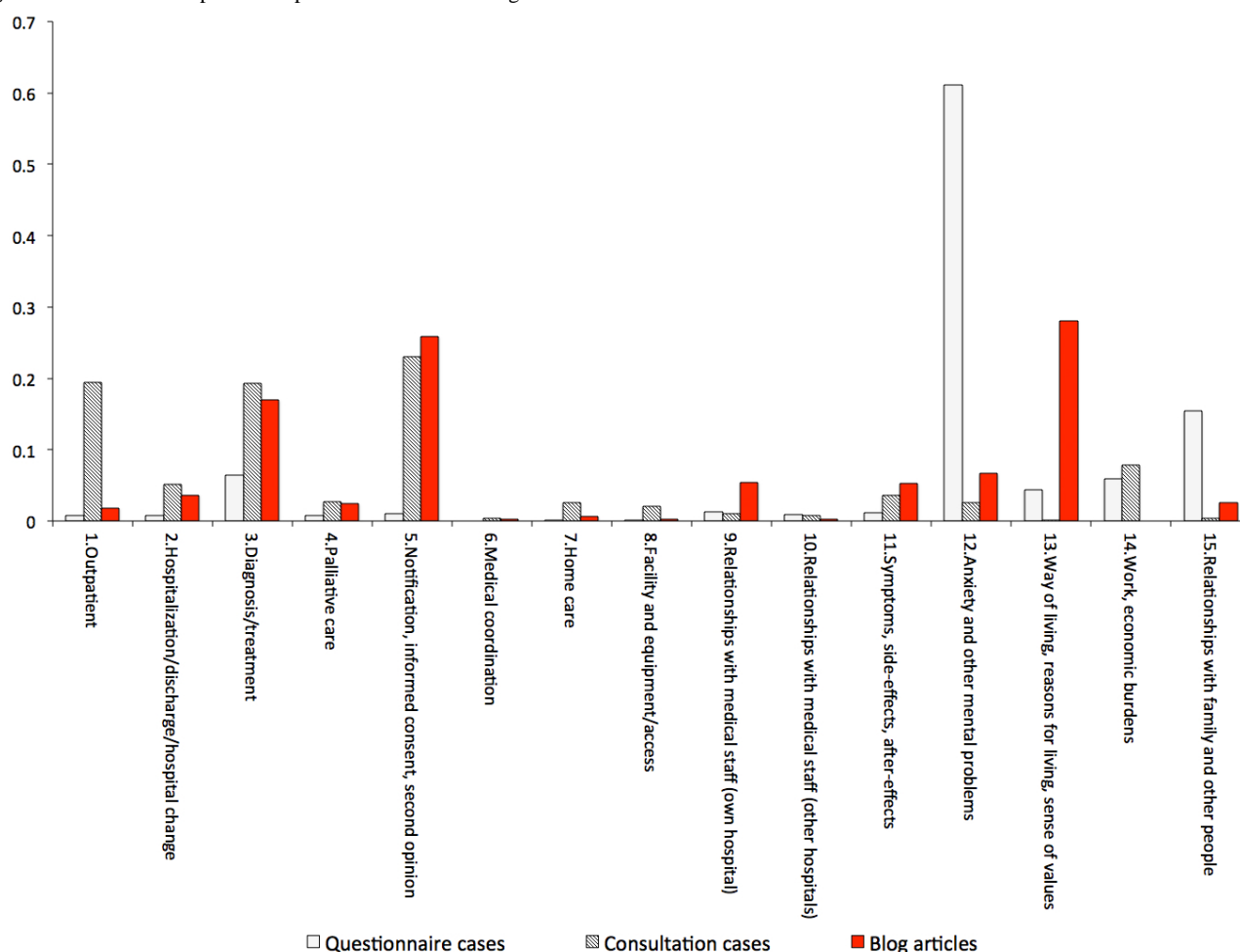
Table 3. Some examples of the actual social networking site posts by patients and their family members (n=100) with Shizuoka Classification System categories.

Shizuoka Classification System category	Posts by the patients
3	“For the first time, I thought I wanted to die...”
3	“I asked what would happen if I left the way as it was, and the answer was I would die within 2 to 3 months, besides, it might be no use even if I had the treatment.”
5	“Mother begged, ‘Please give me a day to think about it’, but the doctor said she did not have much time left for that.”
5	“The doctor told us, ‘I think it is most likely cancer’, and it might have been the notification towards my husband and I. I felt very uncomfortable that he didn’t make it clear that it actually WAS cancer.”
13	“I still have so much I want to do before I die.”
13	“I had a strong will to be cured completely.”
15	“But I pretended I did know nothing in front of my family when I was notified that I only have 1 year left.”
15	“When should I tell my children that I have lung cancer.”

Table 4. Kappa coefficient values of five primary categories in the Shizuoka Classification System.

Category	Description	Statistics ^a	Coefficient value ^a
3	Diagnosis/treatment	.44	Fair agreement
5	Notification, informed consent, second opinion	.71	Moderate agreement
12	Anxiety and other mental problems	.88	Substantial agreement
13	Way of living, reasons for living, sense of values	.69	Moderate agreement
15	Relationships with family and other people	.61	Moderate agreement

^aThe average kappa coefficient obtained was .67, with “moderate agreement” coefficient value.

Figure 1. Results of comparison of previous studies and blog articles.

Discussion

Analysis A: Blog Content

A survey conducted by the MHLW [10] reported that the number of outpatient respondents who were satisfied (49.7%) with the overall care was much higher than those who were dissatisfied (4.4%). By contrast, our analysis—which was not limited to surveys conducted on the day of cancer notification—revealed a large proportion of patients who were dissatisfied with the level of care provided, particularly with regard to their treatment by physicians (13%, 13/100). This proportion of dissatisfied patients was 5 times higher than in the survey conducted by the MHLW. When taking into account the previous discovery that 84% of patients did not share their knowledge of health-related information with health professionals, these findings indicate a lack of active communication between patients and health care providers in Japan. This also suggests the possibility that patients are seeking to voice their opinions through other media. In particular, our study shows the reactions and feelings toward lung cancer notification in middle-aged to senior patients (average age, 52.4 years) who utilize the Internet (with 57%, 57/100, of blog posts written by the patients themselves).

Our analysis focuses only on blog entries that address the lung cancer notification event, where it would be unlikely for patients to express satisfaction toward health care providers. Even among

patients who felt dissatisfied with their treatment by physicians during the notification event, it is possible that the feelings of dissatisfaction would shift to feelings of satisfaction if the patients were surveyed again at a later date. As a result, patients' relationships with health care professionals should be regarded an important determinant of patient's satisfaction level when considering the previously reported high levels of satisfaction.

This study has dealt with the very moment of notification, because it is the point at which the patients' lives have been literally changed, and the articles analyzed were posted not only by the patients themselves but also by their family members, which shows that the cancer notification has a significant impact on the family members as well. This research showed and suggested that after notification, additional supports are required for family members as well.

There are some limitations in this study. Because the prevalence of lung cancer is generally higher in older people, it is likely that the blog authors included in this study are not representative of the overall lung cancer patient population, but instead reflect the feelings of a specific group. The blog post authors represent a group of people who are able to publish such information, and it is therefore necessary for future studies to also include the experiences from patients who are unable to utilize this form of media. A survey regarding the information sources for health-related information in Japan found that approximately 39% of respondents used the Internet or email, with the majority

of these users being in their 20s and 30s [5]. However, as the computer-literate population ages and the use of the Internet continues to spread, there will be a higher proportion of persons in their 50s or older who acquire health-related information online, which subsequently will increase the number of eligible study patients.

Analysis B: Patient's Dissatisfaction and Anxiety

According to a survey conducted by the MHLW [18], patients may or may not seek counseling for a specific disease-related anxiety, depending on the type of concern. For example, patients may actively discuss their treatment options with health care professionals. However, patients may presume that discussions related to symptoms or drug adverse effects would not help to solve these issues, and may therefore choose not to discuss these points with health care professionals despite addressing them in survey responses. Survey items (according to the Shizuoka Classification System) that are not usually discussed include "Symptoms, side-effects, after-effects," "Anxiety and other mental problems," "Way of living, reasons for living, sense of values," and "Relationships with family and other people." In addition, although responses for "Way of living, reasons for living, sense of values" and "Relationships with medical staff (own hospital)" were generally unobtainable in previous studies, our results showed that these important points of anxiety were addressed in blogs. There was a substantially higher number of blog posts that included dissatisfaction and anxieties related to "Way of living, reasons for living, sense of values" after the

lung cancer notification event, indicating that the notification had a considerable effect on patients' approaches to living and their sense of values.

