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Original Paper

eHealth in Modern Patient-Caregiver Communication: High Rate of Acceptance Among Physicians for Additional Support of Breast Cancer Patients During Long-Term Therapy

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Abstract

Background: Lack of adherence and compliance with drug regimens among breast cancer patients represent substantial problems in oral therapies, leading to significant impacts on mortality. Where other systems have failed, electronic health (eHealth) could be a possible solution to improve medication intake, along with the doctor-patient relationship. Initial results from studies concerning new interventions for therapy support are promising, but reports suggest that general acceptance of new treatment support tools is needed among patients and physicians alike.

Objective: The aim of this study was to investigate the actual use of the Internet and other modern media among physicians involved in breast cancer treatment.

Methods: Using a standardized questionnaire, actual utilization of new media among physicians was analyzed. Internet-related behaviors in private, as well as in business life, were investigated. Attention was focused on physicians' opinions regarding modern eHealth tools and how patients could be best supported to enhance adherence.

Results: A total of 120 physicians, all participating in breast cancer care, completed the questionnaire (median age 41 years). Almost all participants (99.2%, 119/120) used the Internet for general purposes and 98.3% (118/120) used it for medical issues as well. Virtually all medical professionals (99.2%, 119/120) reported that they owned a computer, while more recently invented technologies such as tablets and smartphones were owned by 31.9% (38/119) and 73.1% (87/119), respectively. The Internet was favored by 66.4% (79/119) of the physicians in our survey as a source for patient support; 71.2% (84/118) would also favor modern media for side effect registration. Based on our analysis, the most frequent Internet-utilizing physicians were characterized by age <60, worked in a hospital, and were employed as a junior physician.

Conclusions: This study demonstrated a high usage of Internet-related technologies among physicians, indicating that the use of eHealth for advanced and individualized support in breast cancer care is a promising addition to treatment management. Such technologies have the potential to enhance adherence and compliance in therapy among cancer patients.

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KEYWORDS

eHealth; mobile health; telemedicine; physicians; acceptance; breast cancer; patient compliance; patient adherence

Introduction

The Internet has become increasingly relevant for daily use across the globe. General Internet usage among the population of the European Union has increased from 49% in 2006 to 72% in 2013 [1]. In total, approximately 3 billion people around the world used the Internet in 2014, which constitutes an increase of 0.6 billion users since 2012 [2,3].

As reported in 2003, 4.5% of all queries performed on the Internet concerned health-related issues, which represented approximately 67.5 million health-related searches being performed every day [4]. Electronic health (eHealth) and mobile health, as modern mechanisms of patient management, are enhancing the support systems for many different diseases [5,6].

eHealth applications are being successfully used in industrialized countries. Particularly in chronic diseases, such as hypertension, heart failure, or chronic obstructive pulmonary disease, many studies demonstrate that patients could benefit from using online eHealth support systems [7-10]. Many eHealth-related research studies have indicated that patients suffering from diabetes mellitus demonstrate positive, and often significant, improvements in therapy [11-13]. As reported by Appel et al, in the case of obesity among adults, weight loss in the interventional group (which was assigned to different types of online support or assistance by telephone) was higher than in the control group without such support. Reducing the body mass index among participants for 2 years demonstrated that eHealth systems also work over longer time periods [13]. In countries with few resources concerning medical care (eg, Nigeria), mobile phones are being used to improve the health status among cancer patients who cannot afford to visit their doctor every day [14].

A recently published article concerning breast and prostate cancer reported that patients experienced significantly lower symptom distress by using eHealth modalities compared to the control group [15]. Kuijpers et al reported that the usage of eHealth may not just work for chronic diseases, but may also have a positive effect on empowerment and physical activity (and therefore on quality of life) for cancer patients [16].

Breast cancer had a worldwide incidence of approximately 1.67 million in 2012, and is one of the most likely causes of death among women [17]. The implementation of antihormonal medication in endocrine-sensitive disease, or targeted therapies for patients with a human epidermal growth factor receptor 2-positive carcinomas, brought significant new treatment options for women suffering from breast cancer [18]. These advances have resulted in patients undergoing oral treatments for ten years or more, during which time patients have minimal contact with their physicians.

Hershman et al were the first group to specify that early discontinuation and nonadherence during oral antihormonal therapy with tamoxifen or aromatase inhibitors had a significant impact on mortality. Among all patients who were included in the study (8769), 31% discontinued therapy (early discontinuation, meaning patients discontinued therapy after 180 days elapsed from prior prescriptions) [19]. The Patient's

Anastrozole Compliance to Therapy program also reported that even adding special educational materials to standard patient information did not have a significant positive effect on compliance or persistence with adjuvant endocrine therapy in breast cancer care [20]. However, some studies using eHealth interventions to enhance adherence have demonstrated promising results regarding improvements for these problems [21]. These trials suggest that using an eHealth-based support system may have a positive effect on compliance and adherence among breast cancer patients.

Before attempting to improve the connection between physicians and their patients by using the Internet during medical care, and to ameliorate the treatment of early and metastasized breast cancer, it is necessary to first investigate physicians' general attitudes concerning new media and Internet usage. Gund et al indicated that the majority of the health care professionals queried in their study had a positive attitude towards current and future eHealth tools for out-of-hospital care for patients with chronic heart failure [22]. The Telemedical Interventional Monitoring in Heart Failure trial also indicated that eHealth acceptance among medical professionals was very high [23]. The authors also reported that it is necessary for implementation of online support systems to evaluate the acceptance among patients, but also among physicians who have a central role in disease treatment [23].

The aim of this survey was to investigate Internet usage behaviors, and usage of other modern media (eg, smartphones), among health care professionals who were involved in the treatment of patients suffering from breast cancer. This study examined how physicians were equipped with electronic devices (eg, computers, mobile phones) and how they used them in general, and for medical matters in particular. This study also examined physicians' opinions regarding future eHealth applications, and the personal demographic information given by the participants (eg, age, qualification).

Methods

This study was submitted and accepted by the local ethics committee of the medical faculty of Munich University.

Participants

Physicians involved in breast cancer treatment were invited to participate in our survey. The questionnaire was handed out to participants on two occasions in 2012: First at the COMBATing Breast Cancer conference in Munich, Germany, and later at a breast cancer-specific meeting organized by Tumor Center Munich. A paper-based questionnaire was provided for each participant. No individuals were excluded from the survey; all participants were given the opportunity to fill in the questionnaires voluntarily and anonymously.

Questionnaire

The German-language questionnaire contained 4 sheets; three listed questions and one contained information about the survey. The questionnaire was designed by the study investigators (Ludwig-Maximilians-Universität München Breast Center). No physician belonging to the study group completed the questionnaire, in an effort to prevent bias.

The questionnaire contained 33 items in total, separated into 3 sections. In the first section, participants were asked for general demographic information, including age, sex, place of residence and employment, year of examination, current qualifications, and medical specialty. The second section examined Internet usage in general and focused on participants' habits using the Internet for health-related topics. Participants were also interviewed regarding their possession of computers, mobile phones, and other electronic devices, how they use these technologies, and who is allowed to use these media at their place of employment (physicians only, or nurses and other co-workers). In the third section, the medical professionals were asked to state their opinions on future eHealth tools: part one asked about a telephone-hotline, which cancer patients could turn to for support; the second part contained questions focused on future support for patients using the Internet or smartphones, and collecting information regarding side effects of therapy via electronic devices. The responses for this part could be rated on a five-point scale from *agreement* (1) to *denial* (5).

Anonymity was assured by not collecting personal information such as names or birth dates. In each questionnaire, participants were asked to complete every single question, even though this was not absolutely necessary for data analyses. Each participant completed the survey once during one of the meetings. During each convention, participants were given written and verbal instructions to refrain from completing the questionnaire twice.

Statistical Analyses

Results were analyzed using IBM SPSS-Statistics. Student t-tests were used to examine differences between groups. To describe disparities between different parameters, odds ratios were used and *P*-values were computed with a level of significance <5%.

The questions in the questionnaire could be answered as single- or multiple-choice answers. In the third section, which focused on opinions regarding future eHealth tools, there were single answer possibilities of Grades 1 (*agreement*) to 5 (*denial*). For analytical purposes, Grades 1 and 2 were collected together as *agreement*, Grade 3 as *neutral*, and Grades 4 and 5 as *denial*.

Subgroups were formed to further examine which type of physician was most likely and willing to use the Internet or smartphone-related health support systems. Significant differences were evaluated, taking into account gender, age groups, medical facilities, qualifications, and size of the city in which physicians were employed.

Results

Participants' Sociodemographic Characteristics

A total of 120 active medical professionals completed the questionnaire, out of 154 participants who attended one of the events in which data was collected. The median age of participants was 41 years, and the cohort was 57.5% (69/120) female and 40.8% (49/120) male (Table 1). More than half (60.8%, 73/120) of all participants worked in a hospital institution; of these, 65.7% (48/73) worked in a university hospital. Approximately one quarter (26.7%, 32/120) of respondents were employed in any sort of practice. Approximately two thirds of the attendees were gynecologists (68.3%, 82/120), and 46.7% (56/120) were treating patients as gynecological oncologists. A small number of physicians with origins in other medical specializations completed the questionnaire (hematologists and oncologists: 9.2%, 11/120; radiation therapists: 7.5%, 9/120; radiologists: 1.7%, 2/120). All participants were German, which was assured by reporting the region of Germany in which participants were employed.

Table 1. Physicians' sociodemographic characteristics.

Participants' characteristics	%	n/N
Gender		
Female	57.5	69/120
Male	40.8	49/120
Not available	1.7	2/120
Median age in years (range)	41 (25-68)	
Age		
20-29	16.8	19/113
30-39	23.9	27/113
40-49	30.1	34/113
50-59	22.1	25/113
60-69	7.1	8/113
Current qualification		
Medical student	2.5	3/120
Junior physician	16.7	20/120
Board certified specialist	26.7	32/120
Senior physician/head of department	21.7	26/120
Chief physician	17.5	21/120
Others	6.7	8/120
Not available	8.3	10/120
Interdisciplinary specialization		
Oncology (gynecological specialist)	46.7	56/120
General gynecology	21.7	26/120
Hematology and oncology	9.2	11/120
Radiation therapy	7.5	9/120
Radiology	1.7	2/120
General surgery	0.0	0/120
Others	9.2	11/120
Not available	4.2	5/120
Medical facility		
Ambulatory/private practice	25.8	31/120
Medical care center	0.8	1/120
General hospital	5.0	6/120
Hospital with high grade of specialization	1.7	2/120
Teaching hospital	14.2	17/120
University hospital	40.0	48/120
Others	5.0	6/120
Not available	7.5	9/120

Usage of Modern Media and Internet

Almost all participants used a telephone and 73.1% (87/119) of the participants owned a smartphone (Table 2). The ownership of private computers among physicians was very high. The most favored computer was the notebook (83.2%,

99/119), followed by 60.5% (72/119) of physicians who were in possession of a desktop personal computer. Tablet computers were owned by 31.9% (38/119) of the participants. Above age 60, the percentage of physicians owning a tablet declined to less than 12.5% (1/8). With regards to more recently developed devices, smartphones were owned by 71.3% (75/105) of the

participants younger than 60, and by 50% (4/8) of those above 60 years of age. Most physicians (89.7%, 105/117) used the

Internet at work, and in most cases nurses and physicians' assistants were able to use the Internet at work (74.6%, 88/118).

Table 2. Actual usage of modern media by breast cancer specialists.

Technology and media	%	n/N
Phone		
Any type of phone	99.2	119/120
Landline phone	89.9	107/119
Any mobile phone	100.0	119/119
Mobile phone (no Internet)	47.1	56/119
Apple iPhone	53.8	64/119
Smartphone using Android	13.4	16/119
Smartphone (others)	5.9	7/119
Private computer		
Any type of computer	99.2	119/120
Personal computer with Internet access	60.5	72/119
Notebook with Internet access	83.2	99/119
Apple iPad	26.9	32/119
Tablet using Android	5.0	6/119
Tablet (others)	0.0	0/119
Internet access at workplace		
Internet access	89.7	105/117
Divided patient-network and Internet access	10.3	12/117
No Internet access	0.0	0/117
Internet usage at workplace		
Physicians	97.5	115/118
Nurses/physicians' assistants	74.6	88/118
Other coworkers	66.1	78/118
Mobile phone usage		
Always with me	78.0	92/118
Only en route	16.1	19/118
Mostly at home	0.8	1/118
Mostly out of use	5.1	6/118
Smartphone usage		
Business and private	90.9	80/88
Private only	9.1	8/88
Business only	0.0	0/88

Almost all (99.2%, 119/120) participants used the Internet for general purposes (Table 3). Approximately 84.9% (101/119) of medical professionals used the Internet in their daily routine, while the remaining 15.1% (18/119) used the Internet more than once per week. The majority of respondents took advantage of the Internet at home as well as at work. For health-related issues, the Internet was used by 98.3% (118/120) of physicians, and a smartphone was used by 38.1% (45/118) of respondents. Email

communication was the most frequently used function concerning the Internet, followed by reading online news or articles. Approximately one third of the participants (35.8%; 43/120) used the Internet for social networks and 31.7% (38/120) used the Internet for making calls via computer. Concerning health-related platforms, PubMed was the most used resource among physicians, followed by online guideline search (84.2%, 101/120) and Google (79.2%, 95/120).

Table 3. Internet usage among breast cancer specialists.

Usage	%	n/N
Internet usage in general	99.2	119/120
Frequency of Internet use		
Daily	84.9	101/119
>Once per week	15.1	18/119
<Once per week	0	0/119
Site of Internet use		
At home only	0.9	1/115
At work only	2.6	3/115
Both	96.5	111/115
Types of Internet use		
Email	98.3	118/120
Reading news/articles online	66.7	80/120
Wikis/online encyclopedia	60.0	72/120
Gain health information	41.7	50/120
Social networks (private)	35.8	43/120
Making calls via the Internet	31.7	38/120
Educational online courses	22.5	27/120
Social networks (business)	17.5	21/120
Types of Internet use (health-related platforms)		
PubMed	87.5	105/120
Online guideline search	84.2	101/120
Google	79.2	95/120
Adjuvant!	57.5	69/120
Wikipedia	52.5	63/120
Rote Liste (collection of all medications available)	48.3	58/120
Internet usage for health-related issues		
Yes	98.3	118/120
No	1.7	2/120
Smartphone usage for health-related issues		
Yes	38.1	45/118
No	61.9	73/118

Future Use of eHealth Tools

The desire to support patients via new media was accepted by the majority of participants. Table 4 gives a view of physicians' opinions regarding future eHealth tools. Grades 1 and 2 were summed, and therefore demonstrate *agreement*, Grade 3 demonstrates *neutral*, whereas Grades 4 and 5 represent *denial*.

Two-thirds of respondents (66.4%, 79/119) favored the option of their patients using the Internet as a source of support, while more than half (51.3%, 60/117) favored therapy assistance via smartphone. The online registration of side effects via new

media was favored among the majority of physicians (71.2%, 84/118).

If a system existed for the online registration of side effects, most respondents would want to be informed about problems concerning their patients' treatment via email (43.2% *agreement*, 51/118; vs 28% *denial*, 33/118) or via Internet-based platforms (35.7% *agreement*, 40/112; vs 33.0% *denial*, 37/112). Phones and fax machines were disliked for receiving information about side effects (phones: 14.0% *agreement*, 16/114; vs 67.5% *denial*, 77/114. Fax machines: 7.9% *agreement*, 9/114; vs 69.3% *denial*, 79/114).

Table 4. Physicians' opinions regarding future use of eHealth tools.

Description	Total (N)	Agreement, % (n)		Neutral, % (n)	Denial, % (n)	
		Grade 1	Grade 2	Grade 3	Grade 4	Grade 5
Support for patients via Internet	119	28.6 (34)	37.8 (45)	22.7 (27)	0.8 (1)	10.1 (12)
Support for patients via smartphone	117	24.8 (29)	26.5 (31)	25.6 (30)	9.4 (11)	13.7 (16)
Registration of side effects via electronic devices	118	31.4 (37)	39.8 (47)	12.7 (15)	7.6 (9)	8.5 (10)
Getting information about side effects via email	118	17.8 (21)	25.4 (30)	28.8 (34)	7.5 (9)	20.0 (24)
Getting information about side effects via Internet	112	9.8 (11)	25.9 (29)	31.3 (35)	8.0 (9)	25.0 (28)
Getting information about side effects via phone	114	6.1 (7)	7.9 (9)	18.4 (21)	19.3 (22)	48.2 (55)
Getting information about side effects via fax	114	2.6 (3)	5.3 (6)	22.8 (26)	14.9 (17)	54.4 (62)

To further examine how physicians wanted to receive information regarding side effects (Table 5), only the participants who *accepted* or *disapproved* new forms of communication were considered. The majority of medical professionals who accepted online side effect registration preferred to be informed via email or the Internet.

Table 5. Acceptance of documentation of side effects via new media.

Delivery method of registered side effects	Acceptance of side effect documentation, % (n/N)	Disapproval of side effect documentation, % (n/N)
Via email	53.0 (44/83)	36.8 (7/19)
Via Internet	46.8 (36/77)	21.1 (4/19)
Via phone	12.7 (10/79)	15.8 (3/19)
Via fax	10.0 (8/80)	26.3 (5/19)

Correlations and Further Analyses

To determine if there was a typical type of physician whose affinity for new media was particularly high or low, further evaluations were undertaken (Table 6). High rates of acceptance for Internet support were evident among physicians up to the age of 60. Above age 60 there was a distinct drop in acceptance levels, although acceptance rates never declined lower than 50% in the older age group. Concerning the acceptance of online side effect registration among physicians, acceptance decreased with increasing age, with the lowest approval rates in the 50-59 age group (68.4%, 13/19). With regards to medical professionals favoring smartphones for patient support, the highest percentage (90.5%, 19/21) was found in the 30-39 age group.

According to the physicians' place of employment, those who worked in hospitals (general or university hospital) preferred support and side effect documentation via the Internet more than physicians working in out-patient practices. Concerning participants' grade of qualification, junior physicians were the most likely to use new media for patient support regarding all three eHealth methods (Internet, smartphones, and online side effect registration). Gender was not a factor that influenced physicians' opinions on Internet support. Further analysis indicated that physicians who owned a smartphone were more willing to support their patients online (odds ratio 1.70, 95% CI 1.32-20.25, $P=.012$) than physicians who were not in possession of such technology.

Table 6. Subgroup-specific results for supporting patients via eHealth tools.

Characteristics	Acceptance of support via Internet, % (n/N)	Acceptance of support via smart-phone, % (n/N)	Acceptance of side effect registration, % (n/N)
Sex			
Female	85.5 (47/55)	65.5 (36/55)	80.0 (48/60)
Male	86.5 (32/37)	77.1 (27/35)	84.1 (37/44)
Age			
20-29	88.2 (15/17)	73.3 (11/15)	88.2 (15/17)
30-39	95.7 (22/23)	90.5 (19/21)	88.0 (22/25)
40-49	85.7 (24/28)	66.7 (18/27)	81.3 (26/32)
50-59	81.3 (13/16)	65.0 (13/20)	68.4 (13/19)
60-69	66.7 (4/6)	33.3 (1/3)	71.4 (5/7)
Medical facility			
Practice	78.3 (18/23)	68.2 (15/22)	76.0 (19/25)
Hospital	89.5 (17/19)	63.2 (12/19)	86.4 (19/22)
University hospital	87.2 (34/39)	73.7 (28/38)	82.2 (37/45)
Workplace city size			
Less than 1000	0.0 (0/0)	0.0 (0/0)	0.0 (0/0)
1000-9999	100.0 (2/2)	100.0 (2/2)	100.0 (3/3)
10,000-49,999	75.0 (12/16)	40.0 (6/15)	64.3 (9/14)
50,000-99,999	83.3 (5/6)	83.3 (5/6)	100.0 (7/7)
More than 100,000	88.4 (61/69)	75.8 (50/66)	82.5 (66/80)
Qualification			
Medical student	100.0 (3/3)	66.7 (2/3)	66.7 (2/3)
Resident physician	100.0 (18/18)	88.2 (15/17)	94.7 (18/19)
Medical specialist	90.9 (20/22)	72.7 (16/22)	82.1 (23/28)
Senior physician	80.0 (16/20)	59.1 (13/22)	82.6 (19/23)
Chief physician	86.7 (13/15)	71.4 (10/14)	76.5 (13/17)
Others	42.9 (3/7)	40.0 (2/5)	60.0 (3/5)

Discussion

The aim of this study was to describe Internet usage behaviors among breast cancer physicians, and to evaluate their opinions regarding future eHealth applications that may further improve breast cancer treatment. Many surveys have already demonstrated that it is possible to implement a patient support system using eHealth [7,10-13,24-31], but little is known about physicians' acceptance of such technologies. Our study provides information regarding actual Internet usage and modern media habits among gynecological oncologists, breast cancer specialists, and other physicians treating patients with breast cancer. Many surveys are being conducted in specialized centers that already make use of eHealth technologies, and therefore these physicians are considered to be interested in using modern media to communicate with their patients.

This study focused on breast cancer and oncological specialists employed in different work settings (practices and clinics), and participants were not considered to have had a great deal of

experience using eHealth technologies. Future improvements in the management of early and metastatic breast cancer may benefit from physicians' acceptance of new media, in addition to the patients using these resources themselves.

When examining general Internet usage among the participants (Table 3), almost all respondents were Internet users (99.2%, 119/120). This finding is comparable to another international study that examined physicians' characteristics regarding online database usage in regional hospitals (99.6%) [32]. Compared to the general population of Germany (where this survey was conducted), the incidence of daily Internet use (84.9%, 101/119) was higher among participants than the general population (81%) [33]. Email was favored as a communication tool by 98.3% (118/120) of survey respondents (compared to 93% of the general German population), while a similar percentage (66.7%, 80/120; vs 68%) used the Internet for reading news or articles online [33].

Examination of participants' and the general population's possession of new media indicated that a similar percentage of people owned any type of phone (99.2%, 119/120 vs 99.7%) [34]. The rate of computer ownership among medical professionals was 99.2% (119/120), which was higher than the general German population (85%) [34]. General Internet usage was lower among Germany's population (daily use 76%) compared to the participants in this survey (84.9%, 101/119) [35]. In contrast, the participants in our study belonged to a *high end collective* that uses the Internet and different media in their daily practice, as well as for conducting trials. It is assumed that this population owns more electronic devices (and may have more experience in using the Internet) than the general German population. By attending breast cancer-specific meetings (where this study was conducted), participants were considered to be very interested in general research, and therefore might have interests in modern media for patient support. This study only reflects the indicated use of modern media in a specific cohort of participants, which limits the broader applicability of our findings.

Although the questionnaires for this study were completed in 2012, we consider our findings to be up-to-date. General Internet usage (daily use or more than once per week) among German employees increased only 1% from 2012 to 2014 (from 96% in 2012 to 97% in 2014) [36]. Regarding the use of a computer, the percentage of the German population that owned a computer increased from 79% in 2012 to 82% in 2014 [37]. These facts indicate that there should not be a substantial change in percentages now, although we cannot easily calculate these data.

In addition to the high percentage of physicians using the Internet and being interested in future eHealth support, data was provided that 25.4% (30/118) of nurses or physicians' assistants had no access to the Internet in their workplace. Regarding this issue, we have conducted another survey, which will display nurses' opinions on eHealth and modern media use.

The typical physician that is most likely to use modern media for patient support and online therapy assistance (according to the data compiled in this study) is characterized by age <60, working in a hospital, and having the position of a junior physician (Table 6). Other characteristics (eg, gender or the population of the physicians' city) did not have an impact on opinions concerning future eHealth solutions. Chiu et al reported that age <50 is a significant factor for the usage of online databases, and that having a faculty position is a significant factor concerning online database usage [32]. This effect was not present in our study. Chiu et al also demonstrated that gender does not affect the likelihood of using the Internet for gaining information [32].

Our study indicates that there is a great deal of interest among physicians for implementing online support systems to provide additional therapy assistance. Oncologists who already owned

smartphones were more willing to support their patients using this type of media for therapy management than medical professionals who did not own a smartphone. This finding indicates that physicians who are already in possession of modern media are more likely to utilize eHealth.

Implementing new eHealth tools could lead to increased adherence and compliance, reduced health care costs, and consequently to improvements in breast cancer survival, as taking medication regularly is an important factor concerning mortality [19]. eHealth may also help oncologists monitor potential side effects more directly, and thus give physicians the chance to react immediately. Such advances have the potential to improve the doctor-patient relationship and communication between breast cancer patients and their health care teams.

Further studies investigating the opinions of other occupational groups working in breast cancer treatment (eg, nurses, psychologists) regarding future inventions will be useful to introduce a more personalized, patient-oriented approach for managing side effects. Furthermore, clinical trials using eHealth support in breast cancer therapy management are needed to investigate the actual usage of modern media and supportive tools, and their impacts on compliance and outcomes. Therefore, our working group is currently developing an online support system for therapy assistance (CanKado) [38], and future trials will examine the impact of this system on breast cancer treatment. CanKado, which will be one of the first projects to provide additional patient support to breast cancer patients, is an electronic support system that aims to increase therapy success in oncology. Such technologies have the potential to increase compliance, improve doctor-patient relationships, and potentially even improve disease outcomes in the near future.

Conclusion

This survey shows a high rate of Internet and modern media usage among physicians participating in breast cancer care. Online support, as well as online side effect registration, is favored by the majority of health care professionals surveyed. The routine usage of the Internet and modern media, and trust in new interactive communication tools, may enable improvements in doctor-patient relationships as well as in compliance and adherence among patients suffering from breast cancer.

Acceptance of such technologies by patients and other health care personnel involved in therapy management (eg, nurses) is also necessary. Moreover, the actual impact of new interactive media on oncological practice can only be investigated via trials that use newly-developed online platforms (eg, the CanKado-project [38]) for patient support. In conclusion, our results suggest that eHealth tools may have a promising future in patient-physician communication, and the treatment of breast cancer.

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Conflicts of Interest

None declared.

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Abbreviations

eHealth: electronic health

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Original Paper

Clinical Trial Electronic Portals for Expedited Safety Reporting: Recommendations from the Clinical Trials Transformation Initiative Investigational New Drug Safety Advancement Project

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Abstract

Background: Use of electronic clinical trial portals has increased in recent years to assist with sponsor-investigator communication, safety reporting, and clinical trial management. Electronic portals can help reduce time and costs associated with processing paperwork and add security measures; however, there is a lack of information on clinical trial investigative staff's perceived challenges and benefits of using portals.

Objective: The Clinical Trials Transformation Initiative (CTTI) sought to (1) identify challenges to investigator receipt and management of investigational new drug (IND) safety reports at oncologic investigative sites and coordinating centers and (2) facilitate adoption of best practices for communicating and managing IND safety reports using electronic portals.