Patients may be unwilling to describe their misgivings in their relationships with current health care providers in surveys conducted by the providers themselves. As a result, when considering patients' efforts to seek alternative treatments or engage in "doctor shopping," voluntary records of patients' opinions are likely to be better indicators of their actual feelings when compared with surveys conducted by health care institutions. In the future, it would be advantageous to develop an automated sampling system that could identify patients concerns regarding their interactions with health care institutions from written content.

Conclusions

This study provides insight into the feelings of dissatisfaction and anxieties held by lung cancer patients and their families, including those regarding the "Way of living, reasons for living, sense of values" and "Relationships with medical staff (own hospital)," which were inaccessible in previous survey analyses. In this analysis, we were able to obtain precise statistics at the point of cancer notification. When comparing information obtained from patients' voluntary records and that from previous surveys conducted by health care institutions, it is likely that the former would be more indicative of patients' actual opinions and feelings, and it is therefore important to utilize such records as an information resource.

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Authors' Contributions

AS and EA conceived the basic strategies. ST and KK supervised the project. YS performed profile analysis with programs developed with EA. AS and EA designed experiments, analyzed data, and wrote the paper.

Conflicts of Interest

None declared.

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Abbreviations

MHLW: Ministry of Health, Labour and Welfare

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Original Paper

Availability of Information About Lifestyle for Cancer Survivors in England: A Review of Statutory and Charitable Sector Organizations and Cancer Centers

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Abstract

Background: Health behavior change following a cancer diagnosis has the potential to improve long-term outcomes. However, many patients do not receive professional advice about lifestyle and are therefore increasingly using the Internet to seek further information. The statutory and charitable sectors and cancer centers all play an important role in the provision of information and have been found to be favored by cancer survivors searching for information. However, to date there has been no systematic evaluation of the lifestyle information available online for cancer survivors.

Objective: The purpose of this review was to identify the lifestyle information provided for cancer survivors by statutory and charitable sector organizations and cancer centers in the United Kingdom. We aimed to identify information on tobacco, physical activity, diet, weight, and alcohol designed for people who have been diagnosed with breast, prostate, or colorectal cancer.

Methods: The National Health Service (NHS) website was the focus of the search for information provided by the statutory sector. Cancer centers were identified from the Organization of European Cancer Institutes and an Internet search, and charitable sector organizations were identified by searching the Charity Commission database. The three largest generic, breast, prostate, and colorectal cancer charitable organizations were included. A systematic search of the organizations was conducted to identify lifestyle information for cancer survivors.

Results: Ten organizations had some lifestyle information for cancer survivors on their websites. The Christie NHS Foundation Trust, Macmillan Cancer Support, and Prostate Cancer UK had the most comprehensive guides, covering physical activity, diet, weight management, smoking, and alcohol. The NHS website did not provide any information but had a link to Cancer Research UK's information about diet. Eight organizations suggested talking to a health professional before making any changes.

Conclusions: The majority of organizations included in this review would benefit from updating their websites to include adequate information and advice about lifestyle for cancer survivors, or they risk cancer survivors turning to less reliable sources of information. Health professionals should be appropriately trained to deal with questions about lifestyle and to advise cancer survivors about lifestyle changes following their diagnosis.

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KEYWORDS

cancer; survivorship; guideline; health behavior; lifestyle; diet; physical activity; body weight; smoking; alcohol drinking

Introduction

Background

There are more than 2 million people in the United Kingdom living with a cancer diagnosis, and this number is predicted to rise to over 5 million by 2040 [1]. Compared with the general population, cancer survivors are at a raised risk of cardiovascular disease, diabetes, osteoporosis, and second primary cancers [2,3]. Given these increasing numbers, addressing these long-term and late effects of cancer is an increasingly urgent issue to help relieve the burden on health services. In addition to being linked to cancer risk [4,5], smoking, poor diet, low levels of physical activity, and higher body weight have all been associated with increased risk of cancer recurrence and mortality in survivors [6-11], as well as influencing other major causes of morbidity and mortality. This has led to increasing interest in the role of lifestyle change as a means of improving long-term outcomes among cancer survivors.

There is a wealth of evidence linking lifestyle change, such as increasing physical activity levels, with improvements in quality of life and symptoms among cancer survivors [12]. Evidence is more limited for the impact on cancer outcomes, although there is emerging evidence that becoming physically active and intentionally losing weight (if overweight) may be associated with improvements in physiological markers among breast cancer survivors [12,13]. Also among breast cancer survivors, there is some evidence that following a low-fat diet post diagnosis may be associated with a reduced risk of cancer recurrence [14]. Further studies are underway to examine the impact of behavior change on survival [15], but nonetheless, findings to date highlight the potential of behavior change to improve long-term outcomes for cancer survivors.

Prior Work

A cancer diagnosis has been considered as a candidate “teachable moment”: a time or setting at which motivation to adopt risk-reducing health behaviors is raised [16]. In line with this, surveys and qualitative studies have found that some cancer survivors report making positive lifestyle changes following their diagnosis, including eating more healthily [17-19] and being more physically active [19-21]. However, despite these reported changes, the health behaviors of cancer survivors in the United Kingdom have been found to be suboptimal, with only around 51% engaging in moderate physical activity, 15% continuing to smoke, and 8% consuming two or more alcoholic drinks per day [22]. Furthermore, studies that compare lifestyle change over time in groups that either do or do not receive a cancer diagnosis have failed to show evidence of sustained positive lifestyle changes following a cancer diagnosis and typically show a reduction in physical activity [23-25].

A range of factors may influence whether cancer survivors make lifestyle changes following their diagnosis. Mobility impairments, ill health, weather, and time have all been cited as barriers to exercise participation in this population [26,27], and unreliable information has been reported as a barrier to making dietary changes [28]. Lack of access to reliable information may partly be due to the absence of professional advice in the cancer context. This is consistent with surveys of

health professionals that indicate that few of them discuss lifestyle factors such as physical activity with their cancer patients [29,30]. A recent survey of 3300 cancer survivors conducted by the UK Department of Health also found that over 20% of cancer survivors would like more advice on diet and lifestyle, suggesting that many of them are not receiving sufficient information on the topic [31]. This has been echoed by qualitative studies that have found cancer survivors report a lack of information about physical activity, diet, and weight [32].

If cancer survivors desire more information about lifestyle but do not receive much advice within the medical setting, they may choose to seek out information themselves, as was found in a qualitative study of colorectal cancer survivors in the United Kingdom [33]. Internet use is increasing among older adults. A recent report found that 53% of those over the age of 65 years are now online, and 70% of these use the Internet on a typical day [34]. Given that cancer is primarily a disease of older people [35], this age group comprises a large proportion of cancer survivors. A recent analysis of the Health Information National Trends Survey found that the Internet was the preferred source of information for 51% of cancer survivors, highlighting a shift from more traditional sources [36]. Similarly, breast cancer survivors have been shown to use the Internet for information, even after their treatment had ended; this was the most frequently cited source of information at 16 months post diagnosis [37]. This suggests that cancer survivors may desire and continue to search for information long after regular contact with their care team has ended. Another study found that cancer survivors were more likely to use the Internet to search for health-related purposes than the general population [38].

Qualitative research with breast and prostate cancer survivors in the United Kingdom suggests that those who use the Internet for information prefer non-commercial websites, and trust websites supported by the National Health Service (NHS) or other recognized “Centres of Excellence” such as charitable organizations and cancer centers [39]. Given the rising number of cancer survivors and the shift from health professional care to supported self-management [40], it is likely that such websites will increasingly be used to obtain information about a range of topics including lifestyle. Supporting self-management involves educating people about their condition and equipping them with the tools to help them choose healthy behaviors [41]. It is therefore crucial to examine the lifestyle information provided by these sectors in order to highlight any gaps and ensure that cancer survivors not only have access to reliable information but are provided with the tools to help them overcome barriers and make the behavior changes that could ultimately improve their long-term outcomes. If cancer survivors are unable to find the information they are looking for on these websites, they may turn to less reliable websites that put them at risk of misinformation.

Aims of the Current Study

The purpose of this review was therefore to identify the lifestyle information and resources provided for cancer survivors by the statutory and charitable sectors and cancer centers in the United Kingdom. Specifically, we aimed to identify information on

tobacco, physical activity, diet, weight, and alcohol designed for people who have been diagnosed with cancer. In addition to examining organizations that provide information to all groups of cancer survivors, this search also focused particularly on information specifically for patients diagnosed with breast, prostate, or colorectal cancer, as recent figures indicate that these constitute approximately 41% of new cancer diagnoses each year in the United Kingdom [42].

Methods

Identification of Statutory Sector Organizations

We first sought to identify any lifestyle information for cancer survivors provided by the UK Department of Health or NHS. The focus of this search was centered on the NHS Choices website [43], a Department of Health funded website that aims to provide objective and trustworthy information and guidance to the public on all aspects of health and health care. It is the largest health website in the United Kingdom and is certified by the Information Standard as a producer of reliable health and social care information [44].

Identification of Cancer Centers

Comprehensive cancer centers accredited by the Organization of European Cancer Institutes (OECI) were also included in the search. This included cancer centers based in the NHS or in universities. As only a limited number of cancer centers are accredited by the OECI, this search was supplemented with a Google search for “cancer centre”, with cancer centers based in the NHS, charitable sector, or universities from the first page of results being included. Cancer centers in the private sector were excluded.

Identification of Charitable Sector Organizations

The Charity Commission is the official register of charitable organizations in England and Wales [45]. Searches for generic, breast, prostate, and colorectal cancer charitable organizations were done separately using the advanced search function. To identify generic cancer charitable organizations the keyword “cancer” was searched for in “charity name”, “charity objects”, and “charity activities”. The search was refined by selecting only charitable organizations operating throughout England and Wales and those who described their operations as providing “advocacy/advice/information”. This was to ensure that the included voluntary sector organizations could reasonably be expected to provide advice on lifestyle. The three largest generic cancer organizations were selected from this list, provided they met the inclusion criteria outlined below. Organization size was defined by income in 2012; which was the information available from the Charity Commission. The three largest organizations were chosen as the researchers agreed these were the most publically well known in England and also appeared at the top of Internet search results. The search was then carried out using the keywords “breast cancer”, “prostate cancer”, and “colorectal cancer”, and the three largest organizations for each of these cancers was selected. The colorectal cancer search was repeated using the terms “bowel cancer”, “colon cancer”, and “rectal cancer”.

Charitable Organization Inclusion Criteria

The inclusion criteria for charitable organization consisted of the following: registered in the Charity Commission database; within the top three breast, prostate, colorectal or generic (all cancer types) cancer charitable organizations in England (defined by income in 2012); listed in the Charity Commission database as providing advocacy, advice, or information; operating in England or Wales (there was no single category for England); aimed at adults; and colorectal and generic cancer charitable organizations must be for both men and women.

Search for Lifestyle Information

The NHS Choices website was searched using the terms “cancer survivor”, “cancer AND physical activity”, “cancer AND exercise”, “cancer AND diet”, “cancer AND weight”, “cancer AND alcohol”, and “cancer AND smoking” in the website’s search function and manually searching the results and following relevant links. The same search was repeated in the websites of the cancer centers and charitable organizations but without the word “cancer”, as these sites were already specific to cancer information. If filters were available they were used to refine the results to pages aimed at cancer patients or survivors. If the website did not have a search function, a manual search of the site was conducted using the drop-down menus. The searches were conducted between November 2014 and January 2015.

Lifestyle Information Inclusion Criteria

Information was included on physical activity, diet, weight management, alcohol, or smoking, aimed at improving the general or long-term health of cancer survivors. Lifestyle information designed to improve acute outcomes of cancer and its treatment (eg, manage a short-term diet problem or acute symptom management) was excluded as the focus was on longer-term survivorship. Information on cancer prevention was also excluded unless cancer survivors were specifically directed toward it.

Data Synthesis

The initial searching of the 20 websites to identify lifestyle information for cancer survivors was conducted by KW, then a selection (N=4) was checked by FC. Any uncertainties or discrepancies were discussed and resolved with the other authors (RJB and AF). Once all the relevant lifestyle information had been agreed on, KW extracted the content. This included identifying any specific recommendations made by the organization and the basis of these recommendations. Other details about the information were also recorded including the format (eg, print, video, podcasts) and resources or advice for helping patients change their lifestyle behaviors.

Results

Statutory Sector Organizations

As outlined in the method section, the NHS Choices website was used to identify lifestyle information for cancer survivors provided by the UK government [43].

Cancer Centers

Three comprehensive cancer centers in England were accredited by the OECl. These were the King's Health Partners Integrated Cancer Center [46], the Cancer Research UK Cambridge Institute [47], and the Christie NHS Foundation Trust [48]. The top Google search results for "cancer centres" also found Maggie's [49], University College Hospital Macmillan Cancer Centre [50], The Royal Marsden Hospital [51], and The Clatterbridge Cancer Centre [52].

Charitable Sector Organizations

The search for generic cancer charitable organizations found 183 results. Once these had been narrowed down using the inclusion and exclusion criteria, the three largest charitable organizations were Cancer Research UK [53], Macmillan Cancer Support [54], and the World Cancer Research Fund (WCRF) [55]. The search for breast cancer, prostate cancer, and colorectal cancer charitable organizations found 13, 15, and 5 results respectively. The three largest for each cancer site were Breakthrough Breast Cancer [56], Breast Cancer Care [57], Breast Cancer Campaign [58], Prostate Cancer UK [59], Movember Europe [60], the Orchid Cancer Appeal [61], Bowel Cancer UK [62], Beating Bowel Cancer [63], and Bowel Cancer Information [64].

Availability of Lifestyle Information

All the website searches yielded a large number of results, but the majority were not relevant. The NHS Choices website did not contain any lifestyle information for cancer survivors, but it did provide a link to a Cancer Research UK page on diet. It also included a page on lifestyle changes after chronic illness; however, this was not included as it did not specifically mention cancer. Ten organizations (3/7 cancer centers and 7/12 charitable organizations) had lifestyle information for cancer survivors available on their websites. Of these, the Christie NHS Foundation Trust [48], Macmillan Cancer Support [54], and Prostate Cancer UK [59] had the most comprehensive guides, covering physical activity, diet, weight management, smoking, and alcohol. [Multimedia Appendix 1](#) shows a summary of the online lifestyle information provided by the different sources.

Summary of Lifestyle Information

All ten organizations with lifestyle information for cancer survivors had information on diet and physical activity, but only seven had information on alcohol [48,51,54,55,57,59,63], six on weight management [48,51,54,55,57,59], and four on smoking [48,54,59,63] ([Multimedia Appendix 1](#)). The information from six organizations made reference to other guidelines; most often those produced by the WCRF [48,51,53-55,63]. Eight suggested discussing lifestyle with a health professional (including the general practitioner, cancer doctor, cancer nurse specialist, physiotherapist, or dietitian) before making any changes [48,51,53,54,57,59,62,63].

Physical Activity

Ten organizations had information on physical activity. Eight of these provided specific recommendations on the duration and intensity of physical activity that cancer survivors should aim for [48,51,53-55,57,59,63], of which five recommended

150 minutes of moderate physical activity per week, in varying forms (eg, 30 minutes, 5 times per week) [51,53,54,57,59] and the other three recommended 30 minutes every day [48,55,63]. Some also highlighted the importance of reducing sedentary behavior [63]. Bowel Cancer UK and Maggie's did not specify duration or intensity but emphasized the importance of being active [49,62].

Information about physical activity was provided in a variety of formats. Two had DVDs [54,57], one had a podcast [48], and others had booklets, leaflets, or factsheets available to download or order in paper formats [48,54,62,63]. Others had brief advice about becoming active on their own [51,53,59]. Some organizations offered exercise classes that patients could join to help them get active.

The majority of organizations gave suggestions on the types of physical activity cancer survivors could do, for example, walking, swimming, or housework [48,51,54,55,57,59,62], and some provided specific exercises for cancer survivors to try at home [48]. These often included information about the benefits of being physically active following a cancer diagnosis, for example, "exercise for cancer patients can reduce the risk of cancer coming back" [48,53,54,57]. Patients were encouraged to start exercise gently and build up slowly and some organizations gave examples of how to do this, for example, "5 minutes of housework in the morning followed by a 5 minute walk to the shop, followed by a 10 minute dog walk" [48]. Several organizations provided information about safety during exercise and when to be careful, for example, "people with low immunity should avoid public gyms" or "stop exercising if you feel sick or are sick during exercise" [48,53,54,62].

A range of resources were provided to help cancer survivors be physically active. The leaflets included case studies of patients with tips on exercising with cancer, and advice on finding local exercise programs. The DVDs had information on how to become more active, including advice from experts, case studies from other cancer survivors, and exercise demonstrations [54,57].