Methods: CTTI, a public-private partnership to improve the conduct of clinical trials, distributed surveys and conducted interviews in an opinion-gathering effort to record investigator and research staff views on electronic portals in the context of the new safety reporting requirements described in the US Food and Drug Administration's final rule (Code of Federal Regulations Title 21 Section 312). The project focused on receipt, management, and review of safety reports as opposed to the reporting of adverse events.

Results: The top challenge investigators and staff identified in using individual sponsor portals was remembering several complex individual passwords to access each site. Also, certain tasks are time-consuming (eg, downloading reports) due to slow sites or difficulties associated with particular operating systems or software. To improve user experiences, respondents suggested that portals function independently of browsers and operating systems, have intuitive interfaces with easy navigation, and incorporate additional features that would allow users to filter, search, and batch safety reports.

Conclusions: Results indicate that an ideal system for sharing expedited IND safety information is through a central portal used by all sponsors. Until this is feasible, electronic reporting portals should at least have consistent functionality. CTTI has issued recommendations to improve the quality and use of electronic portals.

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KEYWORDS

clinical trials; investigational new drug application; risk management

Introduction

Safety reporting is a necessary element of clinical trials to help ensure patient safety during the investigation of a new drug or medical device. With advances in technology, safety reporting, along with other clinical trial data reporting, is moving to electronic formats from being largely paper-based. To encourage electronic submissions and integration of other technological capabilities into trial document management, the US Food and Drug Administration (FDA) has previously released guidance on electronic submissions and source data [1,2].

Aligned with this progress is the increased use of electronic portals to facilitate communication between sponsors and the investigative staff during clinical trials. Few publications in the scholarly literature have focused on portals; however, it is acknowledged within the clinical research field that use of portals is proliferating. Typically, clinical trial portals are developed by sponsors or contract research organizations (CRO) to provide a centralized location for trial-specific documents and information (eg, regulatory and safety documents, protocols, investigator brochures). Using clinical trial portals can reduce the time and cost associated with processing paperwork, among other advantages. The portal also provides increased security with document management and communication through the use of log-in identification and password protection. Once the portals are developed, investigators are given access to the portal through specific log-in credentials. Investigators can access trial-specific documents provided by the sponsor or CRO. Throughout the trial, investigators periodically log in to review safety reports.

The Clinical Trials Transformation Initiative (CTTI) is a public-private partnership whose mission is to develop and drive adoption of practices that will increase the quality and efficiency of clinical trials. CTTI initiated the investigation new drug (IND) Safety Advancement Project to investigate barriers to implementation of the FDA final rule on expedited IND safety reporting (Code of Federal Regulations [CFR] Title 21 Part 312) and propose solutions to address identified barriers, from the perspective of both investigators and sponsors. The project focused specifically on oncology research, where these issues tend to be most acute.

Evidence gathered during the project indicated that investigators have difficulty using clinical trial portals and that portals may

contribute to confusion and burden investigators' experience related to the IND safety reporting system. Therefore, the CTTI project team sought to identify best practices for managing IND safety reports using electronic portals and formulated recommendations based on data collected through evidence-gathering activities.

Methods

Approach

The IND Safety Advancement Project team included 20 individuals representing a wide range of stakeholders, including industry, academic institutions, institutional review board (IRB), regulatory, patient advocate, and other perspectives; all groups were considered equal partners. The primary focus of the project was to investigate barriers related to the lack of implementation of the final rule (21 CFR 312) and provide recommendations for better compliance; however, a portion of this project was specifically devoted to addressing the use of clinical trial portals. The team employed 3 main research strategies to gather evidence: surveys, expert interviews, and an expert meeting.

Survey

An online survey was designed to assess challenges related to cancer researcher management of IND safety reporting processes, with a subset of questions about the specific challenges related to use of electronic portals to manage safety reports (Textbox 1). The survey was distributed to contact networks via CTTI, the American Society of Clinical Oncology, the American Association of Cancer Institutes, and the US Oncology Network. Recipients were encouraged to freely forward the survey to colleagues; because no data is available describing the number of potential respondents who had access to the survey, a formal response rate cannot be determined. To establish face validity, the survey was reviewed and pilot-tested on a subset of the intended population, but no formal validation or internal consistency checks were performed. Participation was voluntary, anonymous, and uncompensated. The survey was distributed via Constant Contact, an online marketing company, and completed through Qualtrics. Survey data collected from November 18, 2014, through December 30, 2014, were aggregated by the Duke Center for Learning Health Care and distributed to project team members for descriptive analysis. The complete survey can be viewed online [3].

Textbox 1. Survey questions on clinical trial portals.

Questions on current issues:

- If IND safety reports are distributed via a sponsor safety reporting portal, do you have difficulty accessing the IND safety reporting portal?
- Please describe the difficulty you have accessing the IND safety reporting portal.

Questions on suggestions for improvement:

- What things about the current IND safety reporting system should be changed?
- If you were starting from scratch, what would an ideal IND safety reporting system look like?

Qualitative Interviews

A total of 20 in-depth, hour-long interviews were conducted by a professional interviewer as an opinion-gathering effort to more fully understand sponsor and investigative staff perspectives on the management of IND safety reporting processes. Interview participants who were considered experts in the topic were approached by CTTI. Survey respondents were also able to volunteer for interview participation. In January and February 2015, 13 individuals representing investigative staff working on oncology clinical trials and 7 pharmacovigilance leaders from 5 large global pharmaceutical companies were interviewed. Prepared questions were included in an interview guide [4]. The goal was to understand the receipt and management of safety reports. None of the questions explicitly asked about the desired features of clinical trial portals; however, interview respondents were free to comment on their experiences with trial portals and were encouraged to elaborate on current challenges and suggestions for improvement.

The project, including the surveys and interview guides, was designated as exempt research by the Duke University IRB.

Expert Meeting

The IND Safety Advancement Project team analyzed survey results and interviews, developed draft recommendations based on responses, and presented this information at a 2-day expert meeting in July 2015 attended by 47 individuals representing a variety of clinical trial stakeholders. Discussion from the meeting was used by the project team to refine the recommendations through iterative, consensus-driven discussion, and they were approved by CTTI's Executive Committee prior to official release (December 2015) [5]. Approximately half of 1 meeting day was devoted to discussing the common problems with and desired features for clinical trial portals. A summary of the expert meeting is available online [6].

Results

Overview

The survey had 201 respondents. The majority of the respondent population had academic or community-based research backgrounds with more than 10 years of clinical trial experience. A majority of the respondent-affiliated organizations conducted more than 30 studies concurrently and represented all phases of clinical trial development sponsored by industry and government. Full results of the survey and interviews are being reported concurrently elsewhere [7]. This manuscript focuses only on data related to clinical trial portal use.

Current Issues

Responses from investigators and other study staff indicate that 80% (33/41) of investigators and 92% (133/144) of study staff received IND safety reports through portals. Approximately half (21/41, 51%) of investigators and 44% (64/144) of staff reported difficulty accessing sponsors' IND safety reporting

portals. When survey respondents were asked to provide free-text responses specifying difficulties encountered accessing a portal, a common answer was the problem of remembering passwords for numerous individual sponsor portals. Other difficulties voiced by respondents were challenges with operating systems, software compatibility, and differing application versions. Respondents indicated that many interfaces are difficult to navigate and do not incorporate intuitive design elements. Additionally, many portals have slow processing times, and their applications often crash or fail. For these reasons, downloading reports can be time-consuming for the investigative staff. Finally, respondents noted that generic email notifications are not particularly helpful and many choose to block these emails. The top-rated challenges were as follows:

- Remembering numerous, complex passwords for individual sponsor portals
- Encountering problems related to different operating systems, software compatibility, and application versioning
- Navigating through nonintuitive user interfaces and slow sites
- Encountering log-in or site issues due to investigative staff turnover
- Receiving too many generic email notifications
- Time-consuming process of downloading reports

Although distribution of streamlined reports via electronic portals was intended to improve the efficiency of the safety reporting process, interviewees from investigative sites reported that they continue to receive an unmanageable volume of IND safety reports. Active sites described the volume of reports as "staggering."

Beneficial and Desired Features

Respondents described a number of benefits related to use of portals for safety reporting, including automatic notifications of trends or unexpected adverse events, which help guide treatment decisions for patients. Investigative staff indicated that it was easier to identify risks when reports were submitted through the portal. Summary reporting and the defined attribution and causality available on the portal can help filter the safety information for study staff. With enhanced signal detection, the investigative staff can identify information that may generate important changes to the protocol or consent and help them make determinations on the utility of the study and other risk/benefit assessments. Additionally, electronic reports are more efficient and easier to retain and track.

The attributes displayed in [Textbox 2](#) were identified as important and desired features of electronic portals based on the project team's analysis of the survey responses, which highlighted the inconsistent functionality with current portals. These desired attributes can be categorized as improving (1) the overall system functionality, (2) the user interface, (3) report management and analysis, and (4) report notification, acknowledgement, and verification.

Textbox 2. Clinical Trials Transformation Initiative official recommendations for attributes of electronic portals for expedited safety reporting: categories and desired features.

Overall system functionality:

- Cross-browser compatibility; portal works seamlessly with all commonly used browsers
- Operating system independent
- Mobile-friendly
- Quick report download time (ie, externally hosted, cloud-based)
- Simplified security management system (eg, end-user control over password management, biometric identification in lieu of passwords, and/or ability to integrate with various identity access applications)

User interface:

- Intuitive, easy-to-navigate interface requiring few clicks to access safety reports directly or via hyperlink contained in an email notification
- Flexibility within the portal for use with varied institutional processes

Report management and analysis:

- Print reports or download multiple reports with one click to a compact disc, computer, or electronic investigator site file
- Filter reports by event so follow-up safety reports do not appear as new events
- Search and display safety reports using custom dates, by country of origin and/or event name
- Export single reports as well as aggregated data
- Drill down to access single reports and write-ups
- Reports remain visible for the life of the trial

Report notification, acknowledgment, and verification:

- Ability to batch safety report notifications (per day/week) per investigative site user's preference
- Ability for principal investigator to delegate the task of accessing safety reports via portal to another person at the site
- Easy acknowledgement of safety reports by investigative site staff (eg, click on a link to the report, check a box, or check-all option)
- Ability to send and record acknowledgement of a safety report only once across multiple trials for the same investigational product yet still show the report under each trial
- End-to-end audit trail that can be printed and saved or stored for future reference by both the sponsor and investigative site
- Ability of the sponsor to document delivery of reports within the portal if an alternative means of reporting is required (ie, the sponsor cannot access the portal and requires hard copy)
- Two-way communication between the investigative site and sponsor regarding safety reports

Discussion

Summary

As described elsewhere [8], investigative sites are still being inundated with individual safety reports despite new reporting requirements issued in the final rule. A priority for investigators is to identify and review important safety signals to help ensure patient safety during a trial; this can be particularly challenging when there is a large volume of lengthy paper-based reports. Electronic portals have features that can assist with filtering reports, easing the burden on investigators; however, in the opinion of the investigative staff, certain features still need improvement.

Survey results indicated that an ideal system for sharing expedited IND safety information with investigative sites is through a central portal used by all sponsors in order to improve efficiency and reduce paperwork burden (recognizing that electronic systems may not be feasible for all study sponsors).

This approach may reduce the number of passwords and avoid technological issues (eg, software incompatibility) by standardizing the use of a central portal. While literature describing clinical trial portal use is limited, some reports validate survey respondents' perceived obstacles, indicating that investigative staff and investigators struggle to recall 7 to 15 passwords per individual user [9]. Until use of a single, central portal is feasible, electronic reporting portals should at least have consistent functionality.

The attributes listed in [Textbox 2](#) are suggested to increase portal efficiency and ease of use. As noted, important features include the following:

- Browser and operating system independence so that all users can access the portal regardless of software preferences
- An intuitive interface that is clearly labeled and provides easy navigation

- Ability to filter and search reports to quickly access only the relevant documents needed at the time
- Increased functionality to batch reports so that all files can be downloaded simultaneously
- Ability to acknowledge receipt quickly with a check-box option and to update this acknowledgement across multiple trials for the same product

Portal features to more accurately track audit trails can be particularly helpful, as reports can be categorized or searched by date, number, compound, trial number, upload/availability date, download/access date, identity of users who accessed the report, and any actions (eg, downloading, printing, saving) conducted by a specific user. As indicated in [Textbox 2](#), notifications can be useful for study staff; however, given the high volume of reports received, some may be treated as spam. Another desired feature could provide a reminder to designate the source of the email so that it is routed and recognized appropriately. Currently, CTTI does not recommend an electronic signature requirement by the principal investigator or other investigative staff to access portal content, which is consistent with the FDA guidance.

To support appropriate use of the portal, CTTI also recommends that there be improved education for investigative sites including guidance not only on portal functionality but also regarding best practices for incorporating portal management into site report management processes. Finally, we recommend usability testing for portal-related educational material.

Limitations

The main limitation of the study that should be acknowledged is the small sample size that was selected by convenience, which may be susceptible to bias. Additionally, survey response rate was not able to be determined. CTTI acknowledges these shortcomings and that this research is exploratory and qualitative in nature and not statistically measurable. However, change often begins with small steps, and it is our hope that this research sparks a broader discussion across the industry. CTTI encourages additional research on this topic. The perspectives described in this manuscript are descriptive; in order to be conclusive, an appropriately powered study would need to be conducted. CTTI and other independent organizations cannot require that sponsors adopt recommendations nor mandate

inclusion or standardization of portal features, which is why we urge portal developers to consider the perspectives of the portal users to drive change.

Industry technology companies are investing in integrating sponsor trial portals with enhanced capabilities including interactive voice response, electronic data capture, clinical trial management systems, and investigator databases [9,10]. The ability to quickly identify and access individual reports can reduce workload burden and time spent searching considerably; however, it is important to assess how a newly introduced portal affects overall workflow of the study team. CTTI suggests that investigative site users receive more and improved education, including guidance on portal functionality in addition to best practices for incorporating portal management into site report management processes. Depending on the changes, portal management may need to be reevaluated. Finally, CTTI suggests performing usability testing for portal-related educational material in order to maximize the benefits of electronic portal use for IND safety reporting.

Conclusions

The suggestions provided in this manuscript have been released as CTTI recommendations [5]. CTTI believes these recommendations are timely, as a number of groups are currently working on the functionality of clinical trial portals. TransCelerate BioPharma Inc is one example; as noted in their press release, they have launched “a technology that will allow clinical trial sites to streamline investigative site information and establish a central access point for interaction between the site and multiple clinical trial sponsors” [10]. It is our hope that these and similar efforts will improve clinical trial portals. These recommendations combined with this description of desired features, along with other CTTI-developed educational materials, will be disseminated to stakeholders and the public through publications, presentations, and the CTTI website. The recommendations are intended to improve clinical trial portal development, access, and functionality and to enhance user experience overall. Clinical trial portals designed to address the current barriers can also save money for sponsors because they would no longer need alternate processes for safety reporting receipt and management; could increase site user satisfaction, compliance, and tracking; and may help investigators take immediate action on patient safety issues.

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Conflicts of Interest

None declared.

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Abbreviations

CFR: Code of Federal Regulations
CRO: contract research organization
CTTI: Clinical Trials Transformation Initiative
FDA: Food and Drug Administration
IND: investigational new drug
IRB: institutional review board

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Original Paper

EHealth Acceptance and New Media Preferences for Therapy Assistance Among Breast Cancer Patients

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Abstract

Background: Electronic health (eHealth) and mobile communication-based health care (mHealth) applications have been increasingly utilized in medicine over the last decade, and have facilitated improved adherence to therapy regimens in patients with chronic conditions. Due to the long duration of breast cancer therapy, and the long course of disease in metastatic breast cancer, a need for more intensified physician-patient communication has emerged. Various support mechanisms, including new media such as mHealth and eHealth, have been proposed for this purpose.

Objective: The aim of this study was to analyze the correlation between sociodemographic factors, as well as health status of breast cancer patients, and their current utilization of new media, or their willingness to use Internet and mobile phone apps for improvement of therapy management.

Methods: The survey for this study was conducted anonymously during the 2012 Mamazone Projekt Diplompatient meeting (Augsburg, Germany), which hosted approximately 375 participants per day. A total of 168 questionnaires were completed. The questionnaire aimed to assess sociodemographic status, disease patterns, and current use of new media (ie, Internet, mobile phone, and mobile phone apps) in breast cancer patients. Habits and frequency of use for these new technologies, as well as patients' affinity towards eHealth and mHealth tools for therapy management improvement, were investigated.

Results: Almost all participants used the Internet (95.8%, 161/168), with 91.5% (151/165) also utilizing this technology for health-related issues. Approximately 23% (38/168) of respondents owned a mobile phone. When asked about their preferences for therapy assistance, 67.3% (113/168) of respondents were interested in assistance via the Internet, 25.0% (42/168) via mobile phone, and 73.2% (123/168) via call center. Patients diagnosed with breast cancer <5 years before the survey were significantly more interested in a call center than patients diagnosed >5 years before survey participation.

Conclusions: The vast majority of breast cancer patients accept the Internet for therapy assistance, which indicates that eHealth is a promising medium to improve patient-physician communication. Such technologies may improve individual disease management and ultimately lead to an enhanced adherence to therapy regimens.

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KEYWORDS

eHealth; mHealth; breast cancer; adherence; compliance; new media; therapy improvement

Introduction

Breast cancer is the most common cancer among women, with a worldwide incidence of 1.4 million in 2008 [1]. In Germany, the mean age of breast cancer patients is 65 years, but 25% of newly diagnosed women in 2008 were younger than 55 years of age [2]. Due to early diagnoses and therapy advances such as adjuvant endocrine therapy, breast cancer survival rates have increased [3]. Patients with potentially curable breast cancer may be viewed as having a chronic disease, due to adverse treatment effects, other co-morbidities, and the burden of having a life-threatening disease that might recur [4]. Endocrine agents are useful breast cancer treatments, but therapy duration is crucial for optimal treatment benefit [5]. A study by Hadji et al revealed that breast cancer patients with a poor compliance to drug regimens are at high risk for early treatment discontinuation [6]. Thus, despite improved survival rates, breast cancer patients are still at risk for cancer recurrence [7], partly due to improper therapy usage. The long duration of adjuvant therapies may lead to diminished patient adherence (the World Health Organization Adherence Meeting defined *adherence* as the extent to which the patient follows the prescribed instructions [8]) and thus poor health outcomes. Increased adherence may lead to better health outcomes and decreased health care costs [8].

New technologies offer promising strategies to reduce treatment nonadherence. The Internet has become increasingly important and relevant for health-related purposes. In 2013, the Federal Statistical Office estimated that 79% of the population had Internet access in Germany, and Internet use had increased from 65% in 2006 to 79% in 2013 [9]. Another survey stated that almost two thirds of German Internet users search for health information online [10]. Kummervold et al reported that the sources that patients use for health information have changed (with a transition to the Internet), and consequently there was a decrease in patients contacting health professionals [11]. Rozenblum states that the Internet has become a powerful tool for communication and involvement of patients in their own health care [12].

Fogel and colleagues demonstrated a supportive benefit among Internet users with breast cancer [13], leading to more individual responsibility. Patients feeling insecure or overwhelmed during their face-to-face visits can better concentrate, and feel more motivated to ask questions or retrieve information, when communicating by email [14]. Breast cancer diagnoses often cause differing levels of depression, anxiety, and distress (even years after the initial diagnosis), necessitating further patient support [15]. In addition, by providing clear and accurate informative websites, breast cancer patients feel more prepared for their diagnoses [16]. Ybarra et al described the influence of health-related websites as an important influence on patient behavior, leading to less anxiety and increased self-efficacy [17].

Another effect that can be facilitated by new media is *self-management*. Self-management of patients leads to a more actively involved patient population and positively affects chronic disease management [18,19]. However, the prospective Patients' Anastrozole Compliance to Therapy study

demonstrated that the mere provision of educational material (without an interactive component) did not significantly improve compliance with aromatase inhibitor therapy in postmenopausal women with early, hormone receptor-positive, breast cancer [20]. Nevertheless, patients who truly understand their therapy concept may better adopt their care plans, and thus have enhanced adherence, if a more interactive approach is taken. The Internet already plays an established role in such interventions by conveying personalized messages [21]. Furthermore, mobile communication-based health care (mHealth) represents a highly developed tool, and another way to meet the challenges encountered in medicine. In Germany, 44.0 million people owned a mobile phone in 2015 [22], and according to an American survey, 25% of all mobile phone owners already use health care apps [23]. In order to monitor adherence, Morak et al proposed to record the intake of prescribed medication via mobile phone apps [24]. In a review, Fiordelli et al stated that the number of articles discussing mHealth has substantially increased over the last 5 years, and that the main focus of mHealth research is chronic conditions [25].

New technologies may provide an opportunity to improve physician-patient communication and secure better data exchanges. Furthermore, patient education and self-management may be achieved using electronic health (eHealth) and mHealth, eventually leading to better clinical outcomes. While many studies have already analyzed nonadherence in chronic diseases, few have focused on factors influencing breast cancer patients' affinity towards modern technologies. This study aims to identify breast cancer patients' sociodemographic and health factors influencing their affinity towards new media (ie, Internet, mobile phone apps, call centers), and their willingness to use such technologies for health-related problems.

Methods

Questionnaire

A German-language questionnaire was developed with the support of Mamazone and Brustkrebs Deutschland, two large German breast cancer advocacy groups. The questionnaire consisted of 33 items. To prevent any selection bias, the questionnaire was designed as a paper-based handout. This study was approved by the local ethics committee of the Ludwig Maximilian University. The questionnaire contained four parts: closed questions with different choices (parts 1, 2, and 4) and questions with multiple possible answers (part 3).

Part 1 included six sociodemographic items regarding age, sex, residential area (by postal code) and population, number of people per household, education, and employment. Education was divided into either junior high school (9 or 11 years of school attendance) or senior high school (13 years of school attendance). Patients with a university or doctoral degree were added to the group of patients who had a senior high school degree, since a senior high school diploma is a prerequisite for university studies or a doctoral degree.

Part 2 focused on the patient's health condition by examining the following parameters: Eastern Cooperative Oncology Group

(ECOG) score, diagnosis of breast cancer, time since initial diagnosis, metastatic status, therapy, diagnosis of other cancer, and menopausal status. ECOG was used to measure patients' current and subjective well-being and disease-related impairment of their daily life. The measure ranges from 0 to 5 (0=no restrictions from disease, 1=restriction in physically strenuous activity, 2=capable of self-care but unable to carry out work activities, 3=capable of only limited self-care, 4=incapable of self-care, and 5=deceased) [26].

Part 3 assessed the frequency of technology usage, including mobile phones, computers, the Internet, and apps via questions such as, "Which types of electronic equipment do you possess: telephone, computer?" Mobile phone and Internet habits were also examined.

Part 4 measured patients' interest in future interactions with new media. This section assessed patients' interest in purchasing a mobile phone for health support in general, the acceptance of therapy assistance via the Internet and/or mobile phone, the approval of the Internet and/or mobile phone for side effect documentation, and the acceptance of call centers for support (call centers that contact patients to ask for their well-being vs call centers that automatically transfer information to the physician). Answers for this part were rated from 1 to 5 (1=the highest acceptance, 2=high acceptance, 3=a neutral position, 4=low approval, and 5=no acceptance).

Participants

The survey was conducted during the 2012 Mamazone Projekt Diplompatientin meeting in Augsburg, Germany [27]. This meeting involved advanced training for breast cancer patients (and physicians) and took place over 4 days, hosting an average of 375 daily participants. The paper-based questionnaire was handed out on one day with 393 attendants (one questionnaire each), and was completed by the respondents during the meeting. Participation was voluntary and anonymous. There was no prior selection concerning sex, age, or ethnic groups.

Statistical Analyses

Descriptive statistics (ie, frequency, mean, and median) were used to characterize user patterns. In order to better understand patient preferences towards new media, a univariate analysis was used to explore demographic factors associated with certain response types. Odds ratios were used to compare the strength of the correlation between acceptance of new media usage and potential predictors. With the help of logistic regression, the odds ratios between groups were calculated, with a 95% CI. A *P* value of <.05 indicated statistical significance. We analyzed the data using IBM SPSS version 22 for statistical calculations.

Results

The questionnaire was completed by 168 of 393 participants at the Mamazone Projekt Diplompatientin meeting (return rate of 42.7%). Some questions remained unanswered on otherwise completed questionnaires (Table 1).

Part 1: Sociodemographic Facts

The majority of the participants were female (98.2%, 164/167) with a median age of 56.0 years (range 28-76 years). A small proportion of participants (3.9%, 6/154) were younger than 40 years, 12.3% (19/154) were between 40-50 years, 49.3% (76/154) were between 50-60 years, 26.0% (40/154) were between 60-70 years, and 8.4% (13/154) were older than 70 years. Approximately 26.7% (43/161) of patients lived in a household with at least three people, 44.7% (72/161) lived just with their partners, and 28.6% (46/161) lived alone. A senior high school degree was accomplished by 66.5% (111/167) of participants, and 33.5% (56/167) had graduated from junior high school. Approximately one third (32.9%, 53/161) were pensioners, 41.6% (67/161) were employed, 11.8% (19/161) were self-employed, and 1.2% (2/161) were unemployed (Table 1).

Part 2: Patients' Health

Most participants (97.0%, 163/168) identified themselves as breast cancer patients. Approximately half of all patients had suffered from breast cancer for more than five years (46.0%, 75/163), while 15.3% (25/163) were confronted with first diagnosis within the previous year. Furthermore, 25.6% (43/161) already had metastatic disease and 74.8% (119/159) were postmenopausal. More than two thirds of respondents had intravenous chemotherapy (72.6%, 122/168) and 9.5% (16/168) had undergone oral chemotherapy. Most participants (75.0%, 126/168) had undergone anti-hormone therapy and 22.0% (37/168) underwent antibody therapy. Almost all patients (97.6%, 164/168) had undergone an operation and 81.0% (136/168) had received radiation therapy. ECOG 0 and 1 were the most common answers when patients were asked about their physical status.

Part 3: Use of Media

Most participants (95.8%, 161/168) used the Internet. Table 2 outlines the reasons why, and how often, respondents searched the Internet. Multiple answers were allowed. The majority of participants used the Internet daily (61.3%, 103/168) or at least once a week (26.8%, 45/168), with 4.2% (7/168) rarely or never going online. The majority of Internet users (88.1%, 148/168) indicated that the purpose of their use was for reading or sending emails, and 53.0% (89/168) confirmed the use of online encyclopedias. In terms of web-based communication, 26.8% (45/168) of the participants expressed their affinity towards social networks and 16.1% (27/168) of the participants expressed their opinions online. Similarly, 92.1% (139/151) of patients with health-related Internet use specified their search interests. The performed tasks included: seeking general information about breast cancer (92.7%, 140/151), searching for information about physicians/hospitals (66.9%, 101/151), contacting physicians (12.6%, 19/151) or pharmacists (0.7%, 1/151), exchanging information with other patients (34.4%, 52/151), and searching for therapies (64.2%, 97/151) or scientific information (68.2%, 103/151). Approximately 9.8% (15/153) of the participants indicated mobile phone usage for health-related issues.