Diet

All organizations recommended that cancer survivors eat a balanced diet, and the majority provided further details. They highlighted the importance of eating plenty of fruit, vegetables, and starchy foods, and limiting intake of energy dense foods (high in sugar or saturated fat) and red or processed meat. Prostate Cancer UK also provided a list of more specific and unusual foods that may be beneficial (eg, green tea and tomatoes), although they acknowledged that evidence is limited.

The websites provided information about diet in a range of formats. Five organizations had leaflets available for patients to download and print at home [48,51,59,62,63]. Others had videos for patients to watch [48,57] and podcasts for them to listen to [48]. In some cases, the website itself did not provide much information but had details about free courses patients could sign up to in order to learn more about diet [49].

All of the organizations with information about diet gave guidelines for what cancer survivors should be eating. Most provided a diagram of the "Eatwell plate" [65] to help cancer

survivors understand the different food groups on which they should be basing their diet [48,51,57,59,62,63]. Some then gave examples of the types of foods that come under each food group, for example, “meat, fish, eggs, tofu, soya products, pulses and Quorn are a good source of protein” [48,51,62] and reasons why these foods are beneficial or harmful, for example, “fibre keeps bowels working regularly” or “red and processed meat are associated with an increased risk of some cancers”. In order to help cancer survivors eat appropriate amounts of different types of foods, several organizations gave examples of portion sizes, for example, a serving would be “three heaped tablespoons of cooked vegetables” [48,54,55,57]. To inspire patients, many organizations also provided recipe ideas for meals and snacks, for example, breakfast could be “wholegrain cereal topped with sliced banana and semi-skimmed milk” [48,51,54,55].

As well as this fairly general information on what to eat, several organizations provided information about what to eat following specific cancers or treatments, or when experiencing particular symptoms. For example, Beating Bowel Cancer provided an explanation of how bowel cancer treatment and surgery affects the bowel and how this may impact on diet [63]. They also included tips for eating and avoiding bowel symptoms, for example, “eat at regular intervals, and don’t eat on the move”. Other organizations gave information on what to eat when losing or gaining weight. For example, the Royal Marsden suggested that when losing weight, it is best to “eat when your appetite is best and have small regular meals” [51].

Some organizations provided some tools to help cancer survivors with their diet. For example, the Royal Marsden gave some tips for overcoming problems with eating, such as “if you are too tired, get friends to help with shopping or have snacks that don’t require much preparation” [51]. The Beating Bowel Cancer leaflet contained quotes from other patients with tips on what they found useful, for example, “Ginger beer really helped with nausea when undergoing chemotherapy”, as well as tips for family members [63]. Similarly, the Breast Cancer Care DVD was largely narrated by patients who told their stories about how they changed their diet following their cancer diagnosis [57].

Weight Management

Seven organizations provided information on weight management for cancer survivors [48,51,54,55,57,59,62]. They all recommended maintaining a healthy weight (within the normal Body Mass Index range), and the WCRF recommended being as lean as possible without becoming underweight. Several organizations recommended that overweight people should try to lose their excess weight but emphasized that this should be done gradually (at around 0.5-1 kg a week) and should be done in consultation with a health professional [54,57,59,62]. In contrast, the Royal Marsden recommended that those who are overweight should not try to lose weight during treatment as this would make them more susceptible to infections and poor wound healing [51].

Several organizations provided advice on how to lose weight with a focus on healthy eating and physical activity. Four had advice on their websites to help people get started, including tips on weight loss (and weight gain for those who had lost

weight during treatment) [51,54,57,59]. Two included information about weight in their booklets about diet [48,51].

Alcohol

Seven organizations provided information on alcohol [48,51,54,55,57,59,63]. These were almost identical and recommended 2-3 units per day for women and 3-4 units for men (three organizations stated this as the number of drinks: 1 for women and 2 for men) [51,55,63]. The Christie NHS Foundation Trust did not provide a specific recommendation but recommended drinking less alcohol [48]. They did not provide much advice on how to limit alcohol consumption, but one (Prostate Cancer UK, 2014) referred to the NHS Choices website.

Smoking

Four organizations provided information on smoking [48,54,59,63], recommending that smokers should quit. These organizations did not provide their own advice on how to stop smoking but referred smokers to smoking cessation services and the NHS Choices website for further support.

Discussion

Principal Results

The purpose of this review was to identify lifestyle information specifically for cancer survivors provided by the statutory and charity sectors in the United Kingdom. Ten organizations had lifestyle information for cancer survivors on their websites. The Christie NHS Foundation Trust [48], Macmillan Cancer Support [54], and Prostate Cancer UK [59] had the most comprehensive guides, covering physical activity, diet, weight management, smoking, and alcohol. The NHS website did not provide any lifestyle information for cancer survivors but had a link to Cancer Research UK’s information about diet.

The absence of lifestyle information for cancer survivors on the NHS website is a matter of concern, given that the NHS is the preferred source of information for many patients [39]. It is encouraging that the NHS Choices website provides links to Cancer Research UK’s webpage on diet, but it would be helpful if they also directed cancer survivors to advice on physical activity and other health behaviors. Although there was no information on the main NHS website, the Christie NHS Foundation Trust [48] had very comprehensive information on its website, suggesting that lifestyle information from statutory organizations is provided to cancer patients at a local level. However, not all cancer centers provided lifestyle information, which may lead to a geographical disparity in access to lifestyle information. Even if some cancer centers have lifestyle information on their websites, patients from other centers may not know it exists or where to find it.

In the charitable sector, Macmillan Cancer Support [54] and Prostate Cancer UK [59] had the most comprehensive information on their websites, consistent with their being leading cancer charities. Macmillan Cancer Support in particular had dedicated sections on its website, making it easy for cancer survivors to navigate and find the lifestyle information they need. Several of the other charitable organizations (eg, Cancer

Research UK [53]) and Breast Cancer Care [57]) had information on each health behavior in a different section, making it more difficult to assemble the relevant information. This highlights a challenge that cancer survivors may face when searching for information about lifestyle.

Comparison With Prior Work

Where lifestyle recommendations were given, they were similar to UK government guidelines for the general population [66-70]. They included not smoking, limiting alcohol intake, maintaining a healthy weight, being moderately physically active for at least 150 minutes per week, and eating a diet high in fruit and vegetables and low in fat, sugar, and red and processed meat. This is likely to be due to the lack of research evidence to inform development of specific recommendations for cancer survivors. In 2007, the WCRF reviewed the evidence for the role of diet and physical activity in both cancer prevention and survival and concluded that cancer survivors should follow general population recommendations for cancer prevention [5]. More recent study results have been generally consistent with these recommendations, demonstrating associations between cancer survival and physical activity [7,12], low-fat diet [14], not smoking [71], and limited alcohol consumption [72]. However, five organizations suggested that cancer survivors who are overweight or obese should attempt to lose weight [40,48,55,57,59]. This recommendation is less well supported by the literature as weight loss has been associated with poorer disease outcomes for cancer survivors, even among those who are overweight or obese [73,74]. In the absence of good trial evidence, organizations may choose to be cautious about recommending weight loss for cancer survivors and instead emphasize the importance of a healthy diet and physical activity. If they want to provide weight recommendations, the evidence suggests that avoiding weight gain would be preferable. The Royal Marsden's recommendation was more in line with the evidence saying that it is not a good idea to lose weight during treatment, even if overweight [51]. Such inconsistencies in recommendations may be confusing for cancer survivors, particularly those who lose or gain weight during treatment.

Implications

Our findings have considerable implications for the organizations included in this review. On the whole, the level of information provided was suboptimal, as only half of the organizations provided any information about lifestyle and only three provided information on all health behaviors. This was the case even though we included the NHS website and those of charitable organizations that all described their operations as providing "advocacy, advice or information". These findings are concerning given that statutory and charitable sector organizations and cancer centers have been found to be a favored source of information for cancer survivors and are likely to be the first point of call for those seeking information [39]. With the rise of Internet use among older adults [34] and the increasing focus on supported self-management, the websites of these organizations are likely to experience increasing traffic [40]. However, if cancer survivors are unable to find the information they are looking for on these websites, they may turn to less reliable sources. Given the abundance of

misreporting about lifestyle and cancer in the media and online [75], this would put cancer survivors at risk of misinformation and potentially hinder their chances of giving themselves the best long-term outcomes. As a result, it is crucial that the information on the majority of these websites is improved. Specifically, the main NHS website would benefit from including information about lifestyle specifically for cancer survivors, or alternatively add clear links to hospitals already providing good quality information and advice such as the Christie NHS Foundation Trust or the Royal Marsden. Other organizations would benefit from reorganizing their websites so that recommendations are easy to identify and all lifestyle information can be found in one section rather than having to search for behaviors separately [53,57].