Table 1. Patient characteristics.

	%	N (amount/total)
Total	168	
Gender		
Female	98.2	164/167
Male	1.8	3/167
Age in years, mean/median (range)	54.6/56.0 (28-76)	
Education		
Junior high school and below	33.5	56/167
Senior high school and above	66.5	111/167
Residents in the local community		
<1000	7.9	13/165
1000-9999	19.4	32/165
10,000-49,999	29.7	49/165
50,000-99,999	5.5	9/165
>100,000	37.6	62/165
Employment		
Unemployed	1.2	2/161
Official	12.4	20/161
Employed	41.6	67/161
Self-Employed	11.8	19/161
Pensioner	32.9	53/161
Number of people per household		
1	28.6	46/161
2	44.7	72/161
3	13.7	22/161
>4	13.0	21/161
Diagnosed with breast cancer	97.0	163/168
Time since onset		
Last month	0.6	1/163
Last year	14.7	24/163
1-5 years ago	38.7	63/163
>5 years ago	46.0	75/163
Metastatic disease	25.6	43/161
Therapies		
Operation	97.6	164/168
Chemotherapy - intravenous	72.6	122/168
Chemotherapy - oral	9.5	16/168
Anti-hormonal therapy	75.0	126/168
Antibody therapy	22.0	37/168
Radiation	81.0	136/168
Other therapy	17.9	30/168
Menopausal status	74.8	119/159
Other cancer	7.3	12/165

	%	N (amount/total)
ECOG		
0	71.2	116/163
1	25.2	41/163
2	3.7	6/163

Table 2. Internet usage by patients with breast cancer.

	%	N (amount/total)
Internet use in general	95.8	161/168
Frequency of Internet use		
Daily	61.3	103/168
>1/week	26.8	45/168
>1/month	3.6	6/168
Rarely/never	4.2	7/168
Types of Internet use		
Email	88.1	148/168
Social networks	26.8	45/168
Reading online news, articles	48.2	81/168
Usage of Wikis/online encyclopedia	53.0	89/168
Search for information about products/services	54.2	91/168
Read/express opinions on the web	16.1	27/168
Participation in counseling/vote (ie, city planning)	8.9	15/168
Participation in online courses for private education/qualification	5.4	9/168
Internet use for health-related issues		
General information about my disease	92.7	140/151
Search for information about physicians/hospitals	66.9	101/151
Contact my physician	12.6	19/151
Contact my pharmacist	0.7	1/151
Exchanging information with other patients	34.4	52/151
Search for therapies	64.2	97/151
Scientific information	68.2	103/151
Mobile phone use for health-related purposes	9.8	15/153

Internet and mobile phone usage was examined, as detailed in [Table 3](#). All participants (100.0%, 25/25) up to the age of 50 used the Internet on a regular basis, and 81.8% (9/11) of the participants older than 70 years used the Internet for health-related issues. All participants (100.0%, 21/21) living in a household with more than 4 people, and 89.1% (41/46) of the participants who lived alone, were Internet users. Moreover, 97.3% (108/111) of the participants with a senior high school degree used the Internet and 93.6% (102/109) used it for health-related purposes. Most participants with a junior high school degree used the Internet (92.9%, 52/56) and many used

it for health-related purposes (87.3%, 48/55). There was no apparent correlation between place of residence or employment and the use of new media. When examining medical patient characteristics, 96.0% (24/25) of the patients diagnosed with breast cancer within the last year had already searched the Internet for health-related issues, along with 77.3% (58/75) of those diagnosed >5 years prior. Approximately 95.1% (39/41) of patients with metastatic breast cancer and 91.1% (102/112) of patients with a postmenopausal status searched the Internet for health inquiries. There was no correlation between therapies and Internet use.

Table 3. Comparison of Internet and mobile phone usage by patients with breast cancer.

Characteristics	Internet use in general % (n)	Internet use for health-related issues % (n)	Mobile phone owner % (n)
Total	95.8 (161/168)	91.5 (151/165)	22.6 (38/168)
Age (years)			
<39	100.0 (6/6)	100.0 (6/6)	50.0 (3/6)
40-49	100.0 (19/19)	100.0 (29/29)	31.0 (9/29)
50-59	98.7 (75/76)	90.8 (69/76)	19.7 (15/76)
60-69	97.5 (39/40)	89.7 (35/39)	20.0(8/40)
>70	61.5 (8/13)	81.8 (9/11)	15.4 (2/13)
People in household			
1	89.1 (41/46)	88.4 (38/43)	13.0 (6/46)
2	97.2 (70/72)	91.7 (66/72)	26.4 (19/72)
3	100.0 (22/22)	100.0 (22/22)	36.4 (8/22)
>4	100.0 (21/21)	95.2 (20/21)	19.0 (4/21)
Education			
Junior high school and below	92.9 (52/56)	87.3 (48/55)	17.9 (10/56)
Senior high school and above	97.3 (108/111)	93.6 (102/109)	25.2 (28/111)
Employment			
Unemployed	100.0 (2/2)	100.0 (2/2)	0.0 (0/2)
Official	95 (19/20)	94.7 (18/19)	20.0 (4/20)
Employed	97.0 (65/67)	91.0 (61/67)	17.9 (12/67)
Self-employed	100.0 (19/19)	100.0 (19/19)	36.8 (7/19)
Pensioner	92.5 (49/53)	88.2 (45/51)	20.8 (11/53)
Residents in the local community			
<1000	100.0 (13/13)	92.3 (12/13)	23.1 (3/13)
1000-9999	96.9 (31/32)	96.9 (31/32)	34.4 (11/32)
10,000-49,999	98.0 (48/49)	91.7 (44/48)	22.4 (11/49)
50,000-99,999	88.9 (8/9)	100.0 (9/9)	33.3 (3/9)
>100,000	93.6 (58/62)	86.7 (52/60)	14.5 (9/62)
Diagnosed breast cancer	92.3 (144/156)	85.9 (140/163)	22.1 (36/163)
Time since onset			
Last month	100.0 (1/1)	100.0 (1/1)	0.0 (0/1)
Last year	91.7 (22/24)	95.8 (23/24)	20.8 (5/24)
1-5 years ago	95.0 (57/60)	92.1 (58/63)	22.2 (14/63)
>5 years ago	90.1 (64/71)	77.3 (58/75)	22.7 (17/75)
Metastatic disease	95.1 (39/41)	90.7 (39/43)	27.9 (12/43)
Therapies			
Operation	92.4 (145/157)	86.0 (141/164)	22.0 (36/164)
Chemotherapy - intravenous	93.2 (110/118)	87.7 (107/122)	26.2 (32/122)
Chemotherapy - oral	93.8 (15/16)	87.5 (14/16)	31.3 (5/16)
Anti-hormonal therapy	90.9 (110/121)	83.3 (105/126)	21.4 (27/126)
Antibody therapy	94.4 (34/36)	97.3 (36/37)	24.3 (9/37)
Radiation	93.0 (120/129)	85.3 (116/136)	21.3 (29/136)

Characteristics	Internet use in general % (n)	Internet use for health-related issues % (n)	Mobile phone owner % (n)
Other therapy	93.1 (27/29)	86.7 (26/30)	26.7 (8/30)
Menopausal status	91.1 (102/112)	83.2 (99/119)	17.6 (21/119)
Other cancer	81.8 (9/11)	75.0 (9/12)	16.7 (2/12)

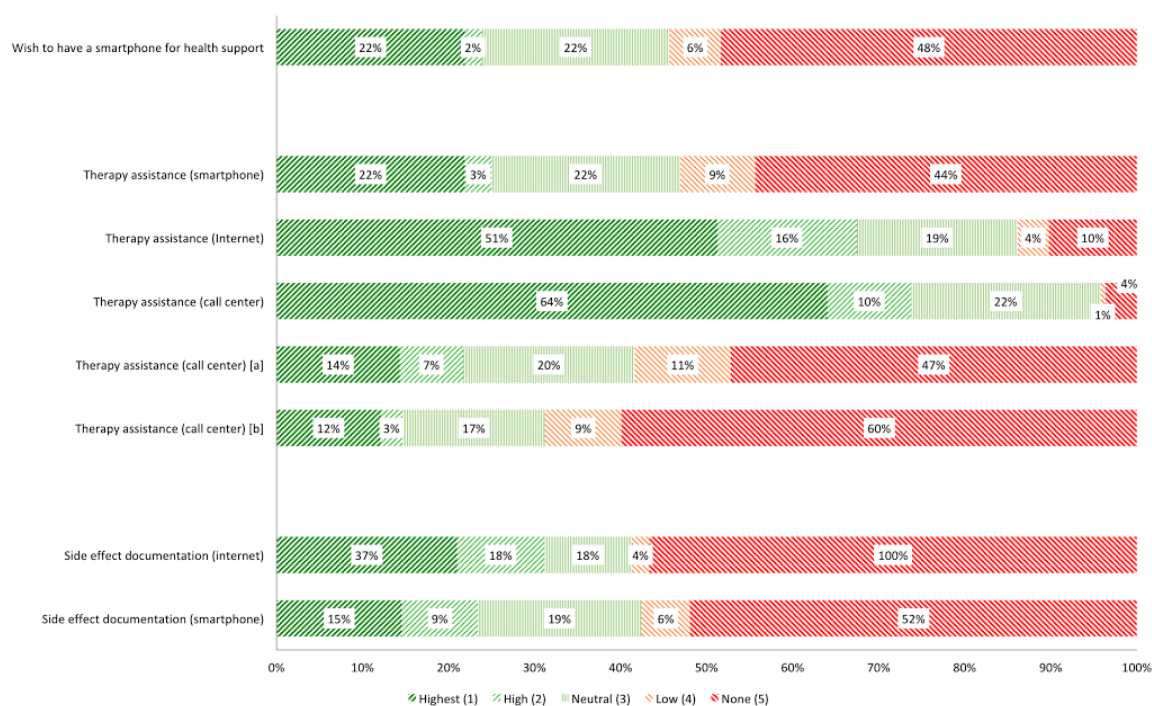
Almost one fourth of participants (22.6%, 38/168) owned a mobile phone, and younger participants were more likely to use this technology. Furthermore, 17.9% (10/56) of participants with a junior high school degree owned a mobile phone, along with 25.2% (28/111) of the participants with a senior high school degree. The highest ratio of mobile phone ownership was observed in self-employed patients (36.8%, 7/19), followed by pensioners (20.8%, 11/53) and public servants (20.0%, 4/20). Patients' health status did not correlate with mobile phone ownership.

Part 4: Patients' Future Interests

Figure 1 shows respondents' acceptance towards various types of communication. The affinity towards each technology is represented by different colors (green=high acceptance; light

green, straight lines= a neutral position; red= negative views or disapproval). A call center that a patient can contact for therapy support was acceptable to 73.2% (123/168) of participants, followed by the Internet (67.3%, 113/168), and mobile phones (25.0%, 42/168). Consequently, mobile phones were rejected by 52.9% (89/168) of participants, the Internet by 13.7% (23/168), and the call center by 4.2% (7/168). Approximately one fourth of respondents indicated a more neutral position towards each of the three categories. Call centers were approved if they actively called the patients and asked about the patients' condition (22.0%, 37/168), or if the center passed on information to the patients' physician (14.9%, 25/168). Furthermore, 54.8% (92/168) of the participants would agree to document their side effects via the Internet, and 23.2% (39/168) would do so via mobile phones.

Figure 1. Breast cancer patients' interests in further interaction with new media. a) those who call and receive information about your condition; b) those who pass forward information to your physician.



Potential Predictors for New Media Use

Odds ratios were used to demonstrate the impact of different factors on the participants' wishes regarding new media for therapy improvement (Table 4). The median age of patients was 56 years. The group of patients was divided into age ranges in order to analyze the impact of age on the use of each medium (>56 years vs <56 years). A highly significant difference was

observed when comparing the acceptance of mobile phones for therapy assistance ($P<.001$) and side effect documentation ($P=.002$) between younger versus older patients. Moreover, therapy assistance via call center ($P=.001$), via the Internet ($P=.036$), and acceptance of side effect documentation with the help of the Internet ($P=.024$), were significantly more likely to be endorsed by younger participants.

Table 4. Correlations of patients' characteristics and their desire for new media usage for therapy assistance.

Characteristics	Odds ratios (CI) with <i>P</i> values			
	Younger versus older	Multiple versus one-person household	Senior high school versus junior high school graduation	Time since onset <5years versus >5years
Acceptance of new media				
Having a mobile phone	1.79 (0.86-3.74) <i>P</i> =.084	2.46 (0.95-6.37) <i>P</i> =.042	1.57 (0.71-3.55) <i>P</i> =.176	1.97 (0.48-2.06) <i>P</i> =.567
Wish to obtain a mobile phone for health support	2.38 (1.06-5.33) <i>P</i> =.027	1.65 (0.68-4.02) <i>P</i> =.185	1.08 (0.48-2.43) <i>P</i> =.515	1.40 (0.63-3.09) <i>P</i> =.263
For therapy assistance				
Via mobile phone	4.15 (1.83-9.43) <i>P</i> <.001	2.68 (1.05-6.82) <i>P</i> =.026	0.96 (0.44-2.08) <i>P</i> =.532	1.26 (0.59-2.69) <i>P</i> =.342
Via Internet	2.64 (1.01-6.91) <i>P</i> =.036	2.78 (1.04-7.47) <i>P</i> =.039	1.17 (0.46-3.02) <i>P</i> =.458	2.50 (0.98-6.38) <i>P</i> =.042
Via call center	3.59 (1.66-7.77) <i>P</i> =.001	0.79 (0.35-1.81) <i>P</i> =.369	1.09 (0.51-2.34) <i>P</i> =.489	3.50 (1.62-7.55) <i>P</i> =.001
For side effect documentation				
Via Internet	2.24 (1.08-4.72) <i>P</i> =.024	1.68 (0.82-4.22) <i>P</i> =.103	1.02 (0.47-2.18) <i>P</i> =.557	1.85 (0.89-3.84) <i>P</i> =.07
Via mobile phone	3.45 (1.52-7.83) <i>P</i> =.002	1.91 (0.77-4.71) <i>P</i> =.114	1.05 (0.47-2.34) <i>P</i> =.536	0.97 (0.45-2.08) <i>P</i> =.54

Patients with a multiple-person household were significantly more often in possession of a mobile phone (*P*=.042), and more likely to accept therapy assistance via mobile phone (*P*=.026) or via the Internet (*P*=.039) compared to patients living alone. No trend was observed when comparing the acceptance of therapy assistance via call center (*P*=.369), or side effect documentation via the Internet (*P*=.103) or mobile phone (*P*=.114), when comparing household sizes.

Participants with a senior high school degree (compared to those with a junior high school degree) showed no significant difference when asked about their acceptance of new media for therapy assistance (mobile phone *P*=.532; Internet *P*=.458; call center *P*=.489). Moreover, participants with a senior high school degree were not significantly more often in possession of a mobile phone (*P*=.176), and do not accept mobile phones (*P*=.557) or the Internet (*P*=.536) more frequently for side effect documentation, than those with junior high school degrees.

When correlating the time since cancer onset with the desire for therapy assistance via new media, patients diagnosed <5 years prior were significantly more interested in therapy assistance via call center (*P*=.001) and the Internet (*P*=.042) than those diagnosed earlier. No significance was observed between the time since disease diagnosis and the acceptance of side effect documentation via the Internet (*P*=.07) or mobile phones (*P*=.54).

Discussion

The intention of our study was to examine the current use of computers, the Internet, and mobile phones among breast cancer patients, as well as their acceptance towards telecommunication

with health care providers. Patients who took part in the survey were very well informed (so-called *diploma* patients); this population was chosen intentionally, as eHealth is a relatively modern issue. The study questionnaire was handed out at a meeting with a full schedule of lectures, so a relatively low response rate was expected. Of the 168 participants, five stated that they did not have breast cancer, which may be due to mistakes, or because family or friends of patients completed the questionnaire.

We compared different sociodemographic and health care factors to technology usage. Future therapy-assistance interventions via new media could be focused according to patient characteristics. Although surveys have already investigated patient characteristics that may affect Internet affinity, this study entailed the first survey focusing specifically on breast cancer patients. It is unclear how many breast cancer patients show Internet affinity, or what their preferences towards new electronic devices actually are.

Our results demonstrate that 86.3% (145/168) of breast cancer patients have at least a neutral opinion towards using the Internet for therapy assistance, while 67.3% (113/168) highly approve it. Moreover, 54.8% (92/168) of patients were willing to document side effects via the Internet. Decisive factors influencing patients' willingness to use new communication technologies include age, number of people per household, and time since breast cancer diagnosis. Education is not a significant predictor for technology acceptance with regard to therapy improvement.

Considering the outcomes of other studies, it is already an established fact that participants using the Internet in general

(and for health-related issues in particular) are mostly young people [11,28]. Recently, Internet acceptance has reached an older age group, meaning that patients older than 60 years in our study are already more familiar with the Internet (88.7%, 47/53) than reported by other studies, in which only 41% of people older than 65 years used the Internet [29]. The patients in the current study possessed a particularly high level of interest in their health (*diploma patients*), while the Federal Office for Statistics reports that the general German population consists of healthy and nonhealthy inhabitants. However, comparing peoples' health-related Internet queries, it appears that 76% of women older than 65 years in the statistics of the Federal Office [29], and 89.7% (35/39) of the women between 60-69 years in our survey, search the Internet for health information. This trend indicates that the Internet is more appealing as a source of health-related information in older populations than general use of the Internet.

Regarding the acceptance of therapy assistance, younger patients were significantly more interested in new forms of communication and documentation of distressful effects via the Internet or mobile phones. Nevertheless, the results of our study demonstrate that participants of all ages have already searched the Internet for therapies and scientific information, along with information about physicians and/or hospitals. This finding indicates that using the Internet for health-related searches is already widespread, and appears to be feasible for most patients. Furthermore, the survey reveals a lower acceptance of communication via mobile phone features (eg, apps), and a significant and substantial difference between older and younger patients' consent towards therapy assistance via mobile phones. This result is not surprising, considering that in our survey, younger people were more often in possession of a mobile phone than the older patient population. Mobile phones are a medium with a quickly growing number of customers; in December, 2010, 14 million Germans were in possession of a mobile phone, and this number increased to 21 million in December, 2011, and 31 million in December, 2012 [22]. Demographic changes may have already spread further, as the questionnaire was completed in 2012 and Internet connectivity and functionality (and prices of mobile devices) are currently more feasible for consumers.

In summary, age appeared to be a significant factor for determining interest in therapy assistance via new media, but this trend may soon change, as Internet access and computer literacy are increasing in society. This trend agrees with Kummervold et al, who noted that the rate of Internet use for health-related issues in Germany increased from 24% in 2002

to 57% in 2007 [30]. Along with the demographic change, we assume that consumers will adapt to new media and thus use mobile phones more often for health concerns.

The second factor influencing patients' affinity towards new media was a multiple-person household. Patients living with a partner or with their children might have assistance with such technologies, and appeared to be more familiar with the Internet. In contrast, a call center was similarly accepted by all patients, regardless of how many people they lived with. This medium does not involve computer knowledge.

Comparing the affinity of breast cancer patients to new media and their time since diagnosis, it can be perceived that the longer patients have been living with the diagnosis, the less interested they were in searching the Internet for health-related issues. This effect may be due to the fact that patients living with the diagnosis for several years have already exploited numerous resources (ie, the Internet or support groups). Thus, these patients have already assembled more information than patients who were recently diagnosed with cancer. Moreover, patients diagnosed >5 years prior to answering the questionnaire might be older, and less interested in modern technologies.

Conclusion

The Internet, as a rapidly growing medium, was used by almost all participants who completed the questionnaire. Not surprisingly, when asked about their willingness to use new technologies for therapy improvement, the Internet was accepted by the majority of patients. However, not all users were interested in using Internet-based applications for therapy improvement. Among those already using the Internet, only two thirds were willing to use it for therapy improvements. The remaining respondents might be unwilling to use the Internet for such purposes due to unknown implementation of the potential applications. The questionnaire did not specify how new media can be used for health care concerns. To overcome this issue, it is necessary to tailor the implementation of eHealth to patients' individual needs. One approach to address this issue would be to explore the feasibility of new media with patients and physicians in a future survey. It will be important to focus further research on the technical availability and educational content of patient-specific applications. We determined that with the help of new technologies, self-efficacy (and thereby adherence to therapy regimens) may be improved. The results of the survey confirmed the potential of new media (ie, Internet portals or mobile phone apps) to provide continuous patient-physician communication.

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Conflicts of Interest

None declared.

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Abbreviations

ECOG: Eastern Cooperative Oncology Group

eHealth: electronic health

mHealth: mobile communication-based health care

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Original Paper

Online Social Engagement by Cancer Patients: A Clinic-Based Patient Survey

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Abstract

Background: The Internet is commonly used as a source of health information, but little is known about the Internet practices specific to cancer patients.

Objective: To understand cancer patients' use of the Internet as an informational resource and for social support.

Methods: The researchers conducted a survey of 1282 patients at a comprehensive cancer center to assess frequency of Internet access and online behaviors.

Results: Of the cancer patients surveyed, 1096 (85.49%) had Internet access; of those with Internet access, 953 (86.95%) reported going online at least weekly, and 747 (68.16%) reported daily online activity. Grouping Internet users by their level of online social engagement revealed that out of 1096 users, 331 (30.20%) had not sought out social connections online, 227 (20.71%) had read about experiences from other cancer patients, 410 (37.41%) had also written about their personal experiences, and 128 (11.68%) had participated in a formal online group for cancer patients. Increased online social engagement was associated with an increased perception that the Internet was useful for social support.

Conclusions: Internet use among cancer patients was common, and most patients reported that they found useful information about their cancer diagnosis online. Cancer patients who actively posted or shared content perceived more social support from the Internet than those who used the Internet solely as an informational resource or to read about other cancer patients' experiences. Physicians have a great opportunity to direct users to quality health information on the Web.

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KEYWORDS

cancer patients; Internet; information; social support

Introduction

In the past decades, there has been rapid growth in the use of the Internet among US adults. The Pew Internet and American Life Project found that 87% of adults have Internet access [1]. Using the Internet to search for health information is common among adult Internet users. The Pew Research Center also found that during the past 12 months, 80% of online adults searched

for health information, 26% of people reported reading about or watching another person's health experience, and 16% went online to connect with others who had the same condition, including 4.6% who took part in an online support group [2]. Patients themselves are not the only ones searching for health information online. Half of the information searches reported were done on behalf of someone else [3].

Cancer patients represent a growing proportion of health information seekers. There are 14.5 million cancer survivors as of 2014, and the current 5-year survival rate is 68%, up from 49% in the 1970s [4]. Data from the Health Information National Trends Survey (HINTS) showed that 81% of the cancer survivors had searched for information about cancer [5]. Younger individuals and those with higher levels of education were more likely to use the Internet as their first source of information, rather than their doctor. The National Cancer Institute also reported that up to 55% of cancer information seekers looked to the Internet first [6]. Other studies have found differing rates of Internet use for cancer prevention information seeking [7], as well as differing information needs by demographic and cancer-related characteristics [2,8].

While online searches for cancer information are common, less is known about cancer patients' familiarity with, and trust of, the Internet or how patients with different cancers differentially seek information on the Internet. People with serious health conditions may be more or less likely than the general public to turn to online resources. For example, a recent study by the Pew Research Center about chronic disease found that adults with chronic disease report lower rates of Internet use: 62% versus 81% in the general population. However, those people with chronic disease who go online are more likely to participate in online discussions and write blogs [9]. Recent studies of online forums for cancer patients have found that these resources can provide valuable emotional and social support for patients [10-15].

Online communities are popular and show promise for meeting cancer patients' needs for information and social support, but there is little known about patients' real-life experiences with a range of websites that can offer online communities [16], or how these online mechanisms can be used to improve social support for cancer patients [17]. This study aims to describe cancer patients' use of the Internet and, in particular, their engagement with online social activities related to their cancer diagnosis and treatment.

Methods

Survey Development and Study Population

A team of physicians, oncologists, cancer nurses, and communication/health literacy experts at the University of Michigan Comprehensive Cancer Center (UMCCC) developed a patient survey to assess a range of behaviors and health experiences of patients at the cancer center, including use of computers and the Internet, information and social support needs, basic demographic and health information, and quality of life. Questions for the survey were adapted from publically

available instruments, including the Pew Internet and American Life Survey [18] and the 2007 Health Information National Trends Survey [19]. The survey was reviewed and approved by behavioral health specialists, a patient advocacy group, and the cancer center administration.

Study staff approached all patients present at seven of the UMCCC clinics during a 2-week period from August 23, 2010, to September 3, 2010. Patients were asked at appointment check-in whether they would like to participate in the study. The paper-and-pencil survey took participants an average of 15 minutes to complete. Participation in the study was voluntary; however, if individuals agreed to participate, they were provided with a US \$2 incentive coupon to redeem at food services vendors within the hospital. Participation was also anonymous; no personal identifying information was collected from the patients. Paper survey responses were double entered and coded by a third-party vendor. This study was determined exempt by the Institutional Review Boards of the University of Michigan Medical School (HUM00039172).

Derived Measures

The independent variable used in this analysis was *level of online social engagement*; this was defined as the type of social interactions the participant reported online, was measured using questions about specific online activities related to health, and was adapted from the 2007 HINTS [19]. Internet users were categorized into four exclusive groups by their reported level of online social engagement. Those in the first group report *no social engagement*, such as reading about other patients or sharing their own experiences. The second group is comprised of *consumers* who read about other patients' experiences but do not share their own. The third group is *producers*, those who write about their own experiences as cancer patients and share with others. The final group is made up of individuals who participate in a *formal online group* related to their health diagnosis. Table 1 shows the full wording of all questions related to online social activities and this study's social engagement classification strategy.

Dependent variables for this analysis were related to the perceptions of Internet users. These included (1) usefulness of Internet for cancer-related health information, (2) usefulness of Internet for cancer-related emotional or social support, and (3) positive and negative Internet experiences. Usefulness questions were adapted from the HINTS [19]. The first two items asked patients, "How useful was the cancer-related information you got from the Internet?" and "How useful was the Internet in helping you get encouragement or emotional support (from family, friends, or others) in dealing with cancer or cancer treatment?"

Table 1. Levels of social engagement characterized by self-reported participation in Internet-based health activities.^a

Internet-based health activities	No social engagement	Social consumers	Social producers	Formal group
Read or learned about other patients' health experiences?	No	Yes	Yes or no	Yes or no
Wrote about or shared your own health experiences with other patients?	No	No	Yes to this one, or to one of next two items	Yes or no
Written or posted updates for family or friends about your health or how you are feeling?	No	No	Yes to this one, or the item above or below	Yes or no
Wrote in an online diary or blog?	No	No	Yes to this one, or to one of the above two items	Yes or no
Participated in an online support group or community for people with cancer?	No	No	No	Yes

^aParticipants were asked to respond to the following: "Below are some ways people use the Internet. Some people have done these things, but others have not. Please tell us whether or not you have done each of these things while using the Internet."

Patients reported reactions to their most recent online search for cancer information using questions adapted from the Pew Internet survey [18]. Patients were asked the following:

Think about the LAST time you searched for information about cancer or cancer treatments. At any point, did you feel: OVERWHELMED by the amount of information you found online; EAGER to share your new health or medical knowledge with others; CONFUSED by the information you found online; RELIEVED or COMFORTED by the information you found online; FRUSTRATED by a lack of information or an inability to find what you were looking for online; CONFIDENT to raise new questions or concerns about a health issue with your doctor; FRIGHTENED by the serious or graphic nature of the information you found online; REASSURED that you could make appropriate health care decisions.

Statistical Analyses

The distribution of demographic characteristics by levels of online social engagement were compared using chi-square tests for association. Because the survey was administered as a paper-and-pencil survey, there was some item nonresponse, especially among demographic variables. The primary analyses compared Internet usefulness and positive and negative experiences by level of online social engagement. The percentage of patients reporting the Internet as *somewhat* or *very useful*, as well as the 95% confidence intervals, was analyzed using chi-square analysis to determine whether the groups were significantly different in their ratings of Internet usefulness. In addition, Wilcoxon signed-rank tests were used to estimate if there were significant differences between ratings for information and social support usefulness. Comparison of usefulness ratings between levels of social engagement, with *no social engagement* as the reference group, was reported using unadjusted logistic regression.

The distribution of positive and negative experiences reported by cancer center patients were evaluated by first assessing each individual item across groups using chi-square tests for each individual item. Then two summary variables were created to represent the total number of positive and negative experiences by person. We then estimated the overall mean, as well as mean by level of social engagement, and used the Wilcoxon signed-rank test to assess whether significant differences between numbers of positive and negative experiences existed. Differences in the mean numbers of positive and negative experiences between groups were estimated using unadjusted ordered logistic regression. Finally, a variable representing the difference between the number of positive and negative experiences was analyzed using a one-way analysis of variance (ANOVA) to test the differences by level of social engagement. All statistical analyses were completed using Stata version 13.1 (StataCorp).

Results

Patient Characteristics

Table 2 summarizes the demographic and health-related information of this sample. The sample size for this study was 1282 patients, which represents a 75.01% (1282/1709) response rate of all scheduled patient visits during the 2-week survey period. Item nonresponse was low overall; the variables with the highest percentage of missing values were *years since cancer diagnosis* (87/1282, 6.79% missing) and *age* (40/1282, 3.12% missing). The majority of patients interviewed were female (768/1282, 59.91%), white (1133/1282, 88.38%), and over 50 years old (922/1282, 71.92%). Patients were highly educated; 44.77% (574/1282) had a college degree. The most common cancer diagnoses were leukemia/lymphoma (326/1282, 25.43%) and breast cancer (298/1282, 23.24%), which is representative of the patients at this center. About half of the patients were diagnosed with cancer in the past 2 years (613/1282, 47.82%), 72.23% (926/1282) reported at least one other major chronic health condition, and 35.26% (452/1282) of participants reported their health as fair or poor (see **Table 2**).

Table 2. Demographic and health data of the survey sample (N=1282^a).

Characteristic		n (%)
Gender	Male	512 (39.94)
	Female	768 (59.91)
Age in years	<50	320 (24.96)
	50-69	701 (54.68)
	70+	221 (17.24)
Race	White	1133 (88.38)
	Nonwhite	142 (11.08)
Education	High school or less	288 (22.46)
	Some college	407 (31.75)
	4-year degree or higher	574 (44.77)
Years since cancer diagnosis	<1	270 (21.06)
	1-2	343 (26.76)
	3-9	373 (29.10)
	10+	209 (16.30)
Cancer site^b	Leukemia/lymphoma	326 (25.43)
	Breast	298 (23.24)
	Cutaneous	176 (13.73)
	Prostate/urological	173 (13.49)
	Gynecological	161 (12.56)
	Gastrointestinal	144 (11.23)
	Sarcoma/soft tissue	80 (6.24)
	Thoracic	46 (3.59)
	Head and neck	41 (3.20)
	Thyroid/endocrine	23 (1.79)
	Neurological	12 (0.94)
	Other/unknown	17 (1.33)
Comorbid conditions	Any comorbid conditions	926 (72.23)
Self-reported health^c	Poor	100 (7.80)
	Fair	352 (27.46)
	Good	521 (40.64)
	Very good	215 (16.77)
	Excellent	55 (4.29)

^aCategories may not add up to the total of 1282 due to item nonresponse on demographic characteristics.

^bCancer site is nonexclusive.

^cPatients were asked, "How would you rate your current health?"

Internet Use

Table 3 summarizes the computer and Internet use reported by patients. Most (1096/1282, 85.49%) of the respondents reported using the Internet at least occasionally. Internet use was less common for males (427/512, 83.4% males vs 667/768, 86.9% females), people over the age of 70 (142/221, 64.3% 70+ years vs 620/701, 88.5% 50-69 years and 303/320, 94.7% <50 years),

and those with a high school education or less (174/288, 60.4% high school or less vs 365/407, 89.7% some college and 546/574, 95.1% 4-year degree or higher). Of Internet users, 86.95% (953/1096) accessed the Internet at least weekly and 68.16% (747/1096) accessed the Internet daily. Almost all Internet users had access through a high-speed or wireless connection (978/1096, 89.23%).

Table 3. Internet use and experiences of cancer center patients (N=1282).

Activity	n (%)
Have a home computer	1083 (84.48)
Use the Internet	1096 (85.49)
Daily Internet use	747 (58.27)
Looked for cancer information	862 (67.24)
Read about other patients' experiences	619 (48.28)
Wrote about own health experiences	234 (18.25)
Participated in an online cancer support group	128 (9.98)
Posted health updates for family or friends	452 (35.26)
Wrote in an online diary or blog	95 (7.41)

Patients reported participating in a range of online activities related to their health and diagnosis. The most common online activities were searching for cancer information (862/1282, 67.24%); searching for information about doctors, hospitals, and treatments (732/1282, 57.10%); and reading about other patients' experiences (619/1282, 48.28%) (see [Table 3](#)).

[Figure 1](#) shows the breakdown of Internet users (1096/1282, 85.49%) by their level of online social engagement. Over a third of Internet users (410/1096, 37.41%) were social producers, 30.20% (331/1096) reported no social engagement, 20.71% (227/1096) were social consumers, and 11.68% (128/1096) reported being part of formal online groups (see [Figure 1](#)).

[Table 4](#) shows the level of social engagement by key demographic characteristics of the patients. Females ($P=.003$), younger patients (ie, <50 years old) ($P<.001$), and those with more formal education ($P<.001$) were significantly more likely to engage in social interactions online. No other demographic and patient characteristics were associated with level of social engagement, including ethnicity, years since cancer diagnosis, presence of comorbidities, and current health status.

[Figure 2](#) summarizes patients' reporting of Internet usefulness by their level of social engagement. Overall, 81.02% (888/1096)

of Internet users rated the cancer information they found on the Internet as *somewhat* or *very useful*, and 62.96% (690/1096) of all Internet users reported that the Internet was *somewhat* or *very useful* for providing social support. Ratings of information usefulness were high for participants in all groups, ranging from 73% to 93%. However, social support usefulness was dramatically higher for individuals who were social media producers or who engaged in a formal online group compared to those who reported no social engagement ($P<.001$).

[Table 5](#) shows the percentage of patients by level of social engagement who reported one of the listed positive or negative feelings during their most recent search for cancer information online. Positive and negative experiences were common among patients who reported searching for cancer information online. Only individuals who searched for cancer information were included (913/1096, 83.30%). The most common experiences were feeling confident to raise new questions with their health care provider (546/913, 59.8%) and feeling reassured about making good health care decisions (541/913, 59.3%). There was significant variation by level of social engagement for all experiences. Increasing levels of social engagement were associated with increases in both positive and negative experiences (both $P<.001$).

Table 4. Level of social engagement of Internet users by key demographic factors (N=1096).

Characteristic	No social engagement, n (%)	Social consumer, n (%)	Social producer, n (%)	Formal group, n (%)	<i>P</i> ^a
All patients (N=1096 ^b)	331 (30.20)	227 (20.17)	410 (37.41)	128 (11.68)	
Gender					
Male (n=427)	152 (35.6)	85 (19.9)	154 (36.1)	36 (8.4)	.003
Female (n=667)	178 (26.7)	142 (21.3)	255 (38.2)	92 (13.8)	
Age in years					
<50 (n=303)	68 (22.4)	54 (17.8)	122 (40.3)	59 (19.5)	<.001
50-69 (n=620)	187 (30.2)	146 (23.6)	224 (36.1)	63 (10.2)	
70+ (n=142)	64 (45.1)	22 (15.5)	52 (36.6)	4 (2.8)	
Race					
White (n=968)	289 (29.9)	194 (20.0)	374 (38.6)	111 (11.5)	.13
Nonwhite (n=122)	41 (33.6)	31 (25.4)	34 (27.9)	16 (13.1)	
Education					
High school or less (n=174)	89 (51.2)	18 (10.3)	56 (32.2)	11 (6.3)	<.001
Some college (n=365)	106 (29.0)	79 (21.6)	137 (37.5)	43 (11.8)	
College degree (n=546)	132 (24.2)	128 (23.4)	213 (39.0)	73 (13.4)	
Years since cancer diagnosis					
<1 (n=234)	80 (34.2)	47 (20.1)	89 (38.0)	18 (7.7)	.15
1-2.99 (n=294)	83 (28.2)	56 (19.1)	119 (40.5)	36 (12.2)	
3-9.99 (n=329)	92 (28.0)	79 (24.0)	110 (33.4)	48 (14.6)	
10+ (n=177)	57 (32.2)	33 (18.6)	69 (39.0)	18 (10.2)	
Comorbid conditions					
None (n=327)	87 (26.6)	77 (23.6)	124 (37.9)	39 (11.9)	.28
1 or more (n=769)	244 (31.7)	150 (19.5)	286 (37.2)	89 (11.6)	
Self-reported health					
Poor (n=86)	23 (27)	17 (20)	31 (36)	15 (17)	.14
Fair (n=284)	80 (28.2)	58 (20.4)	115 (40.5)	31 (10.9)	
Good (n=449)	138 (30.7)	85 (18.9)	172 (38.3)	54 (12.0)	
Very good (n=197)	56 (28.4)	47 (23.9)	73 (37.1)	21 (10.7)	
Excellent (n=53)	22 (42)	17 (32)	10 (19)	4 (8)	

^a*P* values are from chi-square analyses comparing level of social engagement by patient characteristics.

^bCategories may not add to the total of 1096 due to item nonresponse on demographic characteristics.

Table 5. Cancer patients' reports of most recent Internet search for cancer information, among those who reported information searching (N=913).

Feelings reported	No social engagement (n=212), n (%)	Social consumer (n=212), n (%)	Social producer (n=364), n (%)	Formal group (n=125), n (%)	P
Overwhelmed	55 (25.9)	83 (39.2)	169 (46.4)	53 (42.4)	<.001
Eager	39 (18.4)	70 (33.0)	148 (40.7)	75 (60.0)	<.001
Confused	38 (17.9)	66 (31.1)	134 (36.8)	49 (39.2)	<.001
Relieved or comforted	45 (21.2)	104 (49.1)	163 (44.8)	87 (69.6)	<.001
Frustrated	23 (10.9)	50 (23.6)	99 (27.2)	44 (35.2)	<.001
Confident	67 (31.6)	141 (66.5)	243 (66.8)	95 (76.0)	<.001
Frightened	33 (15.6)	66 (31.1)	119 (32.7)	44 (35.2)	<.001
Reassured	74 (34.9)	128 (60.4)	236 (64.8)	103 (82.4)	<.001

Figure 3 shows the sum of positive and negative experiences reported by each Internet user by level of social engagement. Positive experiences were higher for all levels of social engagement (Wilcoxon $P<.001$). There was a significant difference between the means by level of social engagement,

as individuals who had no social engagement had the smallest difference (0.36 more positive than negative experiences on average), and those participating in formal groups had the largest difference (1.36 more positive experiences) ($P<.001$).

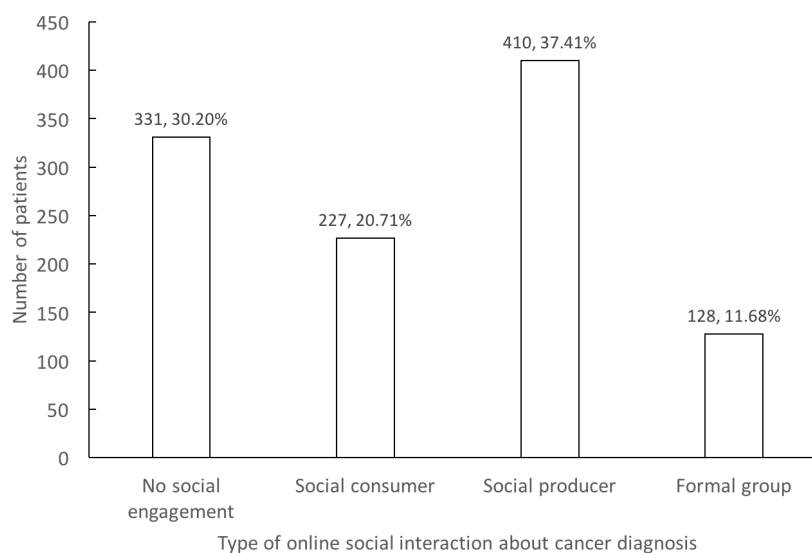
Figure 1. Breakdown of social engagement levels among Internet users (N=1096).

Figure 2. Percentage of patients reporting that the Internet was somewhat or very useful for information about cancer (top line) and social support (bottom line). Bars indicate 95% confidence intervals. Comparisons between the socially engaged groups' ratings and the "no social engagement" group were made and tested using simple logistic regression. * $P=0.001$, ** $P<0.001$.

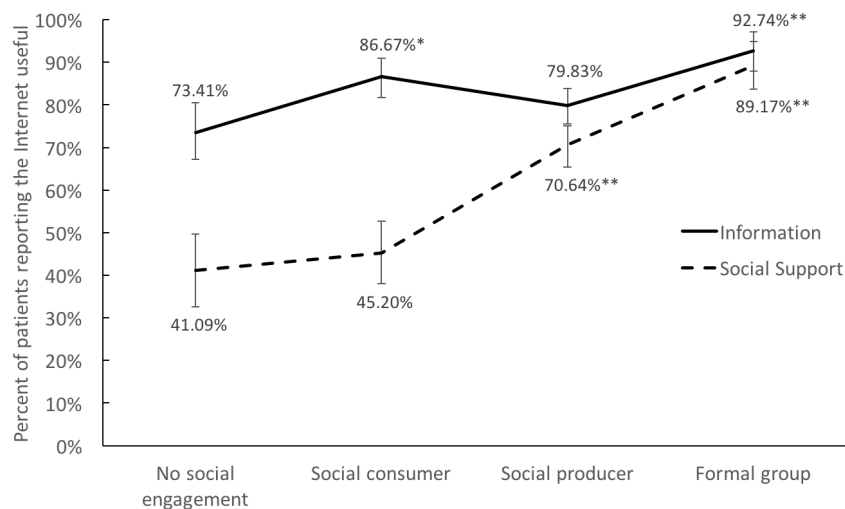
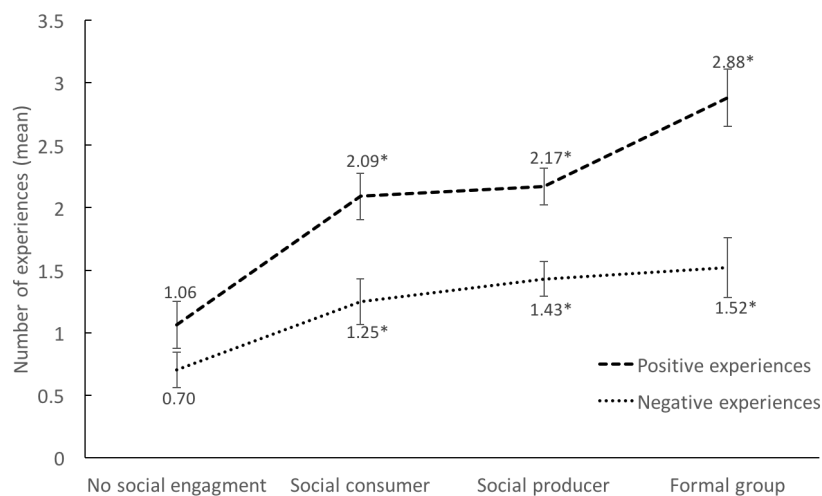


Figure 3. Mean of sum of the positive (top line) and negative (bottom line) experiences of cancer patients searching for cancer information online (n=801). Bars indicate 95% confidence intervals. Comparisons between the socially engaged groups' ratings compared to the "no social engagement" group were made and tested using ordered logistic regression (ologit). * $P<0.001$.



Discussion

Principal Findings

Our survey of cancer patients at a comprehensive cancer center found high rates of Internet use (over 80% of patients), including high rates of content production (over 50% of Internet users). Despite the high levels of reading about patients' experiences and sharing their own personal experiences, very few patients reported being a part of a formal support group.

The vast majority of patients reported that the information about cancer they were able to find on the Internet was useful. However, patients who have written about their own experiences or taken part in a formal group were much more likely to report that the Internet was useful for social support. These findings

support the validity of the categorization of social engagement. Patients who have no social engagement or who are solely social consumers were less likely to find social support from their Internet experience. However, social producers and patients engaged in formal support networks reported that the Internet provided them with the greatest social support as well as information about their diagnosis, suggesting that the real social benefits come from sharing personal experiences.

Regardless of the level of social engagement, both positive and negative experiences while online were common for patients. As people reported more social engagement, their numbers of positive and negative experiences also increased. However, there was a greater increase in the number of positive experiences than of negative ones. Overall, patients' experience of the Internet appeared more positive than negative, and

patients who engaged in social support networks online found value in those interactions.

Limitations

Observations from this survey have a few limitations. The information was collected from a single point in time, and no conclusions can be drawn about a causal effect of online behavior on feelings of social support. The University of Michigan has limited ethnic diversity and a highly educated sample, and the results here may not reflect the larger population of cancer patients and survivors. Finally, there have been rapid changes in the use of technology, especially on mobile devices, in the time since this survey was completed.

Future work should repeat the survey with a larger, more representative sample. This will allow researchers to better understand the population that is using the Internet for social support, and how Internet use varies by age, cancer type, and education. Understanding these differences can inform the development of cancer-specific Web resources that are appropriate for their audiences.

Comparison With Prior Work

Previous nationally representative studies have reported statistics about use of the Internet for searching for and sharing health information. The 2012 Pew Research Center study found that 26% of Internet users had read about or watched another person's experience with a health issue, and 16% of people reported seeking out other people with the same condition [3]. A report based on the 2008 Pew Research Center survey found that among patients with chronic diseases, 37% had read about someone else's experience online, 20% had created their own content related to their health condition, and 7% had participated in an online support group [9]. In this study of UMCCC patients, over half (58%) reported reading about others' experiences, 22% wrote about their own experiences, and 12% participated in a formal online group related to their health. That these percentages are higher than the national average or even the rates among people with chronic disease is not surprising, given the severity of a cancer diagnosis. These results are also consistent with analyses of the HINTS data, which have shown rising levels of cancer information seeking between 2003 and 2013 [5]. The HINTS data have also shown higher rates of social Internet functions among cancer-connected individuals compared to the general public, up to three times higher for activities like writing in a blog or participating in an online support group [2].

It is also important to consider how the online experiences of cancer patients compare to other health information seekers. Cancer patients in this study rated online information on cancer to be useful (41% *very useful* and 40% *somewhat useful*). This

is comparable to results from the HINTS, which found that 46% of online health information seekers rated cancer information to be *very useful* and 43% *somewhat useful* [19]. In contrast, cancer patients' emotional reaction to online information may differ compared to general health information seekers. In a 2006 report from the Pew Internet Project, people searching for health information generally reported high rates of positive experiences and low rates of negative experiences. The positive emotions included feeling reassured (74%), confident (56%), and relieved (56%). Negative feelings were reported much less frequently; 25% of respondents felt overwhelmed, 22% frustrated, 18% confused, and 10% frightened [20]. Among cancer patients at the University of Michigan, there were similar rates of positive experiences—69% reassured, 68% confident, and 51% relieved—but higher rates of negative feelings—45% overwhelmed, 36% confused, 33% frightened, and 27% frustrated. These higher rates of negative experiences mirror concerns that providers have about the quality of the information that patients access online [21,22].

Other recent studies have confirmed that looking online for health information and support has become the norm for most cancer patients: upwards of 80% [23-25]. Receiving a cancer diagnosis has become a recognized major life event, and patients and families have very high information needs in the weeks following an initial diagnosis [21,26]. The findings from this survey of cancer patients add to the growing evidence for the need for quality online avenues for patients. Despite the increasing dependence on online sources, most patients still consider their doctors to be their primary information source [25]. Rather than considering Internet searches a threat to physician-patient trust, there is evidence that patients who seek out information on their own are more active participants in their own care [22]. Providers may have a great opportunity to help patients by proactively recommending online resources that will provide quality information and support.

Conclusions

Internet use and health information searches by cancer patients was common in this sample, but there were varying rates of online social engagement among patients. About half of the cancer patients surveyed were social *producers* who posted and shared content about their experiences with cancer. Social producers were most likely to benefit from perceived positive social support via the Internet, and producing content was associated with higher occurrence of positive search experiences. These findings suggest the need for additional research to examine what types of information and messages lead to patients having positive experiences, and how health professionals can help patients avoid negative experiences online.

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Conflicts of Interest

None declared.

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Abbreviations

ANOVA: analysis of variance

HINTS: Health Information National Trends Survey

ologit: ordered logistic regression

UMCCC: University of Michigan Comprehensive Cancer Center

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Original Paper

Like or Dislike? Impact of Facebook on Ewing Sarcoma Treatment

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Abstract

Background: An increasing number of patients are raising their voices in online forums to exchange health-related information. Facebook is the leading social media platform with more than 1 billion international daily users recorded in the summer of 2015. Facebook has a dynamic audience and is utilized in a number of ways, discussing medical issues being one of them. Ewing sarcoma mainly affects teenagers and young adults. Additionally, many individuals within this age group are regular users of Facebook. However, little is known about the impact of this modern way of communication via Web-based platforms on patients with Ewing sarcoma and their social environment.

Objective: The aim of this study was to analyze and compare Ewing sarcoma patients' and relatives' behavior on Facebook to draw conclusions regarding the impact of Facebook on Ewing sarcoma treatment.

Methods: We examined a Facebook group named "Ewing Sarcoma Awareness" that is used to exchange information for both patients and relatives regarding Ewing sarcoma. A self-designed questionnaire was used to compare patients' and relatives' answers. Additionally, we analyzed all processes (posts, likes, threads, links) in the group for 6 consecutive months. A total of 65 members of the Facebook group (26 patients, 39 relatives) out of 2227 international group members participated in our study.

Results: More than 70% (46/65) of all participants reported that they use the group Ewing Sarcoma Awareness as a source of information about Ewing sarcoma. Of the participants, 89% (58/65) agreed on our scale from a little to a lot that being in contact with other affected people through the group makes it easier to handle the diagnosis. In this study, 20% (13/65) of all participants reported that the group affected their choice of treatment and 15% (10/65) of participants were influenced in the selection of their specialist. Regarding the recommendation of the Facebook group toward other people, significant differences ($P=.003$) were found comparing patients' and relatives' results. During the last 6 months most activities in the group concerned sharing destiny and handling the diagnosis.

Conclusions: The Facebook group Ewing Sarcoma Awareness has a relevant impact on group members regarding their choice of treatment. Moreover, participants turn toward the group to receive mental and emotional support in everyday life. Statements made within the group are in part questionable from a medical point of view and the impact made by these statements on patients' care requires further evaluation.

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KEYWORDS

social media; Facebook; Ewing sarcoma; social media networking

Introduction

Web-based communication is a convenient method of exchanging information regarding health and well-being and is thus increasingly growing in popularity and commonly used [1,2]. Because it is ubiquitous and easy to use, the Web has become the number one source for patients to gather information on health-related issues [2-5].

The term “Web 2.0” describes an interactive way of using the Web by exchanging information via blogs, platforms, podcasts, wikis, and online forums. These tools offer possibilities to simplify Web-based communication between Web users. In this way, the Web is not only a platform to acquire information from websites passively, but also a viable asset to create and share knowledge [6]. Furthermore, Web 2.0 enables users to collaborate by distributing information [7]. This rapidly growing way of using the Web has brought Web-based communication to a new level on social media platforms [2,8,9].

More precisely, the Web enables both experts and laymen to discuss and promote health-related information. Patients are increasingly using social media sites to share sorrow, to exchange information about handling their daily routine, and to discuss treatment options using evidence-based standard therapeutic regimens for various kinds of diseases. This development enables the creation of an active, self-managing, and responsible “expert patient” [10,11]. However, it seems reasonable then that patients might run the risk of receiving pseudoscientific and incorrect information [2].

The leading social media platform presenting medical issues is Facebook (FB). With a record of more than 1 billion active users per day in August 2015, the website FB is besides “Google” the second most viewed site in the world [12]. Facebook is the most frequently used Web-based communication platform [2,13-15]. In 2008, a study reported that 45% of medical trainees, 64% of medical students, and 13% of medical residents have FB accounts [16]. Among US adults, 61% search for health information on the Web, of whom 39% use social media such as FB for health-related information [17]. Considering the growth of FB during the last years these numbers can, therefore, be estimated even higher [15]. Because of its enormous accessibility especially for rare diseases like Ewing sarcoma, FB is a ubiquitous and easy way to connect people with others affected [15,18-20].

The peak incidence of Ewing sarcoma is between 10 and 20 years of age and coincides with the main age group of FB users [21-24]. A study by Duggan and Brenner [25] reported that 86% of all Web users aged between 18 and 29 years use FB, thus making FB an ideal platform for patients with Ewing sarcoma to connect with each other.