Several of the organizations referred patients to other sources of information and emphasized the importance of talking to a health professional before making any lifestyle changes. The latter may be problematic for longer-term survivors as they may no longer have regular contact with their health care team. If patients are required to make an appointment with their general practitioner before making lifestyle changes, they may be less likely to make those changes, whether through loss of motivation or other barriers. Those who do have contact with their health care team may find that their doctor or nurse may be unable to advise them about lifestyle. Health professionals have reported lack of specialist knowledge about risk factors for cancer as a barrier to discussing lifestyle [76]. This made them reluctant to raise the issue of lifestyle change without the appropriate support to help patients make changes. It is therefore important to ensure that clinicians receive appropriate education about the importance of a healthy lifestyle following a cancer diagnosis and that they are trained in how to discuss these issues with patients. Provision should also be made for cancer survivors to speak to a specialist if they would like, such as a dietitian or exercise physiologist, where such referral schemes are in place. Another important source of information for cancer survivors is other survivors who may have already experienced particular issues with lifestyle. Some of the organizations had incorporated the experience of long-term cancer survivors into the information they provided in order to give a unique perspective and help motivate newer survivors.

This study also has implications for Internet research in general. Evaluating the content of these websites is crucial in order to hold organizations accountable for the information they provide. This may drive up quality in a way that anonymous feedback on a website may not. Evaluations such as these can drive positive change in Internet material and should be repeated at regular intervals to ensure that the quality of these websites continues to improve.

Limitations

This study has a number of limitations. Although it included 20 UK-based statutory and charitable organizations and cancer centers, it is likely that users in the United Kingdom who search for information about lifestyle would also encounter websites based in North America or other English-speaking nations. Therefore, a wider search, incorporating all English-language websites, could be useful. Also, in addition to reviewing

information by statutory and charity organizations, it may be useful to expand the evaluation to incorporate commercial organizations (eg, private health care companies) as users will potentially encounter them when searching for lifestyle information on the Internet. However, research has shown that patients do not favor such sites [39]. All searches were conducted between November 2014 and January 2015, and the organizations may continually update the information on their website. However, this review provides an important snapshot of the availability of lifestyle information for cancer survivors at present. Historically, charitable organizations may have websites in order to fundraise rather than provide information, which may explain the limited information available. However, all of the included charitable organizations described their operations as providing “advocacy/advice/information”, so they could reasonably be expected to provide such information. This review focused on the availability of lifestyle information online,

but there are a range of other areas of information that are also important to cancer survivors such as psychological, sexual, and work-related issues, that were not included in this review.

Conclusions

Although several organizations had some information on lifestyle for cancer survivors, there was no advice on the NHS website and only three organizations had comprehensive guides, encompassing diet, physical activity, weight, alcohol, and smoking. These organizations should consider adding or updating their websites to include adequate information and advice about lifestyle for cancer survivors, or they risk cancer survivors turning to less reliable sources of information. The majority of recommendations emphasized that cancer survivors should talk to a health professional before making any lifestyle changes. Health professionals should be appropriately trained to deal with questions about lifestyle and to advise cancer survivors about lifestyle changes following their diagnosis.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Summary of online lifestyle information for cancer survivors.

[[PDF File \(Adobe PDF File\), 155KB - cancer_v1i1e2_app1.pdf](#)]

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Abbreviations

NHS: National Health Service

OECI: Organization of European Cancer Institutes

WCRF: World Cancer Research Fund

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Original Paper

Efficacy of a Mobile-Enabled Web App (iCanFit) in Promoting Physical Activity Among Older Cancer Survivors: A Pilot Study

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Abstract

Background: The benefits of physical activity for cancer survivors are well documented. However, few older cancer survivors are engaged in regular physical activity. Mobile technologies may be an effective method to deliver physical activity promotion programs for older cancer survivors. *iCanFit*, a mobile-enabled Web-based app, was developed based on formative research and usability testing. This app includes interactive features of physical activity, goal setting and tracking, and receiving personalized visual feedback.

Objective: The aim of this study is to pilot test the initial efficacy of iCanFit.

Methods: Older cancer survivors (N=30) were recruited online through our collaborative partnership with a cancer survivor's organization. After the participants completed an online baseline survey, they were asked to use the iCanFit website. Instructional videos on how to use the web app were available on the website. Participants were asked to complete a follow-up survey 2-3 months later. Participants' physical activity, quality of life, and their experience with iCanFit were measured.

Results: A total of 30 participants completed the baseline survey, and 26 of them (87%, 26/30) also completed a follow-up survey 2-3 months later. The median age of participants was 69 years (range 60-78). Participants' quality of life and engagement in regular physical activity improved significantly after the use of iCanFit. Participants indicated a general affinity towards the key function "Goals" in iCanFit, which motivated continued activity. They also provided suggestions to further improve the app (eg, adding a reminder functionality, easier or alternative ways of entering activities).

Conclusion: The interactive Web-based app iCanFit has demonstrated initial efficacy. Even though our study was limited by a small sample size, convenience sampling, and a short follow-up period, results suggest that using mobile tools to promote physical activity and healthy living among older cancer survivors holds promise. Next steps include refining iCanFit based on users' feedback and developing versatile functionality to allow easier physical activity goal setting and tracking. We also call for more studies on developing and evaluating mobile and web apps for older cancer survivors.

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KEYWORDS

physical activity; mobile health; older adults; cancer survivors; iCanFit; pilot

Introduction

More than 87% of American adults have used the Internet. Even among older adults, 88% of those aged 50-64 are online and more than 57% of those older than 64 are online. Furthermore, mobile phone use among older adults has also grown from 11% in 2011 to 18% in 2013 [1]. Literature suggests that older adults are increasingly turning to the Internet for information [2]. Despite high rates of Internet access and mobile device ownership, only a small number of mobile or Web-based apps have been designed specifically for older adults.

Physical activity is particularly important for older adults, especially for those with chronic conditions including cancer [3]. Regular physical activity has been shown to effectively lessen fatigue and improve overall quality of life for cancer survivors [4]. Web- or mobile-based physical activity interventions have been shown to be effective [5-8], but such interventions have rarely targeted older adults, and web or mobile apps designed specifically for older cancer survivors are especially scarce [9,10].

Early detection and improved treatment for cancer have resulted in approximately 13 million survivors being alive in the United States today; this number will increase by nearly a third to almost 18 million by 2022 [11]. A majority of cancer survivors are >60 years of age. Caring for the large number of older cancer survivors presents a significant public health challenge [12]. The benefits of physical activity for cancer survivors have been reinforced through several guidelines [12,13]. However, the level of adherence to physical activity guidelines among cancer survivors is very low. For example, only 4.6% of breast cancer survivors followed physical activity guidelines compared to 12% of women without breast cancer [14]. The level of physical activity among older cancer survivors is believed to be even lower [13]. Thus, there is an urgent need for effective interventions that can reach large numbers of older cancer survivors efficiently. Literature suggests that older cancer survivors are more likely to use the Internet compared to their counterparts without a cancer diagnosis [15]. Once online, cancer survivors are more likely to use the Internet for health-related purposes [16]. Thus, it is potentially efficient and effective to deliver Web- or mobile-based interventions to older cancer survivors.

Prior studies on promoting physical activity for older adults suggested that goal setting is an effective intervention strategy. Through setting specific and achievable goals and regular feedback, people are motivated to exercise. Additionally,

personalized feedback reinforces maintenance of behavioral change [17,18].

With the aim of promoting physical activity among older cancer survivors, the mobile-enabled website app iCanFit was designed with formative research with key stakeholders [19], along with usability and acceptability testing [20]. The major functions in the iCanFit web app include “Goals” (physical activity, goal setting, and tracking), “Community” (an online network for users), “Tips” (regularly updated tips on healthy living), and “Resources” (active links to reliable health information) (Figure 1). Of these functions, “Goals” is the most important tool (Figure 2). Guided by the Theory of Goal Setting [18], “Goals” motivates participants to exercise regularly through goal setting, activity tracking, personalized feedback, and progress reviews. A new participant will be cued to set up a long-term goal; then be cued to set a short-term, usually weekly, goal. Examples of goals are available to guide participants set specific and tangible goals. Each goal includes type, frequency, and duration of the physical activities. The system will automatically calculate total minutes and energy expenditure for each and all of the activities (Figure 2). On an interactive calendar, participants can enter their activity and log the total number of minutes they exercised on a selected day (Figure 3). Their activity log will be compared to their goals and they will receive tailored messages based on this comparison. Examples of such messages are “Congratulations, you’ve achieved your goal, keep up the good work!” or

Sorry you did not meet your goal. You may consider setting a more realistic goal. Keep moving!