Ewing sarcoma is the second most common bone sarcoma after osteosarcoma with an incidence of 1 case per 1 million people [21]. The treatment of choice is neoadjuvant chemotherapy followed by a wide resection of the tumor and adjuvant chemotherapy [21-23]. Survival of patients following this therapy regimen has increased, and two-thirds of patients are cured of their disease [21]. With a 5-year survival rate of 78%

for children younger than 15 years and 60% for adolescents aged 15 to 19 years, Ewing sarcoma remains a severe diagnosis [21].

The diagnosis Ewing sarcoma poses an enormous challenge for young patients, their families, and their social environment. Because of its severity, Ewing sarcoma requires a treatment concept including also psychological aspects. It is well reported that cancer patients profit from peer-to-peer communication [15,26]. These days the Web provides various possibilities to get in contact with fellow sufferers, especially for rare diagnoses like Ewing sarcoma.

It is well known that the Web, particularly social media platforms, offers new dimensions to communication related to medical topics [2,27]. We believe that this way of communication has a relevant influence on the treatment regimen, the choice of consultant, particularly the choice of hospital, and dealing with the disease in general. Furthermore, this hypothesis might be underestimated in traditional treatment concepts.

However, little is known about patients’ and relatives’ behavior on social media platforms regarding Ewing sarcoma. The aim of this study was to examine the influence of interactive Web-based exchanges of information on the FB group “Ewing Sarcoma Awareness” (ESA) for patients with Ewing sarcoma and their relatives.

Methods

Facebook as a Search Engine

The most common way for a large number of people to communicate on FB is through “FB groups.” Facebook groups can be created by all FB users to communicate with a defined group of members about certain topics. To become a member of the group, one can either request to be a member or get an invitation from the group administrator.

In March 2014, we carried out a search for the term “Ewing sarcoma” using the FB search engine. The FB group used in this study is called Ewing Sarcoma Awareness. Ewing Sarcoma Awareness was by far the largest group we found for open Web-based communication for people affected by Ewing sarcoma. Ewing Sarcoma Awareness is defined as a public group and is available to all people with FB accounts. The group has two administrators who are able to control processes in the group. Facebook users are free to follow the group and to view all activity happening on the home page without being a group member. To become a member of the group a request has to be sent to the group administrators who grant admission to the group. The administrators are also able to remove group members or contributions posted to the page.

The ESA group’s main purpose, as declared in its description, is to facilitate the exchange of information regarding Ewing sarcoma for patients and other people affected by the disease (Figure 1). The exchange of information in the ESA group is mainly based on the home page of the group, where only members are able to post contributions. The types of contributions on the home page range from personal opinions,

statements, pictures, and videos to recommendations regarding treatment options, clinical trials, research results, hospitals, doctors, and much more. Members are able to comment, like, or add something to these posts creating lively discussions. To deepen the exchange of information, members are able to use FB chat to communicate via private messages that cannot be seen by other members.

At the time of our investigation, the group consisted of 2227 international members. Most group members indicated that they

live in the United States or Canada, although group members were from countries in all continents of the world. The group administrators and creators did not appear to be medical professionals or associated with health care institutions or organizations [28].

To get in contact with the group we created a FB profile that introduced ourselves to the social media community (Figure 2). Our FB profile became a group member of ESA group after confirmation of request by one of the group administrators.

Figure 1. Screenshot of the description of the Ewing Sarcoma Awareness group on Facebook.

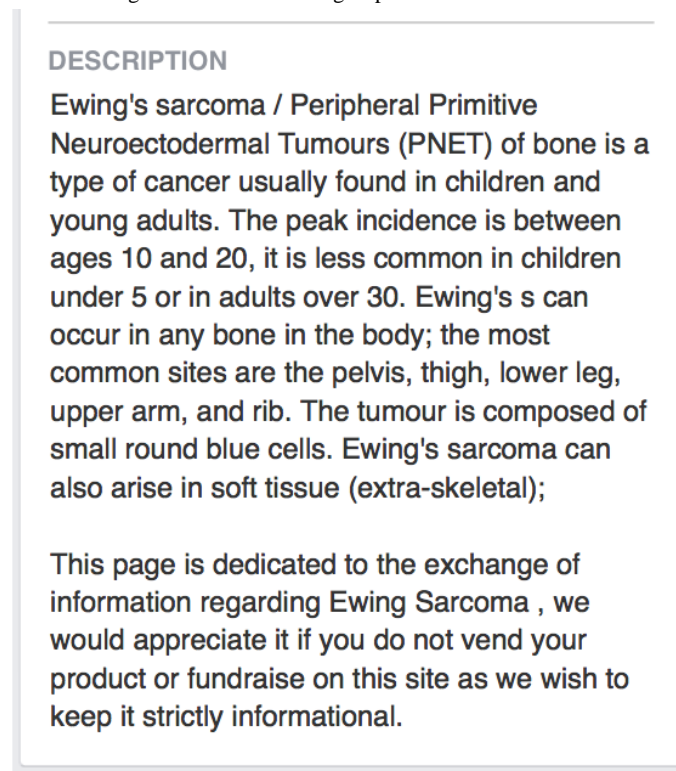


Figure 2. Screenshot of the home page of our research Facebook profile.



Questionnaire

We created a Web-based questionnaire using “SurveyMonkey” to analyze the group members’ behavior regarding their use of the Web and FB for people affected by Ewing sarcoma. SurveyMonkey.com was founded in 1999, and with more than 20 million users worldwide it is one of the leading platforms for Web-based surveys [29]. It offers tools to create and analyze Web-based surveys [29].

The self-designed questionnaire was developed on the basis of the “Checklist for Reporting Results of Internet E-Surveys” [30]. The survey was designed as an open survey for all ESA group members, consisted of 18 multiple-choice questions (Q), and was divided in 4 categories. The first category (Q1-Q4) dealt with the user’s behavior in the FB group. Categories 2 (Q5-Q8) and 3 (Q9-Q13) were composed of questions concerning the reliability and quality of information received in the group. Additionally, questions asking about the effects that ESA group has had on the user’s decision-making processes

were included. The last category (Q14-Q18) consisted of questions about the user’s general activity on the Web regarding medical and health-related issues. Users answered by rating each statement on a scale ranging from 1 to 4 (1=disagree a lot, 2=disagree a little, 3=agree a little, 4=agree a lot).

Accompanying this survey was background information of participants regarding sex, age, and whether participants were patients or their relatives or friends. Answering all questions took approximately 4 to 7 minutes.

We posted a link concerning our Web-based survey on the ESA group’s home page on FB (Figure 3). Additionally, we explained the study’s purpose. On August 23, we posted again in the group to re-invite all group members to participate and maximize study sample before we closed the link by the end of August 2014. To clarify obscurities or other kinds of questions we corresponded with group members via private FB messages.

All responses were automatically recorded via the Web-based survey platform [29].

Figure 3. Screenshot of our survey request on the Ewing Sarcoma Awareness group’s title page.



“Ewing Sarcoma Awareness” Group Analysis

Besides the questionnaire, we analyzed all processes happening in the ESA group over a 6-month period (October 2013 to March 2014). The analysis referred to activities in the group, more specifically to threads and contributions that were posted on

the group’s home page. We started by analyzing the content of each wall post to develop a classification scheme that could be applied to the complete observational time period.

All posts were divided into 2 main groups: informative and emotional contributions. We then further subdivided the 2 main groups each into 3 branches (Table 1).

Table 1. Classification of posts on the Ewing Sarcoma Awareness group's home page.

Categories and subcategories	Description
Emotional	
Sharing fate/getting support	Group members are reporting about their case/destiny or occurring problems
Bereavement/recurrence	Group members are reporting the loss of a relative or child, or the recurrence of the disease
Complete remission/ no evidence of disease	Group members are reporting about successful treatments
Informative	
Information	Group members are asking for helpful advice to handle the disease and the occurring side effects under the therapy
Clinical trials	Group members are asking for new trials or are sharing information about new studies
Recommendations	Group members are reporting about their experiences and satisfaction/dissatisfaction, or are asking for specialists/hospitals in their area

After classifying the intentions of all posts, we evaluated the number of postings in each subgroup. Contributions deleted by the administrator or those without any classifiable content were excluded from our analysis. Three of the authors coded the data independently according to [Table 1](#); in case of a disagreement, the coding was discussed in the group.

Statistics

Statistical analysis was performed comparing patients' and relatives' values for each of the 18 questions using *t* test. Parametrically distributed data are described as the mean and the standard deviation (SD). All tests were 2-sided with a significance level of $P < .05$. Pearson and Spearman correlation were performed where appropriate.

For statistical calculations SPSS version 22 (IBM Statistics, SPSS Software, IBM Vienna, Austria) was used. Data of all participants were anonymized. As all the information is publicly available, no review by an institutional research ethics board was needed.

Results

Survey Results

The study group of our survey consisted of 65 participants: 26 patients and 39 relatives or friends of patients. Incomplete surveys ($n=26$) were excluded. Of the participants, 11 were male (mean 37.4, SD 14.4 years) and 54 were female (mean 39.8, SD 10.4 years). Average age of the patients was mean 32.9 (SD 8.4) years and that of the relatives was mean 43.6 (SD 10.1) years ([Table 2](#)).

Table 2. Age characteristics of study participants (N=65).

Age, years	Patients	Relatives
20-25	4	1
26-30	8	4
31-35	4	6
36-40	4	5
>40	6	24
Total, n (%)	26 (40)	39 (60)

The highest values for patients and relatives with a mean score of 3.01 (SD 0.87) were found in the first category of the questionnaire that focused on the users' behavior. The second category that concerns the influence of the ESA group on participants' therapeutic schedule yielded the lowest results for patients and relatives with a mean score of 1.91 (SD 0.91).

The maximum mean score per question for patients was found in question 15 with 3.65 (SD 0.69), followed by question 4 (mean 3.54, SD 0.58) and question 9 (mean 3.50, SD 0.76).

Lowest agreements for patients were found in question 7 with a mean score of 1.46 (SD 0.86) followed by questions 6 (mean 1.54, SD 0.81) and 5 (mean 1.69, SD 0.97).

In addition, we compared the given answers from patients and relatives ([Table 3](#)). There was a statistically significant difference between patients and relatives concerning question 4 (mean 3.5, SD 0.6 vs mean 3.0, SD 0.9; $P = .003$). All the given answers of the survey significantly correlated with each other as well as within the patients' and relatives' groups ($P < .001$).

Table 3. Survey results of patients and relatives.

No.	Question	Patients		Relatives		P
		Mean	SD	Mean	SD	
1.	I frequently (4=daily, 3=weekly, 2=monthly, 1=less) visit the Facebook group "Ewing sarcoma awareness" to be in contact with other affected people.	2.85	1.12	2.87	0.92	.92
2.	I post, comment, or like activities in the group or contact other group members via private messages.	2.92	0.89	2.79	0.83	.56
3.	I use the Facebook group "Ewing sarcoma awareness" as a source of information about Ewing sarcoma.	3.04	0.96	3.10	0.79	.78
4.	I recommend the Facebook group "Ewing sarcoma awareness" in other social networks or to other affected people.	3.54	0.58	2.97	0.90	.003
5.	The information I received in the Facebook group "Ewing sarcoma awareness" affected the choice of treatment.	1.69	0.97	1.69	0.80	.99
6.	The information I received in the Facebook group "Ewing sarcoma awareness" affected my choice of consultant.	1.54	0.81	1.67	0.77	.53
7.	The reliability of my consultant decreased because of information I received in the Facebook group "Ewing sarcoma awareness."	1.46	0.86	1.56	0.79	.63
8.	I never had the experience that wrong information in the group "Ewing sarcoma awareness" led to a negative dealing with the disease.	2.96	1.11	2.74	1.23	.46

No.	Question	Patients		Relatives		P
		Mean	SD	Mean	SD	
9.	Being in contact with other affected people via the Facebook group "Ewing sarcoma awareness" makes it easier to handle the diagnosis of Ewing sarcoma.	3.50	0.76	3.49	0.72	.95
10.	I received useful information in the Facebook group "Ewing sarcoma awareness," which improved my every-day life in dealing with the disease.	3.23	0.86	3.03	0.84	.35
11.	I trust the Facebook group "Ewing sarcoma awareness" to receive correct information about Ewing Sarcoma.	2.96	0.87	3.03	0.78	.76
12.	The Facebook group "Ewing sarcoma awareness" is an important support for me to handle the disease.	3.27	0.87	3.18	0.79	.68
13.	I received information about new clinical trials as well as specialists through the Facebook group "Ewing sarcoma awareness."	2.38	1.16	2.28	0.94	.71
14.	I take part in other Ewing sarcoma groups or forums on the Internet, including other social media platforms.	3.23	0.99	2.85	1.11	.16
15.	The Internet is an important tool for me to look for information about Ewing sarcoma.	3.65	0.69	3.49	0.85	.39
16.	I trust online platforms like Wikipedia, Twitter, YouTube, and Facebook to receive correct information about Ewing sarcoma.	2.42	0.95	2.36	0.99	.79

No.	Question	Patients		Relatives		P
		Mean	SD	Mean	SD	
17.	I generally look for information about diseases on the Internet prior to consultation.	3.00	1.01	3.15	0.87	.53
18.	The Internet is an important source for me to look for health-related information.	3.27	0.83	3.28	0.79	.95

Processes in the Group

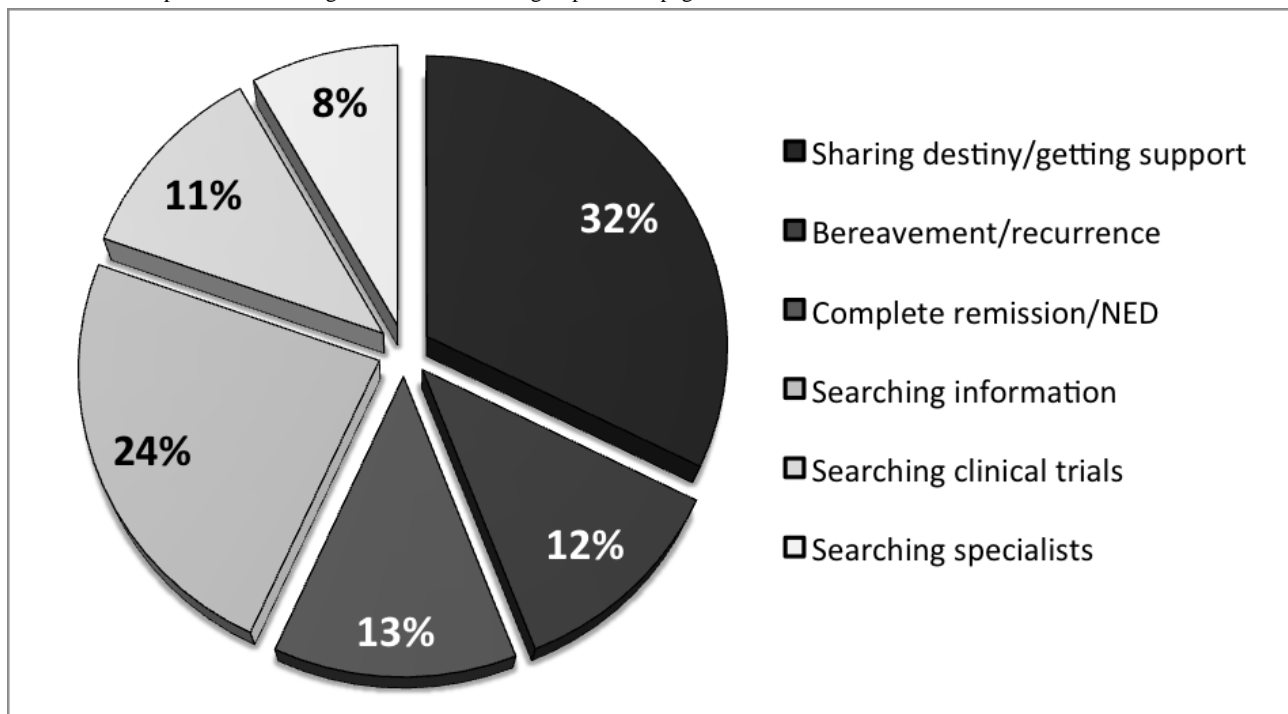
A total of 220 posts on the ESA group's home page and 445 comments were included and categorized accordingly.

We detected a total number of 453 home page posts and 917 comments from 183 different group members. Because of lack of relevance or information, 233 posts and 472 comments were excluded from our study. These were reaction comments to previous posts or posts about everyday topics, not specific to Ewing sarcoma. The posts' contents addressed subjects such as dietary supplements under chemotherapy, correct behavior as a family member, introduction to the group, and others. Overall, 125/220 (56.8%) posts in the ESA group were categorized as emotional posts and 95/220 (43.2%) as informative contributions. As shown in Figure 4, most topics discussed were

about sharing destiny (71/220 posts, 32.3%). Other posts that were assigned to the subgroup of emotional contributions were about the disease's relapse, particularly, bemoaning the loss of a relative (26/220 posts, 11.8%) and reports of complete remission (28/220 posts, 12.7%). The most informative contributions were about searching for Ewing sarcoma-related information (52/220 posts, 23.6%). Group members asked for recommended specialists, hospitals, and reports of experience (25/220 posts, 11.4%). Members also discussed posted hyperlinks with information about new clinical trials (18/220 posts, 8.2%).

Moreover, 15 articles about research results, fund raising, or donations were discussed in the forum. Some of these articles were deleted during the period of our observation by the group administrator.

Figure 4. Results of posts on the Ewing Sarcoma Awareness group's home page.



Discussion

Principal Findings

With respect to our principal findings, the Facebook group Ewing Sarcoma Awareness has a relevant impact on group

members regarding their choice of treatment. Moreover, participants turn toward the group to receive mental and emotional support in everyday life. Reflecting on our results, we believe that a better understanding of this growing interest in peer-to-peer communication for patients may lead to an optimization of a patient-related therapeutic regimen.

The Web has rapidly grown to be one of the leading sources of medical information. It is well known that the Web, in particular social media communication, brings a new dimension to medical subjects followed by possibly improving health outcomes [2]. The idea of this study was to analyze users' behavior regarding Ewing sarcoma on the social media site FB.

Several studies have described users' behavior on FB for health-related issues [15,20,26,31-34]. These studies mainly compared FB groups and/or analyzed processes happening in the group regarding a wide range of different diseases [35]. To the best of our knowledge, there is no study to date that used a comparable approach to interact with FB group members as we did. Therefore, a comparison with other reports was not possible. Yet, we believe that the direct interaction via Web-based surveys with members of FB groups adds a new methodical modality in medical Internet research.

Facebook is a ubiquitous social media platform including health-related issues. Bender et al [18] examined FB groups related to breast cancer. The findings from their study confirmed our presumption that FB is a popular tool for millions of users to seek support via social media platforms. Abramson et al reported about a breast cancer awareness page on Facebook that underlines the increasing use of Facebook pages to discuss severe medical conditions via social media platforms [20]. The visibility of user profiles and personal networks in open FB groups like the ESA group reduces the anonymity but attracts a much wider audience. These key elements of social network sites make public groups ideally suited for fundraising and awareness-raising purposes [18]. Compared with the findings of Bender et al [18], fundraising was of lesser importance in the ESA group. Moreover, marketing and promotion as found by Hale and colleagues [35] played a minor role in our study. General information about the disease, sharing faith, personal support, and assistance in how to handle their daily routine were more important factors reflected in our findings. This might be associated with the rare prevalence of Ewing sarcoma. Different studies reported that FB members use the social media site as a source of information for health-related issues [36,37]. Other studies concluded that FB plays a less important role and has little relevance regarding health-related Web-based information [2,38].

The group ESA was by far the biggest platform (n=2227) we found on FB to exchange general information about Ewing sarcoma. Most other contributions about Ewing sarcoma on FB are blogs about fates of individuals and nonprofit institutions created for fundraising.

It is notable that more than 80% (54/65) of all participants of our Web-based survey were female. Pennbrige et al [39] support this observation and found that 60% of US Internet users using the Web to gather health-related information were women. Most likely, due to caretaking roles and behavior, women appear to visit health-related webpages more frequently [39]. This is consistent with several other studies that reported females regularly visiting social networking sites for the acquisition of health-related information [40-42].

More than half of all participants were aged 36 years or older and 30/65 participants (45%) were older than 40 years. This

explains why mainly parents of patients participated in the relative sample group. This is consistent with the incidence peak of the disease in the teenage years. However, the age of participants of our study differed from the age of participants of most other FB research studies [43,28]. No teenagers participated in our questionnaire although the prevalence of Ewing sarcoma as well as the core age group of FB users would correspond to this age. A possible reason for this could be that the appearance of our FB profile did not attract enough attention for the young group members to participate.

According to the findings of Davison et al [44], social media platforms are less attractive for medical conditions considered to be embarrassing and socially stigmatizing. This also might discourage the adolescent age group to participate in our Web-based survey. Unlike in our study, the average age of participants of other scientific works ranged from 11 to 34 years [41,42,45,46].

The Web in general has become the number one source of medical information for many patients [2]. Referring to the results of our survey, 84% of all participants agreed a little or a lot that the Web is an important source for health-related information (Q18). Moreover, 77% (50/65 participants) reported that they use the Web to look up medical conditions and symptoms before medical consultations (Q17). These findings are in accordance with several studies about public and patients' behavior on the Web regarding medical issues [2,11,20,24,47,48].

Reliability and quality of health-related information found on the Web is considered generally questionable. According to our survey, 47% (30/65) of all participants agreed a little or a lot that they trust the information available on Web-based platforms such as Wikipedia, Twitter, YouTube, and FB, having confidence that the information is correct (Q16). Moreover, 15% (10/65) of patients and 26% (17/65) of relatives reported that wrong information received on the Web had negative effects on everyday life and the control of the disease (Q8). Brown et al [49] reported how doctors see and use social media. The findings of their study are comparable with our results showcasing insecurities for medical professionals and patients alike, regarding the reliability of information received on social media platforms.

Furthermore, we examined the influence of the ESA group on the patients' selection of therapeutic regimens. We found that contents shared in the ESA group had relevant impact on the selection of treatment protocols, hospitals, and specialists. In this study, 20% of patients and 21% of relatives agreed a little or a lot that the group ESA affected their choice of treatment (Q5). Moreover, 19% of all patients reported that the group affected their selection of specialists (Q6). These statements indicate that FB has become an important source of information for patients with Ewing sarcoma and is affecting their treatment. These results underline the relevance of FB for patients with Ewing sarcoma and their treatment of choice [2,5,11,38].

At first sight, results of Q5-Q8 seem to be contradictory to the results of Q14-Q18 where there is a higher mean level of agreement to the statements made. However, the correlational analysis showed a significant positive correlation of all results

($P < .001$). For instance, the information received from FB did not affect the choice of treatment. The reason for this might be that the attending physicians mainly influence the choice of treatment. However, the Web could still be an important primary tool to look for medical information and users could trust the given information about medical conditions like Ewing sarcoma on social media platforms.

The survey results comparing patients and relatives were similar. The only significant difference was found in question 4 (Q4: I recommend the Facebook group "Ewing sarcoma awareness" in other social networks or to other affected people). Patients achieved significantly ($P = .003$) higher results. It can be estimated that patients who are going through the whole course of the disease feel more motivated to include others who are affected. This is in line with statements by Cutrona et al [50] who observed that many adults are willing to use e-communication or email to promote and report cancer screening to peers.

Our post on the ESA group's home page, where we invited all group members to participate in our Web-based survey, resulted in controversial reactions and started a lively debate among ESA group members. After reacting to critical posts and clarifying the survey's credibility and intention of our research work, the number of participants increased.

Limitations

A limitation of our study is the small sample size of the study group. Because of FB's regulations we were unable to send all group members a request (via private message) to answer our survey. Facebook does not allow mass messages. Messages to people you are not connected with usually end up in the FB spam folder. The only way of attracting attention for our questionnaire was by posting on the group's home page. Unfortunately, only members who are frequently following the group's activities were able to see our contribution. A much longer study period might have increased the number of participants. Because of a lack of previous studies on the topic, a sample size calculation was not possible.

A total of 27% of all participants of our survey stated that they visit the ESA group monthly or less and, a total of 183 different ESA group members posted contributions on the group's home page. According to these numbers it can be estimated that only a relatively small number of users compared with the total

number of group members ($n = 2227$) is actively involved in the processes of the group. Another drawback is that information flow (via private message) between ESA group members was not visible to us and could therefore not be analyzed.

Because a larger number of group members were US citizens, it can be expected that the outcomes of other geographical populations differ from our results.

Practical Implications

Our findings suggest that FB is an important platform for many patients with Ewing sarcoma and their relatives. Because of the disease's low incidence, the most comfortable and simplest way to get in touch with other patients might be via FB. Peer-to-peer communication seems to enable considerable support for patients and their relatives.

We believe that implementing interaction tools on FB can benefit patients and their social environment and help individuals deal with the diagnosis of Ewing sarcoma. Web-based communication on FB with others who are affected can be implemented in the multidisciplinary therapeutic regimen for patients with Ewing sarcoma.

However, incorrect medical information received on the Web is an evident weakness that FB groups have. Therefore, we suggest cautious application of health-related information found in FB groups.

Conclusions

In summary, the FB group ESA has a relevant impact on group members regarding treatment selection and in getting support through everyday life. Although the reliability and quality of information obtained from the Web is considered diverse, we believe that online forums are feasible tools for patients and relatives that help individuals not only find support and backing but also to share their experiences. The impact of Facebook regarding patients with Ewing sarcoma and their relatives who join such groups on the Web might be underestimated in traditional medical treatment regimens.

Reflecting on our results, we believe that questionnaires on social media platforms such as Facebook are suitable for a variety of scientific research questions in the future. Statements made in the group are in part questionable from a medical point of view and its impact on patient's care needs further evaluation.

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Conflicts of Interest

None declared.

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Abbreviations

ESA: Ewing Sarcoma Awareness

FB: Facebook

Q: question

SD: standard deviation

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Original Paper

Comparing Web-Based Provider-Initiated and Patient-Initiated Survivorship Care Planning for Cancer Patients: A Randomized Controlled Trial

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Abstract

Background: Survivorship care plans (SCPs) are intended to facilitate communication and coordination between patients, oncologists, and primary care providers. Most SCP initiatives have focused on oncology providers initiating the SCP process, but time and resource barriers have limited uptake.

Objective: This trial compares the feasibility and value of 2 Web-based SCP tools: provider-initiated versus patient-initiated.

Methods: This mixed-methods study recruited clinicians from 2 academically-affiliated community oncology practices. Eligible patients were treated by a participating oncologist, had nonmetastatic cancer, completed acute treatment ≤ 2 months before enrollment, and had no evidence of disease. Patients were randomized 1:1 to either provider-initiated or patient-initiated SCPs—both are Web-based tools. We conducted qualitative interviews with providers at baseline and follow-up and with patients 2 months after enrollment. In addition, patients were administered the Preparing for Life as a (New) Survivor (PLANS) and Cancer Survivors' Unmet Needs (CaSUN) surveys at baseline and 2 months.