The tailored messages (Figure 3) are sent automatically from iCanFit using a pre-designed database that contains >100 messages for different conditions of meeting goals. Finally, “View Progress” allows users to track their progress through various metrics, including total energy expenditure, total minutes exercised, number of days exercised, and comparisons between actual activity and their preset goals (Figure 4). Users have the options to view their progress as bars, lines, and/or as a calendar (Figure 4).

This study targeted the understudied but growing population of older cancer survivors, and explored the feasibility and initial efficacy of an interactive Web-based app to promote their physical activity. Through a pilot test of pre-post design, we aimed to answer the research question of whether participating in iCanFit is associated with changes in physical activity and quality of life among older cancer survivors.

Figure 1. Screenshot of iCanFit.

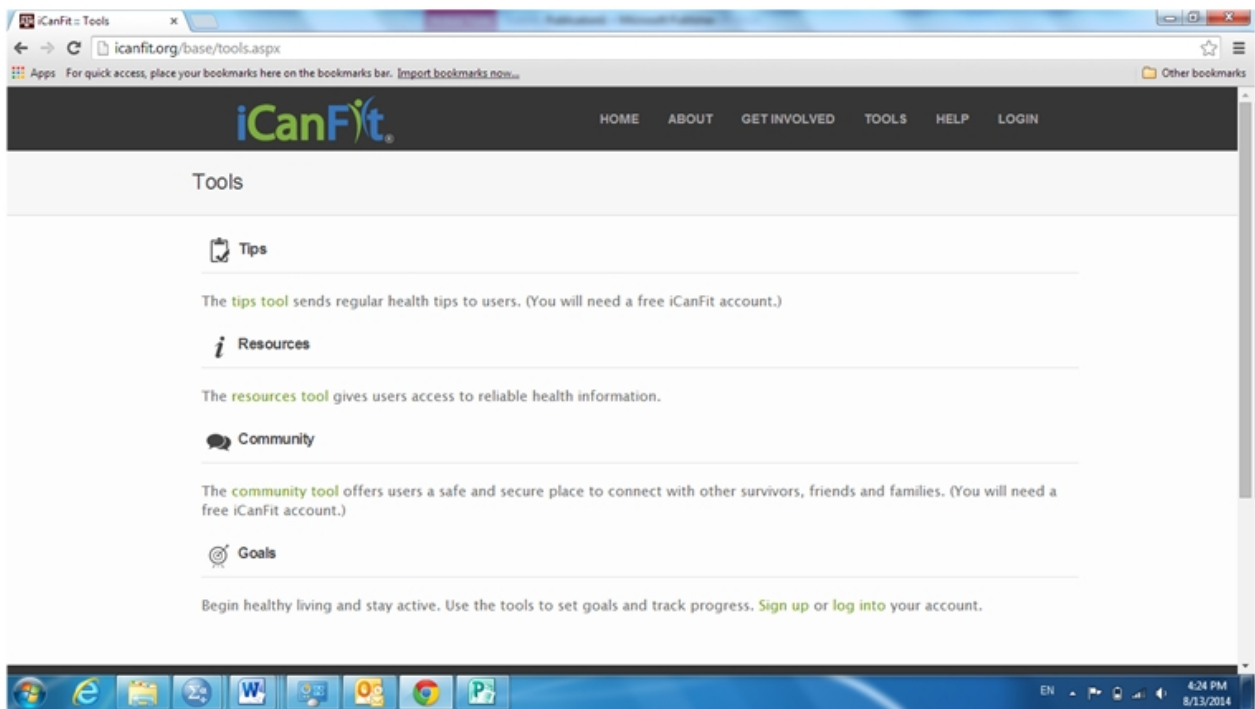


Figure 2. "Goals" function of iCanFit.

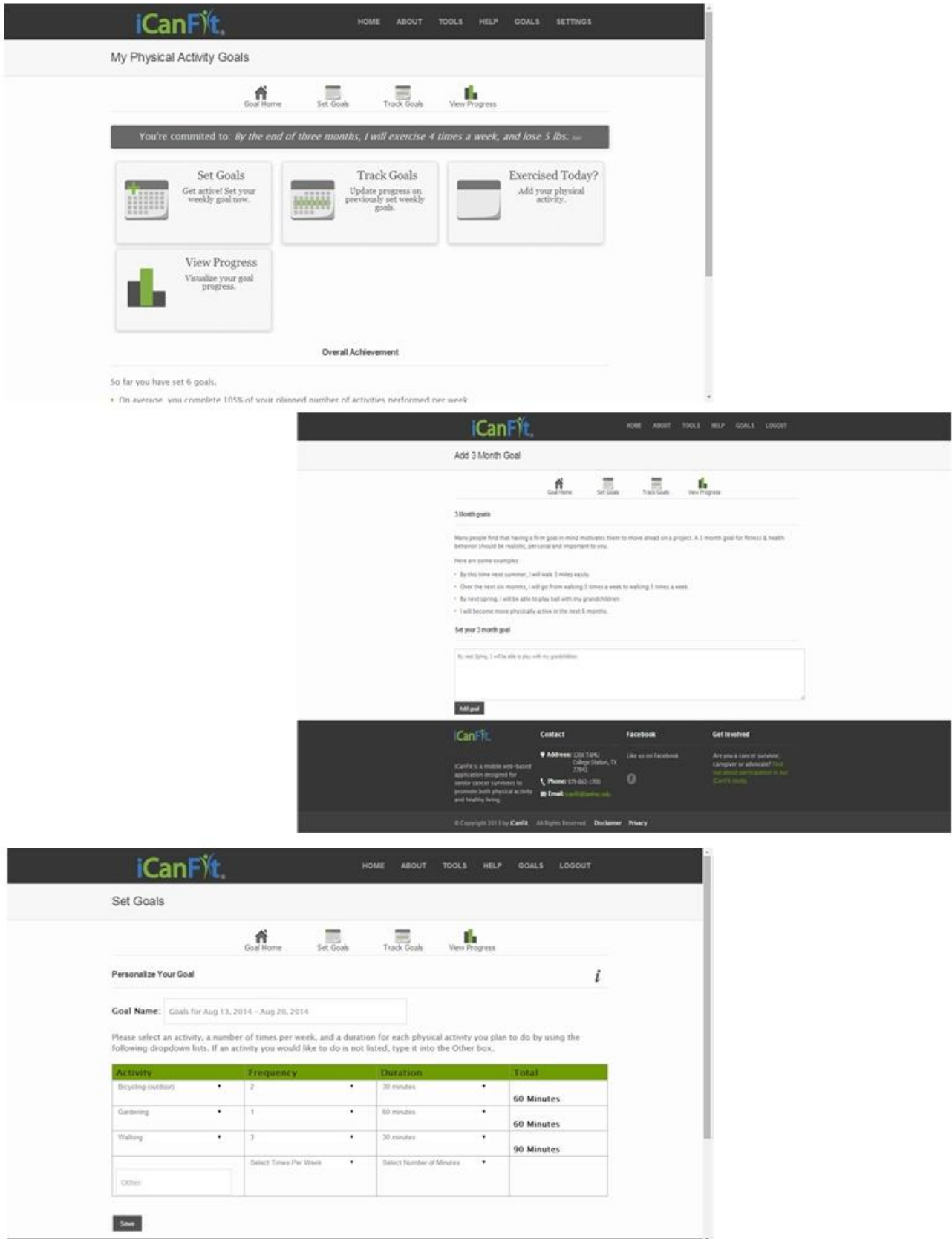


Figure 3. Activity log of iCanFit.