Results: A total of 40 providers were approached for the study, of whom 13 (33%) enrolled. Providers or clinic staff required researcher assistance to identify eligible patients; 41 patients were randomized, of whom 25 completed follow-up (61%; 13 provider-initiated, 12 patient-initiated). Of the 25, 11 (44%) had initiated the SCP; 5 (20%) provided the SCP to their primary care provider. On the Preparing for Life as a (New) Survivor and Cancer Survivors' Unmet Needs, patients in both arms tended to report high knowledge and confidence and few unmet needs. In qualitative interviews, providers and patients discussed SCPs' value.

Conclusions: Regardless of patient- versus provider-initiated templates and the Web-based design of these tools, barriers to survivorship care planning persist. Further efforts should emphasize workflow *functions* for identifying and completing SCPs—regardless of the SCP *form* used.

Trial Registration: ClinicalTrials.gov NCT02405819; <https://clinicaltrials.gov/ct2/show/NCT02405819> (Archived by WebCite at <http://www.webcitation.org/6jWqcWOvK>)

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KEYWORDS

survivorship care plan; mixed methods study; randomized controlled trial

Introduction

The completion of active cancer treatment is a critical juncture when patients need support and communication to ensure optimal health and quality of life outcomes. The 2005 Institute of Medicine (IOM) report “*From Cancer Patient to Cancer Survivor: Lost in Transition*” [1] highlighted the difficulty that many cancer patients face when transitioning from acute treatment. The IOM report recommended that patients completing treatment receive a summary of the treatments received and a plan for follow-up care. These materials have become known as a “survivorship care plan” (SCP). SCPs have become a target initiative for patient-centered improvements to oncology, but the literature on their implementation and impact remains sparse and inconclusive [2-8].

Based on the IOM recommendation, various organizations have developed SCP templates. Most of these templates have been designed with the intention of oncology providers initiating the survivorship care planning process. Uptake of survivorship care planning has, however, been slow and limited [9]. There are now several initiatives underway that are reconsidering survivorship care planning approaches, updating available templates, or both [10-12]. Web-based, patient-initiated SCPs are one alternative whereby the patient is empowered to at least begin completion of a treatment summary and care plan at home. The idea behind the patient-initiated approach is that this may serve to reduce barriers related to available time and resources in the oncology clinic, while further engaging patients in self-care. Journey Forward is a collaboration of the National Coalition for Cancer Survivorship, the UCLA Cancer Survivorship Center, the Oncology Nursing Society, Anthem Inc., and Genentech [12]. The Journey Forward collaboration has developed both the “Survivorship Care Plan Builder” (provider-initiated; see [Multimedia Appendix 1](#)) and “My Care Plan” (patient-initiated; see [Multimedia Appendix 2](#)) Web-based templates and has made these tools freely available on the Web. It is also possible to print the forms and fill them out by hand.

In this study (ClinicalTrials.gov NCT02405819), we sought to compare the feasibility and value of the 2 Journey Forward models of SCP provision. We designed the study to provide initial evidence of the feasibility and possible value of 2 models of SCP provision. We present data from the perspectives of both patients and providers regarding implementation processes and feasibility, facilitators and barriers, and perceived value of the survivorship care planning process.

Methods

Study Design

This mixed-methods study comparing 2 modalities of SCPs (“Care Plan Builder” and “My Care Plan”) used a randomized design and was conducted in 2 community-based, academically affiliated hospitals [13]. We recruited oncologists who manage breast, prostate, and colorectal cancer patients. Patient eligibility was not, however, limited to breast, prostate, and colorectal cancer; patient participants were recruited through the participating clinicians and were adults (21 years and older) diagnosed with any nonmetastatic cancer. Patients were enrolled in the study for a period of 4 months and were followed for 2 months. This study was reviewed and approved by Johns Hopkins School of Medicine Institutional Review Board.

Clinician Participants

Participation of clinicians in the study was determined to be an indicator of feasibility, and we tracked the number of clinicians approached, the number eligible, and the number who consented to participate. Clinicians were approached to participate in the study through both in-person presentations of the work and through emailed requests. Consent to participate was acquired in-person. Once clinicians agreed to participate and provided written informed consent, we conducted a baseline qualitative interview in which we asked about experiences of survivorship care planning, expectations for the study, and the perceived value of SCPs. Once data collection with patients was complete, we conducted a follow-up interview with participating clinicians to ask about experiences with the interventions. In this interview, we revisited the issue of the perceived value of SCPs and obtained clinician feedback on the implementation (including barriers and facilitators) and feasibility of the 2 survivorship care planning approaches implemented in this trial.

Patient Participants

To determine the feasibility of oncologists or oncology staff identifying patients for an SCP, the original study protocol called for participating oncologists to refer adult patients completing active treatment for nonmetastatic cancer to the study team. Specific patient eligibility criteria included having nonmetastatic disease, completed acute treatment within the past 2 months, and no evidence of disease. Although patients had to have completed acute treatment, patients on chronic treatment (>1 year) were eligible. Patient participants were identified in the clinic by clinic staff, and a member of the research team oversaw consent procedures. Eligible patients who agreed to participate provided written informed consent and were randomized 1:1 using a random number generator with the condition concealed until randomization; patients and

their clinicians were then informed of the randomized condition. Patients were paid \$35 for their participation in the study.

Plan Initiation

For participants randomized to the patient-initiated My Care Plan group, the research team directed patients to the Web address for the appropriate tool and provided an instructional hand-out for reference. For participants randomized to the provider-initiated Survivorship Care Plan Builder, the provider was made aware of their randomization and was responsible for completing the SCP. The clinicians were all given information on the SCP Builder website or tool and were also familiarized with the patient-initiated My Care Plan tool.

Data Collection and Outcome Measures

Data collection occurred at 2 time points: baseline and 2-month follow-up. The primary outcome was receipt of an SCP by the 2-month follow-up. Specifically, at the 2-month follow-up contact, we determined whether the patient had a partially or fully completed SCP versus no plan at all.

Secondary outcomes included supportive care needs assessed by the Cancer Survivors' Unmet Needs (CaSUN) survey [14], and knowledge and confidence about survivorship assessed by the Preparing for Life as a (New) Survivor (PLANS) survey [15]. The CaSUN is a validated measure that includes 35 unmet need items with response options of no need or not applicable, met need, and weak, moderate, or strong unmet need. We assigned values of 1=no need or not applicable to 5=strong unmet need and used these to calculate means for the individual items. There are also 6 positive change items with response options of has always been like this, has been a positive outcome, no: want help to achieve this, and no: not important to me; these data are presented descriptively. The PLANS survey includes 11 knowledge items rated on a 4-point Likert scale from 1=strongly disagree to 4=strongly agree, as well as 5 confidence items rated on a 10-point scale from 1=not at all confident to 10=extremely confident. We calculated means for the individual PLANS items. These questionnaires, along with patient demographics, were collected by interviewer-assisted, patient report on paper forms, at baseline. The CaSUN and PLANS were also collected at the 2-month follow-up.

Finally, we conducted a brief, targeted qualitative interview with patients at follow-up regarding perceived impact of cancer, informational and support needs, as well as experiences and attitudes about the SCP tool to which they were randomized. This interview collected information on processes undertaken to complete the SCP (or challenges that prevented successful completion of an SCP), parts of the process the patients found helpful or that presented obstacles, and recommendations for improving the process.

Quantitative data from the CaSUN and PLANS were analyzed with summary statistics and descriptively by comparing the distribution of scores at baseline between intervention arms and the distribution of scores at follow-up between intervention arms using nonparametric Wilcoxon rank-sum tests. Changes from baseline to follow-up were described within interventions arms with Wilcoxon signed-rank tests. To describe the

differential change from baseline to follow-up between intervention arms (ie, interaction), we compared the changes between intervention arms with Wilcoxon rank-sum tests. No formal sample size calculations were conducted for the secondary quantitative outcome measures; however, the results here can inform power calculations for future evaluations. Analysis of interview data from clinicians and patients was thematic and summative, with a focus on identification of perceived and experienced value of SCPs, as well as facilitators and barriers to implementation of both modalities. Interview data were read and reviewed by various members of the research team, with a view to establishing consensus about major emergent themes. All quantitative analyses were completed using statistical software R, version 3.3.0 [16].

Results

Survivorship Care Planning Feasibility: Provider and Patient Participation

Of the 40 eligible oncologists at the 2 hospitals, 13 (33%) agreed to participate in the study. Nearly half of the clinicians were female (46%); the sample included 5 radiation oncologists (38%), 5 medical oncologists (38%), and 3 surgeons (23%). The clinicians who did not choose to participate included 17 surgical oncologists and 10 medical oncologists; all eligible radiation oncologists chose to participate in the study. At the initiation of the study, none of the participating oncologists provided SCPs to patients as part of standard care. We conducted follow-up interviews with 11 of the 13 enrolled clinicians; 2 clinicians did not respond to numerous attempts to schedule an interview at follow-up.

Although the planned approach for patient recruitment was for oncologists and clinic staff to identify patients completing treatment, it became clear after 1 month of passive research observation that processes relying on the clinical teams were ineffective. For the remaining 3 months of recruitment, research staff worked with clinic staff to identify patients eligible for SCPs. A member of research staff was present on clinic days and reviewed schedules to identify potentially eligible patients who were due to have appointments. Research staff prompted clinic staff to discuss joining the study with potential participants.

In total, 74 patients were approached and 41 (55%) enrolled and were randomized—21 to the provider-initiated Survivorship Care Plan Builder and 20 to the patient-initiated My Care Plan (Figure 1). The 41 enrolled patients were recruited from 5 (38%) of the 13 participating clinicians; 3 of the referring clinicians were radiation oncologists, 1 a surgical oncologist, and 1 a medical oncologist. Participating patients were, on average, aged 66 years (range: 44-90 years), 68% female, 81% white, 59% married, and 51% reported excellent or very good health (Table 1). Breast cancer was the most common diagnosis (61%), followed by prostate cancer (20%), and lung cancer (10%). Patients were most commonly retired (46%) or working full-time (37%). Almost all participants had high-speed Web access (95%) and were regular computer users (85%).

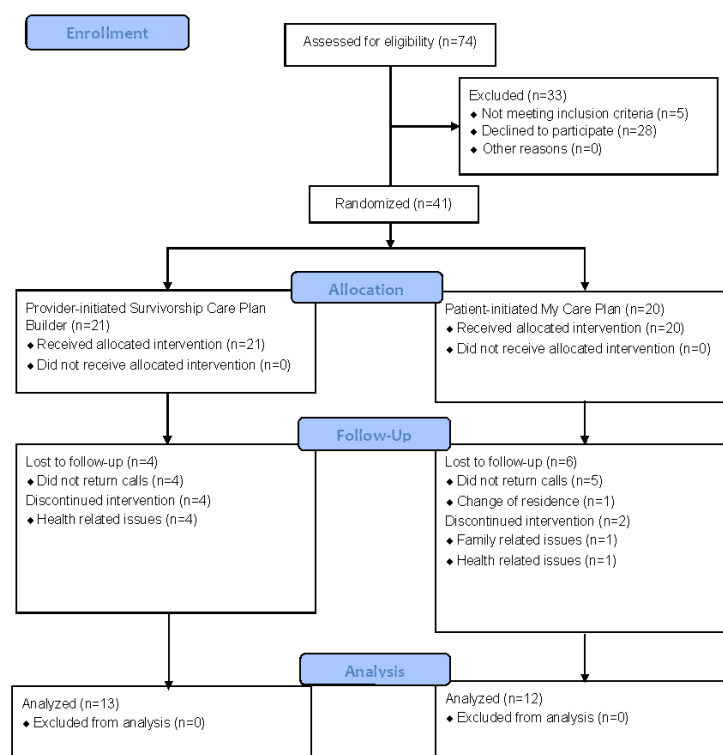
Table 1. Patient characteristics overall and by study arm.^a

Characteristic	All patients (N=41)	Provider-initiated (n=21)	Patient-initiated (n=20)
Age			
Mean (Standard deviation)	66 (11.7)	66 (12.5)	65 (11.1)
Median (Range)	63 (44-90)	64 (44-90)	62 (44-88)
Gender, n (%)			
Male	13 (31.7)	6 (28.6)	7 (35.0)
Race, n (%)			
White	33 (80.5)	16 (76.2)	17 (85.0)
Black or African American	5 (12.2)	4 (19.0)	1 (5.0)
Other	3 (7.3)	1 (4.7)	2 (10.0)
Hispanic	5 (12.2)	2 (9.5)	3 (15.0)
Education, n (%)			
High school graduate or lower	7 (17.1)	4 (19.0)	3 (15.0)
Attended some college	3 (7.3)	2 (9.5)	1 (5.0)
College graduate	8 (19.5)	3 (14.3)	5 (25.0)
Any postsecondary work	23 (56.1)	12 (57.1)	11 (55.0)
Cancer type, n (%)			
Breast	25 (60.9)	14 (66.7)	11 (55.0)
Prostate	8 (19.5)	4 (19.0)	4 (20.0)
Lung	4 (9.8)	1 (4.8)	3 (15.0)
Other	4 (9.8)	2 (9.5)	2 (10.0)
Marital Status, n (%)			
Married	24 (58.5)	13 (61.9)	11 (55.0)
Divorced or separated	4 (9.8)	2 (9.5)	2 (10.0)
Widowed	6 (14.6)	1 (4.8)	5 (25.0)
Never married	7 (17.1)	5 (23.8)	2 (10.0)
Employment status, n (%)			
Working full-time	15 (36.6)	10 (47.6)	5 (25.0)
Retired	19 (46.3)	10 (47.6)	9 (45.0)
Other	7 (17.1)	1 (4.8)	6 (30.0)
Current health, n (%)			
Excellent	6 (14.6)	5 (23.8)	1 (5.0)
Very good	15 (36.6)	6 (28.6)	9 (45.0)
Good	13 (31.7)	6 (28.6)	7 (35.0)
Fair	5 (12.2)	4 (19.0)	1 (5.0)
Poor	1 (2.4)	0 (0)	1 (5)
No response	1 (2.4)	0	1
Computer access, n (%)			
Dial-up or low speed	1 (2.4)	1 (4.7)	0 (0)
High speed	39 (95.1)	19 (90.5)	20 (100.0)
No response	1 (2.4)	1 (4.8)	0 (0)
Computer use, n (%)			
Regular	35 (85.4)	18 (85.7)	17 (85.0)

Characteristic	All patients (N=41)	Provider-initiated (n=21)	Patient-initiated (n=20)
Occasional	3 (7.3)	2 (9.5)	1 (5.0)
Rare	1 (2.4)	0 (0)	1 (5.0)
Never	1 (2.4)	0 (0)	1 (5.0)
No response	1 (2.4)	1 (4.8)	0
Referring clinician type			
Radiation oncology	32 (78.0)	17 (80.9)	15 (75.0)
Medical oncology	8 (19.5)	3 (14.3)	5 (25.0)
Surgical oncology	1 (4.9)	1 (4.8)	0

^aNote: individual values are rounded and may not total 100%.

Figure 1. Enrollment into survivorship care planning trial.



After 2 months, 25 (61%) of the 41 enrolled patients provided follow-up data. We made repeated attempts to contact enrolled participants, except where early contacts resulted in expressed desire for no further participation. Reasons given for not participating in follow-up included ill health and change of residence.

Of the 25 patients who participated in follow-up (13 in the provider-initiated arm, 12 in the patient-initiated arm), 11 (44%) had initiated an SCP. In the patient-initiated arm (n=20), 8 initiated a plan, with 5 of these completing the plan and 3 of these 5 reporting that they had given the plan to their primary care provider (PCP). In the provider-initiated arm (n=21), we were not able to assess the number of plans started but not completed or provided to the patient; 3 patients had received a

completed SCP by the 2-month follow-up, and 2 of these patients reported having provided the SCP to their PCP.

Clinician Perspectives on SCP Facilitators and Barriers

In the baseline qualitative interviews, clinicians noted the *value* of SCPs in terms of (1) providing a good summary of treatment and an “exit strategy”; (2) potential to assist patient communication; (3) potential to increase both patient knowledge and a sense of empowerment; (4) utility if accurate and concise; (5) potential to save clinician time if patient initiated; and (6) valuable if they provide something additional to the clinical encounter. In total, 10 of the 13 clinicians made some comment in support of the concept of SCPs; 5 of these clinicians enrolled patients and only 2 actually completed provider-initiated plans. In the follow-up interviews, cancer providers reiterated many of the same perspectives, including: (1) assisting with improving

transition of care to PCP (both coordination and communication); (2) improving patient knowledge of long-term effects; (3) improving patient general well-being by addressing key concerns; (4) facilitating patient investment and empowerment; (5) providing a good template for multispecialty care teams; and (6) allowing the PCP to be the “survivorship director.” There was one clinician who questioned the value of SCPs at both baseline and follow-up. Overall, however, the follow-up interviews revealed 2 main areas of potential value for clinicians: (1) improving the transition to the PCP and (2) improving patient knowledge of potential long-term effects of their treatment.

At baseline, clinicians noted a variety of *facilitators* for successful implementation of SCPs, including that: (1) plans must be concise and easy to use and understand; (2) there should be a staff member (such as a clinical nurse) dedicated to the task of delivering the plan; and (3) the timing of the plan is important. There was considerable disagreement between oncologists about the optimal time to initiate a SCP; some felt that plans should be provided earlier, whereas others said that they would like to see plans provided later in the care trajectory to avoid overwhelming patients during their cancer care. The providers also noted that patients may not be sufficiently knowledgeable about their disease and treatment to accurately complete the SCP sooner. Facilitators most often mentioned at follow-up were patient engagement/motivation, having dedicated staff, plans being concise, and use of electronic medical records (EMRs) for easy access to patient treatment data between settings.

At baseline, the primary *barriers* identified by the clinicians were clinician time and patient knowledge. In initial interviews, clinicians most often discussed a preference for patient-initiated

SCPs. At follow-up, the main points highlighted by the clinicians regarding barriers were clinician time, patient engagement or motivation, patient knowledge, not having dedicated staff, over-complicated plans, and the use of EMRs to the extent that time spent inputting information reduced time available for interaction with the patient. In addition, clinicians expressed support for the idea that there should be strong patient buy-in for survivorship care planning, such that there was some perception that plans that are patient-initiated might be more successful. Another point raised was that when plans are patient-initiated, there is potential for saving time for the clinician.

Patient Informational and Support Needs and Preparedness for Survivorship

Results from the CaSUN needs assessment at baseline indicated few unmet needs (average > 2.0) in either intervention arm (Table 2). In both the provider- and patient-initiated arms, the areas of unmet needs were *feeling like I am managing my health together with the medical team, knowing that all my doctors talk to each other to coordinate my care, and managing concerns about the cancer coming back*. In the patient-initiated arm, additional areas of unmet need were *needing local health care services and an ongoing case manager*. There was only one statistically significant difference between arms at baseline: *needing local health care* ($P=.03$). At follow-up, patients in both arms continued to report unmet needs in knowing that my doctors talk to each other to coordinate my care and managing concerns about the cancer coming back. Patients in the patient-initiated arm also continued to report unmet needs in *managing my health together with the medical team*, although this was no longer the case for patients in the provider-initiated arm.

Table 2. Cancer Survivors' Unmet Needs at baseline and follow-up by intervention arm.

Mean (Standard Deviation) ^a	Provider-initiated at baseline (n=21)	Patient-initiated at baseline (n=20)	P value for differences at baseline between arms ^b	Provider-initiated at follow-up (n=13)	Patient-initiated at follow-up (n=12)	P value for differences at follow-up between arms ^b
I need up to date information	1.8 (0.5)	1.5 (0.6)	.12	1.8 (0.9)	2.0 (1.3)	>.99
My family and/or partner needs information relevant to them	1.7 (0.8)	1.6 (0.7)	.70	1.3 (0.5)	1.6 (0.9)	.70
I need information provided in a way that I can understand	1.6 (0.5)	1.9 (1.0)	.66	1.6 (0.5)	2.0 (1.1)	.56
I need the very best medical care	1.8 (0.4)	2.0 (0.3)	.11	1.7 (0.5)	2.0 (0.8)	.45
I need local health care services that are available when I require them	1.5 (0.5)	2.1 (1.0)	.03	1.6 (0.5)	1.9 (1.4)	.91
I need to feel like I am managing my health together with the medical team	2.1 (0.9)	2.2 (0.8)	.61	1.7 (0.7)	2.3 (0.9)	.13
I need to know that all my doctors talk to each other to coordinate my care	2.2 (1.3)	2.6 (1.2)	.08	2.3 (1.1)	2.9 (1.5)	.34
I need any complaints regarding my care to be properly addressed	1.8 (0.9)	2.0 (1.0)	.46	1.5 (0.5)	1.6 (0.9)	>.99
I need access to complementary and/or alternative therapy services	1.7 (1.0)	1.9 (1.2)	.69	1.5 (0.7)	1.6 (0.9)	.84
I need help to reduce stress in my life	1.9 (0.9)	1.8 (1.0)	.46	2.0 (1.1)	1.4 (0.5)	.15
I need help to manage ongoing side effects and/or complications of treatment	1.4 (0.5)	1.8 (1.1)	.32	1.9 (0.9)	1.7 (0.7)	.70
I need help to adjust to changes in my quality of life as a result of my cancer	1.8 (1.0)	2.0 (1.2)	.91	1.5 (0.7)	1.5 (0.7)	.90
I need help with having a family due to fertility problems	1.1 (0.2)	1.0 (0.0)	.35	1.0 (0.0)	1.0 (0.0)	_ ^c
I need assistance with getting and/or maintaining employment	1.1 (0.5)	1.1 (0.2)	.58	1.0 (0.0)	1.1 (0.3)	.39
I need help to find out about financial support and/or government benefits to which I am entitled	1.4 (1.0)	1.6 (1.2)	.63	1.0 (0.0)	1.0 (0.0)	_ ^c
Due to my cancer, I need help getting life and/or travel insurance	1.1 (0.2)	1.5 (0.9)	.12	1.0 (0.0)	1.2 (0.6)	.39
Due to my cancer, I need help accessing legal services	1.2 (0.9)	1.2 (0.5)	.58	1.0 (0.0)	1.0 (0.0)	_ ^c
I need more accessible hospital parking	1.4 (0.8)	1.8 (1.2)	.25	1.0 (0.0)	1.2 (0.4)	.19
I need help to manage my concerns about the cancer coming back	2.6 (1.3)	2.3 (1.4)	.34	2.3 (1.3)	2.4 (1.4)	>.99
I need emotional support to be provided for me	1.8 (0.9)	1.5 (0.8)	.27	1.7 (1.1)	1.5 (0.7)	.75
I need help to know how to support my partner and/or family	1.5 (0.8)	1.7 (1.1)	.78	1.3 (0.7)	1.2 (0.4)	.88
I need help to deal with the impact that cancer has had on my relationship with my partner	1.5 (0.9)	1.6 (1.0)	.96	1.5 (0.9)	1.1 (0.3)	.22
I need help with developing new relationships after my cancer	1.2 (0.9)	1.2 (0.7)	>.99	1.1 (0.3)	1.0 (0.0)	.34

Mean (Standard Deviation) ^a	Provider-initiated at baseline (n=21)	Patient-initiated at baseline (n=20)	<i>P</i> value for differences at baseline between arms ^b	Provider-initiated at follow-up (n=13)	Patient-initiated at follow-up (n=12)	<i>P</i> value for differences at follow-up between arms ^b
I need to talk to others who have experienced cancer	1.8 (1.1)	1.6 (1.0)	.45	1.5 (0.7)	1.4 (0.7)	.61
I need help to handle the topic of cancer in social and/or work situations	1.8 (1.1)	1.5 (1.0)	.23	1.1 (0.3)	1.4 (0.7)	.33
I need help to adjust to changes to the way I feel about my body	1.7 (1.0)	1.4 (0.9)	.13	1.5 (0.9)	1.3 (0.7)	.54
I need help to address problems with my/our sex life	1.3 (0.8)	1.6 (1.2)	.84	1.2 (0.4)	1.5 (0.7)	.40
I need an ongoing case manager to whom I can go to find out about services whenever they are needed	1.9 (1.3)	2.2 (1.5)	.57	1.5 (1.0)	1.6 (1.2)	>.99
I need help to move on with my life	1.7 (1.1)	1.7 (1.2)	.75	1.4 (0.7)	1.4 (0.7)	.81
I need help to cope with changes to my belief that nothing bad will ever happen in my life	1.5 (0.9)	1.3 (0.7)	.54	1.9 (1.1)	1.4 (0.9)	.13
I need help to cope with others not acknowledging the impact that cancer has had on my life	1.4 (0.8)	1.4 (1.0)	.58	1.8 (1.3)	1.0 (0.0)	.06
I need help to deal with my own and/or others expectations of me as a "cancer survivor"	1.6 (1.0)	1.6 (1.1)	.96	1.9 (1.3)	1.2 (0.6)	.09
I need help to try to make decisions about my life in the context of uncertainty	1.5 (0.8)	1.5 (1.1)	.84	1.7 (1.1)	1.3 (0.7)	.49
I need help to explore my spiritual beliefs	1.5 (0.6)	1.3 (0.6)	.27	1.1 (0.3)	1.1 (0.3)	>.99
I need help to make my life count	1.3 (0.5)	1.5 (0.9)	.74	1.2 (0.4)	1.3 (0.7)	.96

^aMean scores with 1=no need, 2=met need, 3=weak unmet need, 4=moderate unmet need, 5=strong unmet need.

^b*P* values for Wilcoxon rank-sum tests for differences in scores between intervention arms separately at baseline and follow-up.

^cFor this question, all patients reported the same answer at follow-up, so there is no *P* value to compute.

In terms of changes on the CaSUN from baseline to follow-up (Table 3), patients in the provider-initiated arm had statistically significant improvement on *family/partner needing information* (mean change: 0.5; *P*=.04), *handling the topic of cancer in social/work situations* (mean change: 0.8; *P*=.03), and *exploring spiritual beliefs* (mean change: 0.6; *P*=.04). None of the changes

within the patient-initiated arm were statistically significant. There was one statistically significant difference in change between treatment arms: needing help managing my concerns about cancer improved by 0.3 in the provider-initiated arm but worsened by 0.7 in the patient-initiated arm (*P*=.03).

Table 3. Cancer Survivors' Unmet Needs change from baseline to follow-up by intervention arm.