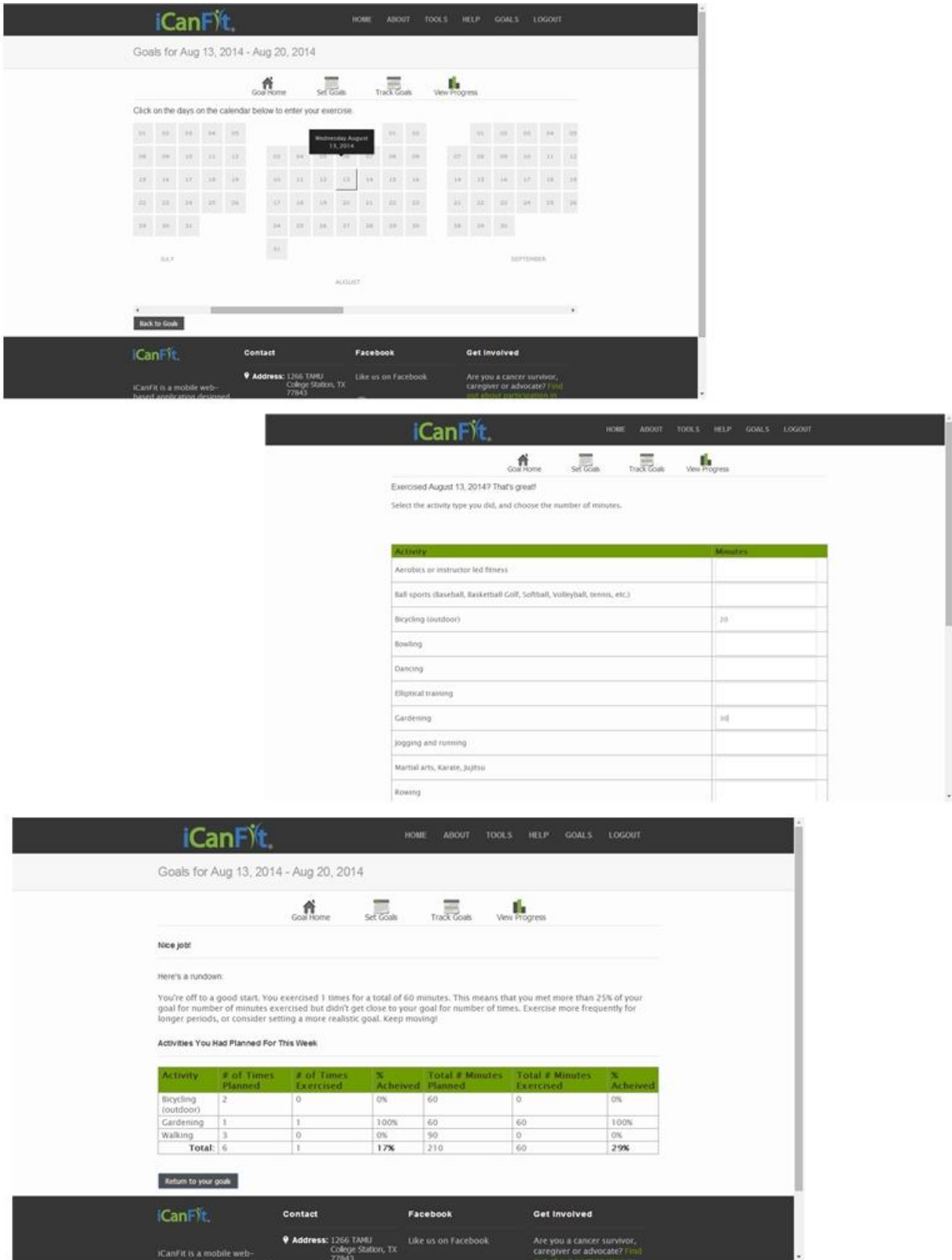


Figure 4. "View Progress" function of iCanFit.



Methods

Overview of Study Design

This was a pre-post design study with 2-3 months of follow-up. Online surveys and a mobile-enabled web app were used to collect participant data.

Participant Recruitment

All participants were recruited online. Through our collaborative partnership with a cancer survivor's organization, emails were sent out to their list-serve inviting eligible cancer survivors to participate. Inclusion criteria for participation included (1) ≥60 years, (2) having ever been diagnosed with cancer, (3) reporting the ability to do physical activity, and (4) having access to the

Internet. Potential participants were instructed to the iCanFit website [21]. On the homepage, there was a screening survey for potential participants. Individuals who completed the screening survey (including the provision of contact information) received a phone call from our research staff to re-verify their eligibility. Eligible participants received instruction on how to participate in the study. Instructional videos on how to use iCanfit were also available on the “Help” page.

Data Collection Procedures

Project information was sent out to participants via email with a link to an online survey. Prior to the survey, an informed consent with a detailed project description, benefits, and potential risks of participation was provided. Participants who completed the informed consent were directed to the baseline survey, which took approximately 10 minutes to complete. After the survey, participants were directed to the project site and instructed to create a username and password. The “Help” page also contained instructional videos on how to use the web app. All participants were instructed to use iCanFit for about 8-12 weeks. During that time, 4-6 emails were sent to participants reminding them to continue using iCanFit. The emails were sent automatically and contained personalized information such as participant’s name, duration of the study, and when the follow-up survey would be sent. After 8-12 weeks, participants were sent a link to the follow-up survey, which took approximately 10 minutes to complete. Participants who completed the baseline survey received a \$15 gift card and those who completed the follow-up survey received an additional \$35 gift card. The study protocol was approved by the Institutional Review Board (IRB) of the Texas A&M University.

Measures

The baseline survey included participant demographics, use of mobile tools, quality of life, and current physical activity. The quality of life was measured with 7 items, including self-rated health (1 being poor and 5 being excellent), overall quality of life, fatigue, pain, shortness of breath, stress, and sleep. The response options ranged from 0-10, with 0 being the worst and 10 the best. The Cronbach alpha value for the 7 quality of life items was .79. We also asked the participants how many days in the past 30 days did they not have good physical health, good mental health, or could not do usual activities.

Participants were asked about their current engagement in regular physical activity with the following 5 response options (1) not engaged in physical activity and have no plan of doing so, (2) not engaged but plan to do so in 3 months or less, (3) engaged occasionally but not on a regular basis, (4) engaged in regular physical activity but started less than 3 months, and (5) engaged in regular physical activity and has been doing so for more than 3 months.

In the follow-up survey, participants were asked about the same outcomes on quality of life and engagement in regular physical activity, as well as their experience with the program. Some open-ended questions were included to solicit their feedback and suggestions for iCanFit. In addition to the above self-reported subjective data, users’ activities on iCanFit

including the number of goals set and achieved were captured by the web app.

Data Analysis

All data from the online surveys were downloaded and stored in SPSS 22.0. Descriptive statistics were used for data analysis; paired *t* test was used to compare pre-post changes and assess level of significance at the $P < .05$ level. Open-ended responses were entered into Microsoft Word to identify ranges and patterns of responses.

Results

Demographics and Mobile Technology Use

Of the total eligible participants who created an online account and completed the baseline survey (N=30), 87% (26/30) completed the follow-up survey. These 26 participants were the sample to test the efficacy of iCanFit.

As shown in [Multimedia Appendix 1](#), the median age of the 26 participants in the baseline sample was 69 years (range 60-78). About 70% (18/26) of them were female, 73% (19/26) were white, 77% were married (20/26), 38% (10/26) had some college education, and 42% (11/26) had completed college. Only 2 participants (7%, 2/26) were still in cancer treatment, while the remaining majority weremajority was not, including 46% (12/26) that were being monitored but not in treatment, and 46% (12/26) that were post-treatment survivors. All participants had other chronic conditions, including high blood pressure (46%, 12/26), heart disease (23%, 2/26), arthritis (31%, 8/26), osteoporosis (23%, 6/26), sciatica (12%, 3/26), diabetes (12%, 3/26), chronic back pain (12%, 3/26), and depression or anxiety (8%, 2/26). About 46% (12/26) of participants talked to their health care providers about physical activity almost every time they saw the provider, 27% (7/26) said sometimes they did, and 23% (6/26) said they rarely or never did.

All of the participants had high-speed Internet access at home, and most of them used multiple mobile tools for Internet access. Specifically, 69% (18/26) used a desktop, 46% (12/26) used a laptop, 46% (12/26) used a tablet, and 81% (21/26) used a mobile phone with app capabilities; and as many as 23% (6/23) of participants used a mobile phone for Internet access every day. Their weekly online hours varied from 1-60 hours (median 10 hours). Most older cancer survivors frequently searched health information online, for example, only 1 person (4%, 1/26) never searched health information online, 8% (3/26) did so twice a month, 19% (2/26) did it once a week, 27% (5/26) did it 2-3 times a week, and 15% (6/26) did it every day. Most participants were active users of social media. For instance, 65% (17/26) of them were on Facebook, 50% (13/26) subscribed to an email listserv, 31% (15/26) used LinkedIn, and 19% (5/26) used an online messenger.