Mean (Standard Deviation)	Change ^a in provider-initiated arm (n=13)	P value for change within provider-initiated arm ^b	Change ^a in patient-initiated arm (n=12)	P value for change within patient-initiated arm ^b	P value for differences in change between arms ^c
I need up to date information	0 (0.9)	>.99	0.4 (1.0)	.34	.37
My family and/or partner needs information relevant to them	-0.5 (0.5)	.04	-0.1 (0.5)	.77	.11
I need information provided in a way that I can understand	-0.1 (0.6)	.77	0.3 (1.5)	.58	.74
I need the very best medical care	-0.3 (0.5)	.15	-0.1 (0.6)	.77	.45
I need local health care services that are available when I require them	0.1 (0.6)	.77	-0.3 (1.1)	.48	.23
I need to feel like I am managing my health together with the medical team	-0.4 (0.7)	.13	0.3 (1.0)	.41	.11
I need to know that all my doctors talk to each other to coordinate my care	-0.1 (1.2)	.89	0.4 (1.1)	.28	.37
I need any complaints regarding my care to be properly addressed	-0.2 (0.6)	.42	-0.4 (0.8)	.20	.72
I need access to complementary and/or alternative therapy services	0.0 (0.9)	>.99	-0.5 (1.2)	.27	.45
I need help to reduce stress in my life	0.2 (1.1)	.59	-0.1 (0.8)	.85	.82
I need help to manage ongoing side effects and/or complications of treatment	0.3 (1.0)	.37	0.0 (1.3)	.82	.82
I need help to adjust to changes in my quality of life as a result of my cancer	-0.1 (0.7)	.77	-0.1 (1.3)	>.99	.82
I need help with having a family due to fertility problems	0.0 (0.0)	_d	0.0 (0.0)	_d	_d
I need assistance with getting and/or maintaining employment	0.0 (0.0)	_d	0.0 (0.5)	>.99	>.99
I need help to find out about financial support and/or government benefits to which I am entitled	0.0 (0.0)	_d	-0.5 (1.0)	.37	.19
Due to my cancer, I need help getting life and/or travel insurance	-0.1 (0.3)	>.99	-0.5 (1.0)	.37	.56
Due to my cancer, I need help accessing legal services	0.0 (0.0)	_d	-0.3 (0.7)	.37	.19
I need more accessible hospital parking	-0.3 (0.7)	.37	-0.2 (0.6)	.42	.93
I need help to manage my concerns about the cancer coming back	-0.3 (0.5)	.15	0.7 (1.2)	.09	.03
I need emotional support to be provided for me	0.0 (0.7)	>.99	0.1 (0.9)	>.99	.77
I need help to know how to support my partner and/or family	-0.3 (0.7)	.37	-0.5 (1.1)	.27	.97
I need help to deal with the impact that cancer has had on my relationship with my partner	-0.2 (0.4)	.35	-0.5 (0.8)	.17	.60
I need help with developing new relationships after my cancer	0.1 (0.3)	>.99	-0.3 (0.9)	>.99	.19
I need to talk to others who have experienced cancer	-0.3 (0.7)	.23	-0.1 (0.8)	.85	.39
I need help to handle the topic of cancer in social and/or work situations	-0.8 (0.8)	.03	-0.2 (0.6)	.42	.08

Mean (Standard Deviation)	Change ^a in provider-initiated arm (n=13)	P value for change within provider-initiated arm ^b	Change ^a in patient-initiated arm (n=12)	P value for change within patient-initiated arm ^b	P value for differences in change between arms ^c
I need help to adjust to changes to the way I feel about my body	-0.2 (1.0)	.71	-0.4 (0.8)	.20	.81
I need help to address problems with my/our sex life	-0.2 (0.4)	.35	-0.2 (1.3)	.71	.57
I need an ongoing case manager to whom I can go to find out about services whenever they are needed	-0.5 (1.1)	.20	-0.6 (1.1)	.11	.79
I need help to move on with my life	0.0 (0.7)	>.99	-0.3 (0.9)	>.99	.69
I need help to cope with changes to my belief that nothing bad will ever happen in my life	0.0 (0.7)	>.99	0.3 (1.0)	.59	.72
I need help to cope with others not acknowledging the impact that cancer has had on my life	0.2 (1.2)	.85	-0.3 (0.7)	.37	.46
I need help to deal with my own and/or others expectations of me as a "cancer survivor"	0.1 (1.5)	>.99	-0.2 (1.0)	.71	.68
I need help to try to make decisions about my life in the context of uncertainty	-0.1 (0.6)	.77	-0.2 (0.8)	.59	>.99
I need help to explore my spiritual beliefs	-0.6 (0.5)	.04	-0.2 (0.8)	.59	.17
I need help to make my life count	-0.1 (0.6)	.77	-0.1 (1.2)	>.99	.75

^aPositive mean changes indicate more unmet needs; negative mean changes indicate less unmet need.

^bP values for Wilcoxon signed-rank tests for change from baseline to follow-up within intervention arm, among patients with data at follow-up only.

^cP values for Wilcoxon rank-sum tests for differences in the change from baseline to follow-up between intervention arms (interaction), among patients with data at follow-up only.

^dFor this question, all patients reported the same answer at baseline and follow-up, so there is no P value to compute.

Table 4 presents the CaSUN positive change items descriptively at baseline and follow-up by intervention arm. In the provider-initiated arm, the most frequently endorsed positive outcome at baseline was *growing as a person* (n=12 of 21; 57%). At follow-up, 9 of 13 (69%) endorsed *growing as a person* and also *benefiting from contact with other cancer survivors/families* as positive outcomes. In the patient-initiated arm, *appreciating relationships with others* more was most frequently endorsed at baseline (n=12 of 20; 60%) and at follow-up (n=7 of 12; 58%).

On the PLANS (Table 5), patients in both arms reported high survivorship knowledge and confidence. Ten of the first 11 items from the PLANS had mean scores ≥ 3.0 , indicating that participants were between "agree" and "strongly agree" on each of the items. The only items with a mean < 3.0 were knowing what to expect over the next year (mean 2.9 in the provider-initiated group) and communication with PCP (mean 2.9 in the patient-initiated group). Similarly, patients in both study arms reported high scores, on average, on the 5 "confidence" PLANS items (1=not at all confident;

10=extremely confident). In both study arms, mean scores were lowest for health care providers communicating well (8.4 provider-initiated and 7.4 patient-initiated) and highest for going to follow-up appointments (9.7 provider-initiated and 9.9 patient-initiated). There were no statistically significant differences in mean scores by intervention arm at baseline.

We also found no statistically significant differences in mean scores by intervention arm at follow-up. Again, almost all of the 11 knowledge items had mean scores ≥ 3.0 . Among patients with follow-up in the provider-initiated group, the 2 items with mean scores < 3.0 were being clear on normal symptoms (2.9) and knowing symptoms to look for (2.8). Among patients with follow-up in the patient-initiated group, the 2 items with mean scores < 3.0 were communication among cancer care providers (2.8) and communication with PCP (2.7). For the 5 confidence items, scores ranged from 7.6-9.7 in the provider-initiated arm and 7.7-9.8 in the patient-initiated arm, with the same item rated lowest (health care providers communicating well) and highest (going to follow-up appointments) in both groups, similar to baseline.

Table 4. Cancer Survivors' Unmet Needs positive change items at baseline and follow-up by intervention arm.

n (%)	Provider-initiated at baseline (n=21)	Patient-initiated at baseline (n=20)	Provider-initiated at follow-up (n=13)	Patient-initiated at follow-up (n=12)
I have benefited from contact with other cancer survivors and/or their families				
<i>Yes, but I have always been like this</i>	5 (23.8)	2 (10.0)	1 (7.7)	2 (16.7)
<i>Yes, this has been a positive outcome</i>	11 (52.4)	10 (50.0)	9 (69.2)	6 (50.0)
<i>No, and I would like help to achieve this</i>	2 (9.5)	3 (15.0)	1 (7.7)	1 (8.3)
<i>No, and this is not important to me</i>	3 (14.3)	5 (25.0)	2 (15.4)	3 (25.0)
I focus more on things that are important to me				
<i>Yes, but I have always been like this</i>	10 (47.6)	9 (45.0)	5 (38.5)	6 (50.0)
<i>Yes, this has been a positive outcome</i>	9 (42.9)	9 (45.0)	7 (53.8)	5 (41.7)
<i>No, and I would like help to achieve this</i>	0 (0)	1 (5.0)	0 (0)	1 (8.3)
<i>No, and this is not important to me</i>	2 (9.5)	1 (5.0)	1 (7.7)	0 (0)
I realize how precious life is				
<i>Yes, but I have always been like this</i>	14 (66.7)	10 (50.0)	9 (69.2)	6 (50.0)
<i>Yes, this has been a positive outcome</i>	6 (28.6)	9 (45.0)	3 (23.1)	6 (50.0)
<i>No, and I would like help to achieve this</i>	0 (0)	0 (0)	0 (0)	0 (0)
<i>No, and this is not important to me</i>	1 (4.8)	1 (5.0)	1 (7.7)	0 (0)
I have made lots of positive changes in my life				
<i>Yes, but I have always been like this</i>	10 (47.6)	3 (15.0)	5 (38.5)	2 (16.7)
<i>Yes, this has been a positive outcome</i>	6 (28.6)	8 (40.0)	5 (38.5)	4 (33.3)
<i>No, and I would like help to achieve this</i>	2 (9.5)	4 (20.0)	1 (7.7)	2 (16.7)
<i>No, and this is not important to me</i>	3 (14.3)	5 (25.0)	2 (15.4)	4 (33.3)
I have grown as a person				
<i>Yes, but I have always been like this</i>	7 (33.3)	5 (25.0)	3 (23.1)	4 (33.3)
<i>Yes, this has been a positive outcome</i>	12 (57.1)	10 (50.0)	9 (69.2)	5 (41.7)
<i>No, and I would like help to achieve this</i>	1 (4.8)	0 (0)	0 (0)	0 (0)
<i>No, and this is not important to me</i>	1 (4.8)	5 (25.0)	1 (7.7)	3 (25.0)
I appreciate my relationships with others more				
<i>Yes, but I have always been like this</i>	11 (52.4)	7 (35.0)	5 (38.5)	4 (33.3)
<i>Yes, this has been a positive outcome</i>	9 (42.9)	12 (60.0)	8 (61.5)	7 (58.3)
<i>No, and I would like help to achieve this</i>	1 (4.8)	0 (0)	0 (0)	0 (0)
<i>No, and this is not important to me</i>	0 (0)	1 (5.0)	0 (0)	1 (8.3)

Table 5. Preparing for Life as a (New) Survivor Scale at baseline and follow-up by intervention arm.

Mean (Standard Deviation) ^a	Provider-initiated at baseline (n=21)	Patient-initiated at baseline (n=20)	P value for differences at baseline between arms ^b	Provider-initiated at follow-up (n=13)	Patient-initiated at follow-up (n=12)	P value for differences at follow-up between arms ^b
I know which health care providers to call with questions about my <i>cancer and its treatment</i>	3.6 (0.7)	3.6 (0.6)	>.99	3.5 (0.7)	3.5 (0.7)	.77
I am clear which health care providers to call if I have questions about <i>symptoms</i>	3.5 (0.6)	3.5 (0.6)	.88	3.3 (0.8)	3.5 (0.7)	.66
I am clear what symptoms are normal for me to experience	3.1 (0.7)	3.2 (0.6)	.49	2.9 (0.6)	3.2 (0.8)	.37
I know what symptoms or problems I should be looking for	3.1 (0.7)	3.1 (0.7)	.94	2.8 (0.6)	3.2 (0.6)	.11
I know how frequently I should be having appointments for follow-up care	3.4 (0.6)	3.3 (0.6)	.53	3.4 (0.5)	3.2 (0.8)	.56
I am always clear about the purpose of my visits	3.3 (0.7)	3.4 (0.6)	.79	3.4 (0.5)	3.5 (0.7)	.65
I know what tests are part of my follow-up care	3.0 (0.8)	3.1 (0.8)	.77	3.3 (0.6)	3.2 (0.8)	.73
I know other things I need to do to take the best care of myself	3.3 (0.6)	3.1 (0.7)	.54	3.2 (0.6)	3.6 (0.5)	.10
The health care providers who treat me for cancer communicate well with each other	3.2 (0.9)	3.1 (1.0)	.83	3.3 (0.5)	2.8 (1.0)	.28
The health care providers who treat me for cancer communicate well with my primary care/family provider	3.3 (0.7)	2.9 (1.0)	.31	3.0 (0.5)	2.7 (1.0)	.46
I feel prepared for what to expect over the next year	2.9 (0.8)	3.0 (0.7)	.97	3.1 (0.5)	3.0 (0.9)	.97
Mean (SD) ^b						
You will call or ask questions of your health care providers when you need to	8.8 (1.5)	8.8 (2.0)	.72	8.9 (1.5)	8.6 (2.7)	.45
You will go to all your follow-up appointments	9.7 (0.7)	9.9 (0.2)	.09	9.7 (0.6)	9.8 (0.6)	.45
You will do what you need to do to take the best care of yourself	9.2 (1.0)	8.9 (1.6)	.85	8.9 (1.0)	9.2 (1.2)	.50
Your health care providers will communicate well with each other during the next year	8.4 (1.9)	7.4 (2.5)	.18	7.6 (1.2)	7.7 (2.7)	.41
There is a well-coordinated plan for your cancer care	8.7 (1.4)	8.3 (2.5)	.79	8.0 (1.4)	8.2 (2.9)	.15

^a1=strongly disagree to 4=strongly agree.

^b1=not at all confident to 10=extremely confident.

^cP values for Wilcoxon rank-sum tests for differences in scores between intervention arms separately at baseline and follow-up.

Changes on the PLANS tended to be small in both groups (Table 6). The greatest worsening was seen in the provider-initiated group whose confidence that their health care providers will communicate well decreased by an average of 1.2 points ($P=.01$). This change was statistically significantly different

from the 0.1 point improvement in the patient-initiated arm ($P=.04$ for between-group difference). No other within-group changes were statistically significant in either the provider-initiated or patient-initiated arm, nor were there any other statistically significant differences between arms.

Table 6. Preparing for Life as a (New) Survivor survey change from baseline to follow-up by intervention arm.

Item	Change ^a in provider-initiated arm (n=13)	P value for change within provider-initiated arm ^b	Change ^a in patient-initiated arm (n=12)	P value for change within patient-initiated arm ^b	P value for differences in change by arm ^c
Knowledge items					
I know which health care providers to call with questions about my <i>cancer and its treatment</i>	0.0 (0.6)	>.99	-0.3 (0.7)	.23	.28
I am clear which health care providers to call if I have questions about <i>symptoms</i>	-0.2 (0.7)	.48	-0.2 (0.8)	.48	.92
I am clear what symptoms are normal for me to experience	-0.2 (0.7)	.48	0.0 (0.5)	>.99	.51
I know what symptoms or problems I should be looking for	-0.2 (0.7)	.34	0.1 (0.5)	.77	.28
I know how frequently I should be having appointments for follow-up care	0.0 (0.7)	>.99	-0.1 (0.9)	.85	.95
I am always clear about the purpose of my visits	0.0 (0.6)	>.99	-0.1 (0.5)	.77	.72
I know what tests are part of my follow-up care	0.5 (0.9)	.10	0.0 (1.0)	>.99	.21
I know other things I need to do to take the best care of myself	0.0 (0.8)	>.99	0.3 (0.8)	.30	.30
The health care providers who treat me for cancer communicate well with each other	-0.1 (0.5)	.77	-0.5 (1.2)	.34	.50
The health care providers who treat me for cancer communicate well with my primary care/family provider	-0.1 (0.4)	>.99	-0.1 (0.7)	.77	>.99
I feel prepared for what to expect over the next year	0.0 (0.8)	>.99	-0.2 (0.8)	.59	.51
Confidence items					
You will call or ask questions of your health care providers when you need to	0.2 (0.4)	.35	-0.7 (2.8)	.79	.94
You will go to all your follow-up appointments	0.1 (0.8)	.85	-0.1 (0.3)	>.99	.68
You will do what you need to do to take the best care of yourself	-0.2 (1.5)	.72	-0.2 (0.8)	.59	.64
Your health care providers will communicate well with each other during the next year	-1.2 (1.2)	.01	0.1 (3.3)	.63	.04
There is a well-coordinated plan for your cancer care	-0.6 (1.5)	.16	-0.6 (2.5)	.28	.74

^aPositive mean changes indicate improvement; negative mean changes indicate worsening.

^bP values for Wilcoxon signed-rank tests for change from baseline to follow-up within intervention arm, among patients with data at follow-up only.

^cP values for Wilcoxon rank-sum tests for differences in the change from baseline to follow-up between intervention arms (interaction), among patients with data at follow-up only.

Patient Perspectives on the Benefits of SCPs and SCP Implementation

In qualitative interviews conducted at follow-up, patients expressed ongoing needs related to information and support, with almost all of those interviewed describing some ongoing negative impact of cancer in their lives. Patients discussed the

emotional impacts of cancer, including depression, fatigue, anxiety, and fear. Some expressed emotions related to concerns about recurrence, and there were some descriptions of physical impacts such as pain. Even those who initially described cancer as nonimpactful tended to describe ways in which it had affected them as the interview unfolded. Several patients expressed some belief that the SCP would improve communication that would

in turn help to address these concerns: *It would be a tool to communicate issues better. My biggest fear is that I know nothing about medicine.* (#27, My Care Plan; All quotes included are illustrative of broader themes to emerge from review of the patient interviews unless it is specifically noted that an idea came from just one person.)

One element of the SCP process that was seen as particularly attractive and useful for patients was “having everything in one place,” as a “quick reference document.” In general, patients seemed to like how plans made connections to health concerns other than their cancer, although not all interviewees understood why noncancer information was included on the plan. The patients who were interviewed at follow-up expressed almost universal confidence in their ability to get the care that they needed in the coming months and years. This group of patients tended to portray themselves as proactive and involved in the management of their health and health care. In some cases, patients described already having been engaged in information gathering and maintenance, but expressed that the SCP further facilitated this process. In addition to their own capacity and the value that the SCP provided, patients explained their confidence about future care with reference to their family given the quality of their health insurance and their health care providers. The SCP was seen as helping patients to identify “who to go to” and “who is responsible for what” as they moved beyond acute treatment. *I am 100% certain that I will be able to handle it. Whether I do it according to someone's protocol is another matter I will handle it to the best of my ability. As a former journalist and researcher, I am certain that I will do my research and tap all of the sources.* (#35, My Care Plan); *I feel good about it but I feel that I have to be an active participant in getting it. I have to be an active advocate—actively involved in advocating for myself. The care plan will absolutely help with this.* (#28, SCP Builder)

For the process of plan completion, several participants articulated that either putting together the plan or even simply receiving it had served to educate them about their cancer and the care received and to provide useful information that they may not have even realized they were lacking. When we asked about the potential value of the plan for improving communication with one's PCP, patients described having existing, functional relationships with their PCPs. Patients did not mention the Web-based format of the SCP as being problematic. Their responses varied in relation to the question about whether or not they had shared their plans with their PCP, but generally patients expressed the opinion that the information provided and the format in which it was provided would be helpful in their communication with their PCP. Even patients who had not yet shared their plans with their PCP generally expressed an intention to do so. One reason provided for why they might not share a plan was that the PCP was perceived as being too busy to have time to deal with the SCP. Some patients were unsure as to whether they (or someone else) had shared the SCP with their PCP, and others expressed some uncertainty as to whether their oncologist or their internist would now act as their PCP. Patients were not universally confident that PCPs had the necessary expertise to manage their care: one patient expressed concern that their PCP would not be familiar enough

with the anemia associated with his radiation treatment to effectively treat him.

In line with much of what the clinicians discussed, the timing of plan provision emerged as an important issue with patients, with several expressing a desire to have the plan earlier in the process. Several patients also noted that the plans seemed to be more summative than forward looking (planning), and some raised questions about how the plan might be updated over time. *It would have been really helpful to have more information up front.* (#25, My Care Plan); *The only question that I would have is how it gets updated over time. Does it get updated if things change? Medications? Therapy that I am undergoing... Is it a document that stands on its own? Is it reviewed annually? I don't know anything about that. It is not a static document.* (#23, SCP Builder)

In terms of content, most patients expressed satisfaction with the information provided. Areas for additional content mentioned by 1 or 2 patients included diet, contact information for specialists and information on clinical trials. A few mentioned aspects of the information provided that they did not understand; the one specific example provided was the idea of “ongoing toxicities.” There was also a potential concern expressed about the accuracy of the content provided by the providers completing the form.

Discussion

Principal Findings

In this mixed-methods study, we evaluated 2 models of Web-based survivorship care planning in the real-world context of 2 academically-affiliated, community hospitals. This study provides preliminary evidence of the feasibility and perceived value of 2 SCP templates, as well as possibly informing the design and implementation of future, larger studies. The combined qualitative and quantitative data provide important insights regarding the feasibility and value of the 2 SCP templates tested here, as well as survivorship care planning in general.

In terms of feasibility, a number of challenges emerged, irrespective of the study arm. First, the somewhat limited participation of eligible oncologists in this research initiative (33%) suggests that the imminent Commission on Cancer accreditation standards [17] do not provide a sufficient incentive for many oncologists to develop systems for survivorship care planning, nor does the Web-based nature or potential patient-initiated structure overcome existing barriers. Birken et al [18] identify the resources necessary for the use of SCPs as a considerable barrier to their implementation; this study does not suggest that such resource barriers are easily overcome by the mere availability of patient- or provider-initiated templates. There was higher engagement in the study (overall and in terms of actually referring patients) by radiation oncologists compared with other clinical specialties, possibly indicating an opportunity for targeted SCP initiatives. In the initial month of the study, it became clear that oncologists and their staff were experiencing considerable difficulty in identifying eligible patients for study purposes. As a result, the research team played an active role

in recruiting patients, but such approaches are not sustainable for real-world applications. Even with the additional research team support for recruitment, only 5 of the 13 participating clinicians enrolled patients in the study, suggesting possible challenges in identifying eligible patients and engaging them in the process of Web-based survivorship care planning. Finally, at follow-up, fewer than half of the patients from whom we were able to collect data had access to any SCP document (including incomplete plans from the patient-initiated arm). Participants in the patient-initiated arm were more likely to have a SCP, if one included an initiated (but not completed) SCP.

Our study reveals a need for explicit consideration of how preparing and delivering the SCP should be integrated into existing practices and routines of care provision. This finding is supported by the assertion made by Keesing, McNamara, and Rosenwax [6] that there is much work to be done to resolve the practical issues in developing and delivering Web-based SCPs that originate with the provider or the patient. If the goal is that every patient completing acute treatment for cancer should have an SCP, then it is important to acknowledge that completing an SCP can be complex and requires a considerable amount of time and resources [18,19]. Effort should be spent identifying strategies for enabling providers and their staff to be reimbursed for the time that it takes to either prepare and provide the SCP or to complete a plan that is initiated by the patient. One possible way to reduce the time burden is to look for ways that SCP templates can be integrated into EMRs and/or cancer registries such that some or much of the information is auto-populated.

These findings also inform our understanding of the value of survivorship care planning. The Web-based nature of the 2 SCP modalities did not emerge as problematic, but nor was this sufficient to overcome the feasibility challenges of providing SCPs. Although both providers and patients generally supported the importance of SCPs during the qualitative interviews, data from the CaSUN and PLANS questionnaires at baseline demonstrated that the patients who enrolled in the study had relatively few unmet needs and high *perceived* knowledge of and confidence about survivorship. However, the areas rated lowest at baseline were issues that SCPs aim to address, including communication within the cancer care team and with the patient and knowing what to expect after treatment completion. In addition, at the time of transition, survivors may not know what they do not know. For example, follow-up scores were statistically significantly worse in the provider-initiated group regarding confidence health providers will communicate well with each other. In a study of SCPs for endometrial cancer survivors in the Netherlands, Nicolaije et al [20] found that patients in the SCP arm had more concerns, reported more symptoms, and experienced a greater emotional impact than

control patients. Survivorship care planning may create awareness of issues that had not previously existed and uncertainty may emerge as time passes from the end of treatment. Cheung et al [21] noted that both patients and physicians may have a reason to avoid engaging in survivorship care planning discussions because of the difficult issues about long-term impacts of cancer and possible psychosocial challenges to survivorship. It is possible that this contributes to ambivalence on the part of physicians to prioritize SCP provision, at least for some patients, although this is not directly observable from our data.

In interpreting these findings, it is important to note that the 2-month follow-up was designed to evaluate delivery of the plan, not the impact of it on the secondary patient-reported outcome measures. This study was conducted in only 2 hospitals and is intended to provide preliminary evidence of the feasibility and possible value of these 2 Web-based survivorship care planning approaches and to inform the design of larger studies. The sample size was determined based on feasibility and the analysis of the quantitative data intended to inform power calculations for future studies. However, given the small numbers, the results should be applied cautiously if used to support power calculations. Statistically significant *P* values should be interpreted with caution, given the large number of tests performed. Because randomization occurred at the patient level, with providers managing patients in both study arms, it may have been more difficult for providers to establish standard processes than if they had only had to address one approach to survivorship care planning. We did not collect any patient-specific data in our follow-up interviews with clinicians, and we therefore are not able to explore whether plans were initiated (or completed), but not delivered to some patients in the provider-initiated arm. Future studies should capture process-specific data to better determine specific places or issues where any system to get SCPs to patients meets difficulties.

Conclusion

Strengths of this study include collection of both quantitative and qualitative data from both patients and providers in 2 academically-affiliated, community hospitals. Furthermore, we used a randomized design to compare 2 SCP templates. The findings of this study provide preliminary evidence regarding the advantages and disadvantages of the 2 Web-based templates, as well as issues with survivorship care planning in general, and can inform future research in larger populations with longer follow-up. In summary, the findings of this study suggest that the primary barriers to survivorship care planning are not the templates (the *forms*), but rather the processes for completing SCPs (the *function*).

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Journey Forward Care Plan Builder Template.

[[PDF File \(Adobe PDF File\), 1MB - cancer_v2i2e12_app1.pdf](#)]

Multimedia Appendix 2

Journey Forward My Care Plan Template.

[[PDF File \(Adobe PDF File\), 1MB - cancer_v2i2e12_app2.pdf](#)]

Multimedia Appendix 3

CONSORT-EHEALTH checklist V1.6.2 [21].

[[PDF File \(Adobe PDF File\), 735KB - cancer_v2i2e12_app3.pdf](#)]

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Abbreviations

CaSUN: Cancer Survivor's Unmet Needs
EMR: electronic medical records
IOM: Institute of Medicine
PLANS: Preparing for Life as a (New) Survivor
PCP: primary care provider
SCP: Survivorship Care Plan

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Original Paper

Alcohol Intake Among Breast Cancer Survivors: Change in Alcohol Use During a Weight Management Intervention

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Abstract

Background: Daily alcohol intake in quantities as small as half a drink/day significantly increases the risk of breast cancer recurrence for postmenopausal survivors. Interventions designed to modify alcohol use among survivors have not been studied; however, lifestyle interventions that target change in dietary intake may affect alcohol intake.