Physical Activity and Quality of Life

The differences in quality of life and physical activity at baseline and follow-up are shown in [Table 1](#). The mean self-rated health score (1-5) increased from 3.23 to 3.81, the overall quality of life score increased from 8.12 to 8.50, fatigue-related quality of life score increased from 6.04 to 6.77, pain-related quality

of life score increased from 8.85 to 9.11, shortness of breath-related quality of life score increased from 8.65 to 9.04, stress-related quality of life score increased from 6.27 to 7.04, and sleep quality also increased from 6.19 to 7.00. All of the quality of life-related changes were significant ($P < .05$). The number of days without good physical health, good mental health, or reporting they could not do usual activities did not have significant changes due to flooring effects of the numbers.

Table 1. Efficacy of iCanFit on promoting physical activity and quality of life among older cancer survivors.

Outcome measure	Baseline (N=26)	Follow-up (N=26)	P value
Quality of life, mean score			
Self-rated health (1-5)	3.23	3.81	.0001
Overall quality of life (0-10)	8.12	8.5	.004
Fatigue (0-10)	6.04	6.77	.002
Pain (0-10)	8.85	9.11	.016
Shortness of breath (0-10)	8.65	9.04	.023
Stress (0-10)	6.27	7.04	.0013
Sleep (0-10)	6.19	7.0	.013
Number of days without good physical health in past 30 days	3.57	1.65	.06
Number of days without good mental health in past 30 days	1.54	1.19	.07
Number of days could not do usual activities in past 30 days	1.54	0.88	.07
Current level of physical activity, n (%)			
Not engaged in physical activity and have no plan	3 (12%)	0	.083
Not engaged in physical activity but plan to do so in 3 months	5 (19%)	0	.022
Engaged in physical activity occasionally, but not on a regular basis	7 (27%)	5 (19%)	.77
Engaged in regular physical activity, but started less than 3 months	0	5 (19%)	.022
Engaged in regular physical activity, and has been doing so for 3 months	11 (42%)	15 (58%)	.043

In terms of self-reported physical activities at baseline, 3 participants (12%, 3/26) were not engaged in physical activity and had no plan of doing so and 5 participants (19%, 5/26) were not engaged in physical activity but planned to do so in less than 3 months. All of these 8 participants were engaged in physical activity in the follow-up. The number of participants engaged in regular physical activity also increased from 11 (42%, 11/26) to 15 (58%, 15/26).

Experience With iCanFit

Participants' use of and experience with iCanFit is depicted in [Table 2](#). Most participants accessed iCanFit with multiple mobile

devices including 58% (15/26) via desktop, 38% (10/26) via laptop, 23% (6/26) via tablet, and 27% (7/26) via mobile phones. Participants used iCanFit with varying frequencies; 12% (3/26) used it once every 2 weeks, 62% (16/26) used it once a week, 19% (5/26) used it 2-3 times per week, and 8% (2/26) used it 4-5 times a week. Their weekly median time on iCanFit was 25 minutes (range 5-60). About 65% (17/26) of participants had talked to their family and friends about iCanFit, and 27% (7/26) used iCanFit with their family or friends.

Table 2. User experience with iCanFit (follow-up, N=26).

Measure	n (%)
Mode of accessing iCanFit	
Desktop	15 (58%)
Laptop	10 (38%)
Mobile phone	7 (27%)
Tablet	6 (23%)
How often did you log into iCanFit?	
Once every 2 weeks	3 (12%)
Once or twice per week	16 (62%)
2-3 times per week	5 (19%)
4-5 times per week	2 (8%)
Every day	0
Minutes on iCanFit each week, median (range)	25 (5-60)
Talked to family or friends about iCanFit, n (%)	17 (65%)
Used iCanFit with family or friends, n (%)	7 (26.9%)
Ease of use iCanFit (1-5), mean (SD)	
Overall	4.1 (1.7)
Goals	3.9 (2.1)
Healthy tips	4.2 (0.9)
Resources	4.5 (0.8)
Community	4.1 (0.9)

Table 2 also demonstrates that participants reported an overall positive experience with iCanFit. On the scale of 0-5, the mean (SD) value of overall ease of using iCanFit was 4.1 (1.7), 3.9 (2.1) for "Goals", 4.2 (0.9) for "Healthy Tips", 4.5 (0.8) for "Resources", and 4.1 (0.9) for "Community".

Participants also shared their experience of using iCanFit. Most participants made comments like "Great program, it helps me track my exercise." Their favorite functions included the graphic display of their progress and the personalized feedback of their physical activities. For example, one shared "I like it sends me feedback right after I enter my activities," and "It's great to see a bar chart comparing my goals and my activities." Participants who did not exercise regularly or have an exercise plan prior to the intervention reported using iCanFit to set goals and track their activities. For example, one participant reported, "It motivates me to exercise more so I can meet or exceed my goals," and "After some weeks of using it, I know how much I can do on a weekly basis."

Participants also shared suggestions on further improving the programs. Nearly half of the participants had frustration with forgetting to enter activities. "I often forget to enter my activities, and at the end of the week, I would totally forget what I've done," and "It'd be better if I don't need to enter my activity because I easily forget." Some suggested using automatic function; for example, a participant had proposed a pedometer "If you could link my pedometer to iCanFit, then I don't need to enter activity." Participants also commented that they mostly

used the "Goals" function and didn't use the other functions (Healthy tips, Resources and Community) very often.

Within 2-3 months of using iCanFit, participants set a total of 289 goals, with a mean of 11.1 per participant. Nearly half of these goals were met. The most typical activities included walking, jogging, aerobics, and gardening.

Discussion

Principal Findings

To our knowledge, there has been little systematic research of mobile-enabled, Web-based apps for older cancer survivors. As one of the first pilot studies, the initial efficacy of iCanFit as a web app has been demonstrated in this study. Significant improvement in quality of life and engagement in physical activity all indicate that this, and similar mobile-enabled, web apps may, be able to have positive effects for older cancer survivors. Positive user experiences with iCanFit, coupled with improvements in health-related items all point to the promising utility of this interactive web app. The already large, parallel advances in similar technology including mobile and web apps, fitness trackers, and other devices, may potentially benefit millions of older adults with chronic conditions.

Limitations

Our study has the following limitations. First, the use of convenience sampling, the sample being mostly drawn from a cancer survivor's organization in Texas, and the relatively highly

educated sample (eg, most with some college education or above) limits generalizability to all older cancer survivors in the country. In addition, there was a voluntary bias in the sampling as the older cancer survivors who signed up for this study might have been those who were already physically active. Second, our measures of quality of life were mainly developed from our own research and might not be comparable to other studies with validated quality of life scales. The pilot study described here aimed to test the initial efficacy of iCanFit and it took participants <10 minutes to complete the online survey. Third, the quality of life measures focused on physical and mental health functioning and not a more broad application of multiple quality of life domains. Even so, lifestyle factors such as physical activity were the focus of this study. Future studies need to include validated, multi-dimensional quality of life scales to increase its comparability to other studies. Fourth, the measure of physical activity was dependent on self-entry and self-report, which may incur recall or social desirability biases. Future research should thus include alternative forms of data entry. For example, the recent popularity of accelerometer and sensors can be used to capture users' physical activity to reduce users' burden and potential errors and biases in data entry. Finally, our study did not have a control group and had only one follow-up. Future studies need to include a larger sample, a control group, and long-term follow-ups to further establish the efficacy of the intervention. While the vast majority of older adults have at least one chronic condition, nearly three quarters

have ≥ 2 [22]. Thus, effective interventions must be multi-faceted and recognize that older adults are likely to have co-morbidities which bring greater complexity to adopting and maintaining healthy lifestyles [23,24]. In this study, all older cancer survivors had multiple chronic conditions, which is important to consider when determining their specific needs and barriers to physical activity [25,26]. For example, more tailored messages about how to manage chronic conditions and tips on easy access to opportunities for physical activity and enhanced communication with healthcare providers may be helpful [27-29]. We also need to explore innovative multicomponent interventions to tailor the needs of older adults [30]. Online and mobile health programs designed for older adults need to tailor for their literacy level, cognitive function, and physical abilities [31].

Conclusions

Since the population of older cancer survivors is expected to grow; interventions to improve quality of life among this population are timely and will continue to be needed at even greater levels. The high rates of Internet access and mobile phone ownership throughout the United States and globally have driven greater searches for health-related information online via various mobile devices. Thus, the utility of this timely research is of global interest. Our next steps will be focused on two aspects: building the mobile app with support for communication with smart devices (eg, devices with sensors), and disseminating this mobile-enabled app to greater numbers of older cancer survivors.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Demographics, health conditions, and use of mobile tools among participants (baseline and follow-up).

[PDF File (Adobe PDF File), 111KB - [cancer_v1i1e7_app1.pdf](#)]

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