Objective: To evaluate change in alcohol use during a weight loss intervention for obese, rural-dwelling breast cancer survivors.

Methods: Data were derived from an 18-month trial that included a 6-month weight loss intervention delivered via group conference calls, followed by a 12-month randomized weight loss maintenance phase in which participants received continued group calls or mailed newsletters. Participants who reported regular alcohol use at baseline (N=37) were included in this study.

Results: Mean daily alcohol intake significantly decreased from baseline to 6 months during the weight loss intervention (19.6-2.3 g; $P=.001$). Mean alcohol intake did not significantly increase ($b=0.99$, $P=.12$) during the weight loss maintenance phase (months 6-18) and did not depend on randomization group ($b=0.32$, $P=.799$).

Conclusions: Findings provide preliminary evidence that a weight loss intervention may address obesity and alcohol use risk factors for cancer recurrence. Minimal mail-based contact post weight loss can maintain alcohol use reductions through 18 months, suggesting durability in these effects. These results highlight a possibility that lifestyle interventions for survivors may modify health behaviors that are not the main foci of an intervention but that coincide with intervention goals.

Trial Registration: Clinicaltrials.gov NCT01441011; <https://clinicaltrials.gov/ct2/show/NCT01441011> (Archived by WebCite at <http://www.webcitation.org/6lsJ9dMa9>)

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KEYWORDS

alcohol drinking; breast cancer; weight loss; weight reduction programs; obesity

Introduction

Results of comprehensive meta-analyses have indicated that daily alcohol use, even in small quantities, is associated with an increased risk of both developing breast cancer and breast cancer recurrence [1-3]. There is a significant dose-response relationship between daily alcohol use and breast cancer risk [4], and for every 1 drink per day (10 g) increase in alcohol consumption, there is a 12% increased risk of breast cancer [1].

As little as 5-6 g of daily alcohol intake has been found to significantly increase the risk of developing breast cancer [5] and breast cancer recurrence [3,6]. Mechanisms responsible for the increased risk may be due to increased estrogen and androgen levels [7,8] or increased levels of plasma insulin-like growth factors produced by the liver following alcohol consumption [9]. In addition, alcohol-related breast cancer risk may be compounded for individuals who have other lifestyle risk factors, such as obesity [6]. Both the American Cancer

Society [10] and the National Institute on Alcohol Abuse and Alcoholism (NIAAA) [11] recommend that women consume no more than 1 drink per day, and the recently published European Code against Cancer 4th Edition stresses that zero alcohol intake is recommended for cancer prevention [12]. Newly proposed UK drinking guidelines specify that individuals should have some non-drinking days each week [13].

Multiple breast cancer survivor cohort studies have found that alcohol use prevalence among female survivors is similar to that in the general US female population; 15-23% of survivors drink in excess of low-risk drinking guidelines [14-16]. Although cancer diagnosis may be a teachable moment to prompt health behavior change, 1 large-scale, population-based study among cancer survivors have found no significant long-term changes in daily alcohol consumption pre- to post-cancer diagnosis [17]. One smaller breast cancer cohort study found that the prevalence of heavy episodic drinking decreased following the diagnosis, however levels of daily alcohol use were not reported [18].

Interventions designed to modify alcohol consumption among breast cancer survivors have not previously been studied; however, it is possible that lifestyle interventions that target weight loss and promote change in dietary intake may affect alcohol consumption. Alcohol has an energy density that is second only to fat [19] and reducing alcohol intake would coincide with lifestyle intervention goals of calorie restriction and energy balance. The purpose of this study was to examine change in alcohol use among obese, rural breast cancer survivors participating in an 18-month weight management intervention who reported regular alcohol use at baseline. Specifically, we evaluated initial change in alcohol use during a 6-month weight loss intervention phase and the durability of these effects during a 12-month weight loss maintenance phase.

Methods

Parent Study Overview

The parent study from which the data for this study were derived compared group phone-based counseling with mailed newsletters on weight loss maintenance following successful weight loss among rural, obese breast cancer survivors. The study has previously been detailed [20,21] and is briefly described here. Participants (N=210) were recruited in 8 cohorts from oncology centers in the Midwestern United States. Participants were female breast cancer survivors aged 75 years or younger, with a BMI between 27 and 45 kg/m², who had been diagnosed with Stages 0-III disease within the past 10 years, were at least 3 months out of treatment at the time of enrollment, had physician clearance to participate, and resided in rural areas [22]. Current alcohol or drug abuse [23] was an exclusion criterion, however no participants were excluded for this reason [20]. The trial included a nonrandomized 6-month weight loss phase (0-6 months), where all participants received weekly group phone sessions, followed by a 12-month randomized weight loss maintenance phase (6-18 months) in which participants who lost ≥5% of their baseline weight were randomized to continued group phone sessions or a newsletter

comparison condition. The Institution's Human Subjects Committee approved the study.

Intervention

During the weight loss phase, groups of 10-15 participants met for weekly counseling sessions via conference call with a group counselor (registered dietitian or psychologist). Intervention and technology accessibility were a primary focus with our rural-dwelling sample; thus, we used a conference call format that did not require participants to have regular access to a computer or mobile phone. Participants joined the conference sessions by calling into a toll free, 1-800 number accessible from any landline, mobile phone, or Internet-based telephone system (such as Skype or Google Voice). During the calls, participants were instructed to follow a structured meal plan that included whey-based protein shakes, prepackaged portion-controlled meals (eg, Lean Cuisines), and at least five fruits or vegetables per day. Snacks that were not fruits or vegetables, as well as eating out were discouraged. Participants were instructed to gradually increase their physical activity each week with the goal of completing 225 min/week of moderate-intensity physical activity by week 12.

The weight loss phase focused on behavioral skills for healthy eating, increasing physical activity, and self-monitoring daily calorie intake and physical activity. Two sessions focused on evidence-based nutrition recommendations for breast cancer survivors specifically, including alcohol use as a risk factor for breast cancer recurrence and American Cancer Society recommendations for consuming 1 or less alcoholic drinks per day. During this session, leaders also discussed the calorific content of alcoholic beverages as related to participants' goals of limiting their total calorific intake and losing weight.

During the weight loss maintenance phase, participants randomized to the group phone condition continued to meet every other week via conference calls, while participants in the newsletter control condition received bi-weekly newsletters highlighting the same content. The maintenance phase focused on problem solving related to maintaining diet and physical activity behaviors and increasing motivation, and did not specifically address alcohol use.

Data and Measures

Multiple pass 24-h diet recalls were collected from participants at baseline, 6 months, 12 months, and 18 months. United States Department of Agriculture (USDA) multiple pass 24-h dietary recalls are the gold standard for measuring typical dietary intake [24] and are also valid as a measure of alcohol consumption when compared with a 1 week recall of alcohol use [25].

Of the 210 participants enrolled in the parent study, 42 participants (20%) reported daily alcohol intake of at least 5 g at baseline. Of the 20% (42/210), 11% (5/42) of the participants drank more than 1 standard drink per day and 9% drank about half a standard drink per day.

Thirty-seven participants provided 2 valid diet recalls at both baseline and 6 months that reflected their typical dietary intake and thus were included in these analyses. A total of 277 diet recalls were collected from the sample out of a possible 296,

representing a 94% assessment compliance rate. Sixty-seven recalls were completed at 12 months and 62 at 18 months.

Statistical Analyses

A paired-samples *t* test was utilized to test whether daily alcohol grams significantly decreased during the weight loss phase (0-6 months). Generalized estimating equation (GEE) models were used to examine change in daily grams of alcohol intake during the randomized weight loss maintenance phase (6, 12, and 18 months), while accounting for the within-subject report correlation structure of the longitudinal data [26]. GEE Model 1 controlled for age, college education, and randomization group. A second GEE model included an interaction between time and randomization group to evaluate whether change in alcohol use depended on randomization group. For both GEE models, we determined that an exchangeable correlation

structure fit the data best based on the Quasi-Likelihood under the Independence Model Criterion (QIC) [27]. All statistical analyses were conducted using SPSS version 22 (IBM Corporation) [28].

Results

Demographic characteristics of participants (N=37) are presented in Table 1. The majority of participants (28/37; 75%) were obese and 25% (9/37) were overweight. Participants were a mean of 3.5 years beyond cancer treatment at the start of the study. At 6 months, participants lost a mean of 12.9 kg (SD 5.4), corresponding to a mean of 14.4% (SD 5.9) of their baseline weight. By 18 months, participants regained a mean of 3.3 kg (SD 5.2) of the weight they lost.

Table 1. Participant Demographics (N=37).

Variable	Mean (SD) or %
Age	57.8 (7.9)
Marital status (% Married or cohabitating)	89
Race or Ethnicity (% white)	100
Education (% BA degree or higher)	31
Employed full-time	75
Weight variables	
Body mass index	33.3 (4.3)
Overweight	75
Obese	25
Cancer variables	
Age at diagnosis	54.0 (8.3)
Time since cancer treatment (years)	3.5 (2.4)
Stage	
0	19
I	41
II	27
III	13
Treatment received	
Breast-conserving surgery	57
Mastectomy	43
Radiation	71
Chemotherapy	57
Anti-hormone Therapy	82
Alcohol variables	
Grams of alcohol per day	19.6 (17.85)
10 g of alcohol or more per day ^a	62
14 g of alcohol or more per day ^b	51
Daily heavy alcohol use (>3 drinks/42 g) ^c	15

^a10 g=definition of 1 standard drink per meta-analyses on alcohol use and breast cancer risk.

^b14 g=definition of 1 standard drink per the US National Institute on Alcohol Use and Alcoholism (NIAAA).

^cDaily heavy alcohol use = alcohol consumption in excess of NIAAA guidelines for low-risk drinking for women.

Table 2. Change in alcohol use during a weight management intervention.

Alcohol intake	Full sample (N=37)		Group phone counseling (n=17)	Newsletter comparison (n=20)	P value (between groups)
	Mean (SD)	P value (full sample)			
Baseline daily alcohol use (grams)	19.61 (17.8)	<.001	17.0 (13.5)	20.5 (20.9)	.35 ^c
Daily alcohol use at 6 months (grams)	2.28 (5.1)	.001 ^a	1.3 (2.4)	2.7 (6.1)	.25 ^d
Daily alcohol use at 18 months (grams)	4.20 (9.2)	.12 ^b	3.52 (7.9)	5.1 (10.7)	.80 ^e

^aPaired samples *t* test of change in alcohol use from baseline to 6 months during the weight loss intervention phase.

^bGeneralized estimating equation (GEE) model of change in alcohol use during weight loss maintenance (months 6-18); full results of this model are presented in [Table 3](#).

^cIndependent samples *t* test of baseline alcohol use by group.

^dRepeated measures analysis of variance testing change in alcohol use by group during weight loss phase (baseline to 6 months)

^eGEE model of change in alcohol use during weight loss maintenance phase, testing for moderating effects of randomization group.

Table 3. Change in alcohol use during a weight loss maintenance intervention using a generalized estimating equation model.

Variable	DV ^a : Daily alcohol intake (in grams)			
	B ^b	SE ^c	P value	95% CI
Time	0.99	0.64	.119	-0.26 to 2.26
Age	0.14	0.13	.268	-0.11 to 0.40
Education (college degree/not) ^d	2.27	2.66	.393	-2.94 to 7.46
Randomization group (intervention/control) ^e	-1.70	1.91	.373	-5.45 to 2.05

^aDV: dependent variable.

^bB: unstandardized regression coefficient.

^cSE: standard error.

^dNo 4-year college degree was the reference category.

^eThe mail-based control group was the reference category.

Participants drank a mean of 19.6 g of alcohol per day at baseline (SD 17.85; Range 5.5-92.3), which corresponds to 1.4 US standard drinks [11]. Participants consumed a mean of 6.4% (SD 5.9; Range 1.4-32.8%) of their daily calories from alcohol at baseline.

Change in alcohol use during the study is presented in [Table 2](#). Mean daily alcohol grams significantly decreased from baseline to 6 months during the weight loss intervention (19.6-2.3 g; $t_{36}=6.07$, $P=.001$, 95% CI 11.5-23.1), corresponding to a mean decrease of 1.2 US standard drinks.

During the weight loss maintenance phase, alcohol intake did not significantly increase when controlling for randomization group, age, and education level ([Table 3](#)). For every unit increase in time, participants consumed 0.99 more grams of alcohol. Change in alcohol use during Phase II did not depend on randomization group when accounting for potential confounding variables ($b=.32$, $SE=1.27$, $P=.799$, CI -2.16 to 2.81).

Results indicate that the significant and clinically meaningful decrease in alcohol intake that occurred during the weight loss phase was maintained during the weight loss maintenance phase

among participants in both the group phone counseling condition and the newsletter condition.

Discussion

Principal Findings

The risk for breast cancer recurrence increases significantly for postmenopausal breast cancer survivors who regularly drink alcohol, even at very low levels [3,6]. This study is the first to our knowledge to report on significant change in alcohol use among breast cancer survivors following a behavioral weight loss intervention. The findings suggest that among postmenopausal, obese survivors who drank regularly at baseline, participation in a behavioral weight control intervention was associated with significantly decreased alcohol intake in addition to clinically meaningful weight loss. Importantly, participants decreased their alcohol use to less than the 5 g per day level that is associated with increased recurrence risk [3,6]. Thus, findings suggest that a behavioral weight control intervention may simultaneously change multiple lifestyle risk factors for breast cancer recurrence.

A growing body of literature has focused on changing multiple health behaviors including dietary intake, physical activity, and substance use, either simultaneously or sequentially using dually focused interventions [29]. Our results are unique as they suggest that an intervention designed to address a single issue may influence change in other risk behaviors that coincide with the overall goals of the intervention. At a population level, epidemiologists have observed such tag-along behavior change effects in some circumstances in which individuals attempt to change a single behavior; for example, Brown et al found that individuals in England who reported attempted to quit smoking in a cross-sectional survey also reported fewer heavy drinking episodes during that time [30]. Our findings are novel in that we observed these effects longitudinally in an individually focused clinical intervention trial. In this regard, it is also important to emphasize that our intervention was focused on improving coping skills and self-efficacy, problem solving, addressing environmental barriers, and identifying triggers, all of which can also be helpful in decreasing alcohol use.

Our findings also indicate that alcohol use reductions were durable over an 18-month period. The decrease in alcohol use achieved during the weight loss intervention was maintained during the weight maintenance phase across both conditions, despite some weight regain. These sustained reductions in alcohol intake may in part be attributed to lower drinking levels at baseline, and also because decreasing alcohol intake was in accordance with the dietary goals of restricting overall caloric intake, and the intervention addressed alcohol consumption as an independent risk factor for recurrence.

The prevalence of daily drinking among the total sample from the parent study was in line with national estimates (20%) [14-16]; however, drinking quantity was lower than that found in other survivor samples. Specifically, 15-18% of breast cancer survivors from large cohort samples reported consuming 1+ drinks per day [15,16], compared with our sample where 11% of participants drank more than 1 standard drink per day and an additional 9% drank about half a drink per day. This difference may be due to our rural sample of overweight or obese women interested in losing weight. Rural survivors have been found to drink less than the survivors in urban environments [31], and our findings were similar with Weaver et al (2013) having estimated that 13% of rural survivors drink daily.

Limitations

This study had several limitations. First, the sample size in our study was small. However, given that this study is the first to report a reduction in survivors' alcohol use during a behavioral intervention, our findings provide valuable initial information on change in survivors' health risk behaviors and suggest that future research on this topic using larger samples is warranted. In addition, all participants completed the weight loss intervention, thus we did not have a nonweight loss control condition with which to compare initial change in alcohol use. However, 1 large-scale study found that survivors did not change daily alcohol use patterns long-term [17], suggesting that daily alcohol use among survivors may be stable long-term without behavioral intervention. Second, the findings may not be generalizable to nonrural survivors or those with heavier drinking at baseline. Findings also may not be generalizable to more racially and ethnically diverse samples; a limitation of our study was that the sample comprised all Caucasian women. Finally, alcohol use was measured using 24-h dietary recalls, thus it was not possible to evaluate heavy episodic drinking rates.

Future research in this area should incorporate additional alcohol measures and investigate whether weight loss interventions decrease alcohol use among breast cancer survivors who are heavier drinkers. Researchers should examine the effects of heavy alcohol use on obesity to determine whether alcohol use as a cancer recurrence risk factor contributes to obesity, another risk factor. Relatedly, researchers could investigate whether heavy alcohol use hinders weight loss and contributes to weight regain. We were not able to address this question because participants in this study reduced their alcohol use to less than what would be expected to interfere with weight loss or maintenance.

Implications

Our findings provide preliminary evidence that a weight loss intervention for obese breast cancer survivors may address both obesity and alcohol use risk factors for breast cancer recurrence with durability in alcohol reduction even with minimal content directly targeting alcohol use. Thus, lifestyle interventions for survivors may modify health behaviors that are not the main foci of intervention but that coincide with the overall goals of an intervention. This study highlights the possibility of improving the health of survivors using behavioral interventions focused on developing behavioral skills that might generalize to related risk behaviors.

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Conflicts of Interest

None declared.

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Abbreviations

GEE: Generalized estimating equation.

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Short Paper

Online Versus Telephone Methods to Recruit and Interview Older Gay and Bisexual Men Treated for Prostate Cancer: Findings from the Restore Study

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Abstract

Background: Recently, researchers have faced the challenge of conflicting recommendations for online versus traditional methods to recruit and interview older, sexual minority men. Older populations represent the cohort least likely to be online, necessitating the use of traditional research methods, such as telephone or in-person interviews. By contrast, gay and bisexual men represent a population of early adopters of new technology, both in general and for medical research. In a study of older gay and bisexual men with prostate cancer, we asked whether respondents preferred online versus offline methods for data collection. Given the paucity of research on how to recruit older gay and bisexual men in general, and older gay and bisexual men with prostate cancer in particular, we conducted an observational study to identify participant preferences when participating in research studies.

Objective: To test online versus offline recruitment demographic data collection, and interview preferences of older gay and bisexual men with prostate cancer.

Methods: Email blasts were sent from a website providing support services for gay and bisexual men with prostate cancer, supplemented with an email invitation from the web-host. All invitations provided information via the study website address and a toll-free telephone number. Study tasks included respondents being screened, giving informed consent, completing a short survey collecting demographic data, and a 60-75 minute telephone or Internet chat interview. All materials stressed that enrollees could participate in each task using either online methods or by telephone, whichever they preferred.

Results: A total of 74 men were screened into the study, and 30 were interviewed. The average age of the participants was 63 years (standard deviation 6.9, range 48-75 years), with most residing in 14 American states, and one temporarily located overseas. For screening, consent, and the collection of demographic data, 97% (29/30) of the participants completed these tasks using online methods. For the interview, 97% (29/30) chose to be interviewed by telephone, rather than Internet chat.

Conclusions: Older gay and bisexual men, when given choices, appear to prefer a mixed methods approach to qualitative investigations. For most aspects of the study, the older men chose online methods; the exception was the interview, in which case almost all preferred telephone. We speculate that a combination of the deeply personal nature of the topic (sexual effects of prostate cancer treatment), unfamiliarity with online chat, and possibly the subject burden involved in extensive typing contributed to the preference of telephone versus online chat. Recruitment of older men into this study showed good geographic diversity. We recommend that other qualitative researchers consider a mixed methods approach when recruiting older populations online.

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KEYWORDS

Qualitative research; Aged; Gays

Introduction

The literature regarding the recruitment of older cohorts and sexual minorities reads as a study in contrasts. In 2014, while 86% of all adults reported being online, only 59% of seniors (age >65) were online [1]. Although 68% of Americans in their early 70s go online, Internet use drops to 47% after age 75 [1]. The implication for qualitative researchers is that traditional recruitment and data collection methods, such as telephone or in-person interviews, are preferred (or necessary) to recruit many older adults [2]. In addition, online research on older adults raises ethical considerations in at least four areas: (1) providing sufficient support to facilitate ongoing social interactions, (2) managing older adults' expectations, (3) providing encouragement without coercion, and (4) responding to individual needs [3]. In contrast, the literature on gay, bisexual, and other men who have sex with men indicates that online methods are preferred and more effective for recruiting gay and bisexual men into studies [4,5]. Gay and bisexual men are a minority group identified as early adopters of new technology [6]. Given the popularity of apps and websites for dating and partner-seeking [4,7], and high rates of online pornography consumption [8], being online has become an integral part of the experience of being a gay or bisexual man in the United States [9] and other developed countries [10,11]. Multiple studies note a disproportionately high use of the Internet and apps by the youngest cohorts of gay and bisexual men [7,9]. This finding leads to the question of whether older cohorts of gay and bisexual men are better recruited using online or traditional methods.

Research on older gay and bisexual men is scarce, potentially contributing to undocumented health disparities [12]. Prostate cancer research is one such area, in which treatment outcomes appear worse for gay and bisexual men than other men [13-15], but there has been insufficient research to understand this phenomenon [16]. Detailed qualitative studies are needed to document the experience of gay and bisexual men with prostate cancer. Historically, recruiting gay and bisexual men with prostate cancer into studies has proven extremely challenging. Only three quantitative studies exist, each using small cohorts ranging from 89 to 111 participants [15,17,18]. Cancer registries do not routinely collect demographic data on sexual orientation, leaving this population relatively invisible. Similarly, in all but the largest cities, there are insufficient numbers of gay and bisexual men undergoing prostate cancer treatment to make tailored group support services feasible.

In designing a qualitative study of gay and bisexual men with prostate cancer, we encountered insufficient research to guide best practices. Given the lack of methodological studies of older gay and bisexual men, we conducted an observational study to identify and test the preferences of older gay and bisexual men.

Methods

Study participants were recruited via *Malecare*, the largest men's cancer support group (utilizing both online and in-person groups) and advocacy organization in the United States. Each year, an estimated 800 to 1000 gay and bisexual men with

prostate cancer join *Malecare*. *Malecare* members received an email with information about this study, and the same information was included in *Malecare*'s e-newsletter. Both invitations identified the *Restore* study, as funded by the National Cancer Institute at the National Institutes of Health, and its purpose as, "looking at how prostate cancer treatment affects gay and bisexual men, our life and sexual partners, and our family and friends who provide care for us during treatment." Eligibility criteria included: adults aged >18; ability to speak English; identification as a gay, bisexual, or other man who has sex with men; diagnosed with, and treated for, prostate cancer; and resident of the United States. In addition, we stratified recruitment by major treatment type (surgery, radiation, or other) until saturation was reached. Given the high rates of radical prostatectomies, the stratification resulted in this group being capped at 19 participants.

In the email blast, potential participants were provided information that listed both the study website and a toll-free telephone number. Study tasks included respondents being screened, giving informed consent, completing a short survey collecting demographic data, and a 60-75 minute interview. All materials stressed that enrollees could participate in each task either by going online (to the website) or by telephone, *whichever they preferred*.

Results

A total of 74 men were screened into the study, 30 completed the consent process, and all 30 were interviewed. Average age of the participants was 63 years (standard deviation 6.9), ranging from 48 to 75 years. One man was under 50, six were in their 50s, ten were aged 60-64, six were aged 66-69, and seven were in their 70s. Twenty-six participants described their race/ethnicity as white, three as African American, and one as Latino. Two of the men reported their Human Immunodeficiency Virus status as positive, one as unsure, and the remainder as negative. The participants resided in 13 states (Alabama, California, Florida, Georgia, Illinois, Kansas, Massachusetts, Minnesota, New York, Oklahoma, Rhode Island, Washington, and West Virginia); seven resided in New York, and one US resident was temporarily located in Europe. For screening, consent, and the collection of demographic data, 97% (29/30) of the participants completed these tasks using online methods. For the interview, 97% (29/30) chose to be interviewed by telephone, rather than online chat (with a different person absenting in each case).

Discussion

Older gay and bisexual men, when given choices regarding participation in qualitative research, appear to prefer a mixed methods approach to qualitative investigations. For most aspects of the study, almost all gay and bisexual men chose online methods. This result is consistent with efficiency; when reading an email or newsletter, it is easier and faster to click on a link than to telephone a study. Consistent with best online practices [19], we designed the screener to lead into a description of the study, then several pages of consent, followed by a brief demographics survey (as one seamless unit). It is not surprising,

therefore, that all but one gay or bisexual man completed this entire process online. Given our experience using online chat in other studies of gay and bisexual men [20], we expected more participants to choose this option. However, when given the option to be interviewed by telephone or online chat, all but one participant chose telephone. We speculate that a combination of the deeply personal nature of the topic (sexual effects of prostate cancer treatment), possible lack of familiarity with online chat, the anticipated subject burden involved in extensive typing in chat for 60-75 minutes, and/or slow Internet connection contributed to the participants choosing telephone over online chat. Given that multiple participants expressed appreciation for the opportunity to discuss their experience of having prostate cancer, and the sexual challenges that treatment entails, a desire to talk about this taboo topic may also have contributed to their decision.

We highlight the geographic diversity in the sample as a strength of online recruitment of older gay and bisexual men with prostate cancer. Similar to early studies of gay and bisexual men online [21,22], and studies of younger cohorts of gay and bisexual men [23], examination of the residential zip codes of participants demonstrated participation across all regions of the United States, and participation by rural as well as urban respondents.

This study had several limitations. First, this was a very small study focused on individual interviews, which we share to help other researchers proposing similar studies. Given the lack of studies on how to recruit older sexual minorities, we cannot know how generalizable these results are. Second, the older gay and bisexual men in this study were all recruited from a website. This detail likely biases findings towards online preferences, making the choice to be interviewed by telephone more apparent. Third, there are only a handful of websites offering

support services to gay and bisexual men with prostate cancer. Choosing the largest of these websites made practical sense; however, we do not know how well members on this website reflect the broader population of gay and bisexual men with prostate cancer, or how well our findings might generalize to other websites or health conditions. Fourth, we did not ask participants why they chose their preferences, or the strength of their preference. We recommend that researchers consider adding both questions to advance research on methods. Finally, consistent with the Pew Internet and American Life Project's results [1], none of our participants were older than 75 years. Researchers aiming to study gay and bisexual men older than 75 may need to use other methods to recruit and research this cohort.

Conclusions

Although an unprecedented number of gay and bisexual men are reaching middle and old age, little is known about aging and age-related health conditions for sexual minority men. While new research efforts may emerge to address this evidence gap regarding healthy aging in this cohort, it remains unclear how best to identify, recruit, and include this population in social and biomedical research. This limitation is particularly true for Internet-based research efforts, which may be better at identifying and recruiting gay and bisexual men than the collection of qualitative interview data. Specifically, we recommend that qualitative researchers (and others interested in studying this cohort via online recruitment) consider a mixed methods approach to recruitment, but continue to use telephone or in-person methods to interview. To advance research methods, we encourage other researchers to set up naturalistic experiments to test research preferences, particularly for difficult to recruit populations.

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Conflicts of Interest

None declared.

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