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Internet-based interventions for cancer-related distress: exploring the experiences of those whose needs are not met

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Abstract

Objective—Low levels of engagement in Internet-based interventions are common.

Understanding users' experiences with these interventions is key to improving efficacy. Although qualitative methods are well-suited for this purpose, few qualitative studies have been conducted in this area. In the present study, we assessed experiences with an Internet-based intervention among cancer survivors who made minimal use of the intervention.

Methods—Semi-structured interviews were conducted with 25 cancer survivors who were minimally engaged (i.e., spent around 1 hour total on website) with the online intervention, [health-space.net](#). The intervention was a 12-week, facilitated support group with social and informational components. Interviews were analyzed using an interpretive descriptive design.

Results—Three broad categories, consisting of 18 specific themes, were identified from the interviews, which included connecting with similar others, individual expectations, and problems with the site ($K = 0.88$). The “similar others” category reflected the significance of interacting with relatable survivors (i.e., same cancer type), the “individual expectations” category reflected the significance of participants' expectations about using online interventions (i.e., personally relevant information), and the “problems with the site” category reflected the significance of study procedures (i.e., website structure).

Conclusions—The data indicate that minimally-engaged participants have high variability regarding their needs and preferences of Internet-based interventions. Using qualitative methodologies to identify and incorporate these needs into the next generation of interventions has the potential to increase engagement and outcomes. The current study provides a foundation for future research to characterize survivors' needs and offer suggestions for better meeting these needs.

Keywords

cancer; oncology; distress; Internet; engagement; support

INTRODUCTION

Elevated levels of distress are common in cancer survivors, and Internet-based interventions have shown promise for improving psychological adjustment, including depression [1–2], distress [3–5], and quality of life [5–7]. These online interventions have strong potential to reduce barriers to psychosocial care by making participation convenient, confidential, and less stigmatizing. However, results of Internet-based interventions for cancer survivors have been mixed. Some studies have shown positive effects [1, 7], some studies have shown null effects [4], while others have reported negative effects [3, 5]. Low levels of engagement in Internet-based interventions are common, which makes it difficult to determine how effective these interventions have the potential to be [8–9].

Typical patterns of engagement in psychological interventions have suggested that only a small percentage of participants use the intervention through to completion (1.0–22.5%) [10–11], and engagement generally declines significantly with time [12]. Since engagement is an important mechanism of action for behavioral modification and symptom reduction in Internet-based interventions [13–15], it is remarkable that many Internet-based interventions have yielded positive effects despite relatively low levels of engagement. Reported outcomes from extant studies may represent a floor for future effect sizes, particularly if we are able to adequately address this problem of poor overall engagement with Internet-based interventions [14, 16–17].

Existing interventions could be incompatible with participants' expectations and needs, which could easily explain observed levels of low engagement and relatively high attrition [9, 14]. Focusing more attention on the target population's needs during the development of intervention materials has been shown to increase levels of engagement with interventions [18–19]. Interventions are often designed without a clear understanding of the relevant issues for potential participants.

Qualitative methodologies have an important role since the goal of this type of investigation is to learn the solution to a problem by going to the source: individuals with knowledge and direct experience of the problem [20]. To date, there have been two qualitative studies assessing participants' experiences and expectations with Internet-based interventions for cancer survivors. In a qualitative study of an online breast cancer self-help group, five barriers to engagement were identified: avoiding painful cancer details, not being as sick as others, difficulty fitting in the group, busy schedules, and different disease trajectories among participants [8]. In another qualitative study of an online breast cancer support group, barriers to participation were a mismatch between participant expectations with the study, confusion of the purpose of the study, and confusion about what was expected of participants [2]. Whether these same factors are associated with use of a social-networking intervention, or are generalizable across cancer types, is unknown. There were two primary aims of the present study: 1) to identify expectations and experiences related to minimal use of a group-based social-networking intervention (health-space.net) and 2) to assess participants' attitudes about specific intervention components (e.g., coping-skills training exercises, discussion board, professionally-facilitated chat, etc.).

METHODS

Participants

Participants were recruited into the intervention through the Loma Linda University cancer registry and online recruitment strategies, including posts on facebook (www.facebook.com), craigslist (www.craigslist.org) and many cancer-focused websites. Participants had a cancer diagnosis, were at least 18 years old, had regular access to the Internet, were fluent in English, and had a clinically significant distress score (4 or above on the distress thermometer). For the current study, participants ($n = 204$) had already consented, enrolled, and completed the intervention within the previous two years. Participants were categorized by their level of engagement: Non-Engaged Users (19.9%), who spent less than 10 minutes on the site, Minimally-Engaged Users (38.2%) who spent 10 minutes to 3 hours on the site, and Moderately- to Highly-Engaged Users (41.9%) who spent 3+ hours on the site. Minimally-engaged users were selected as they were expected to have enough knowledge and experience with the website to provide thorough information as well as a comprehensive understanding of the barriers to using the intervention. Seventy-five participants met criteria to be considered minimally-engaged participants. Although we attempted to contact all 75 of the minimally-engaged participants, recruitment ceased once saturation of categories was found, categories were dense and validated, and no additional categories were identified. This process resulted in a final sample of 25 subjects. Three (6.0%) participants declined due to not remembering the health-space.net website or being too busy, 41 (82.0%) participants were unable to be reached after 3 phone calls or had the wrong contact information, 1 (2.0%) participant was deceased, and 5 (10.0%) participants elected to participate, but were unable to be reached after the initial phone call.

Intervention

The intervention, health-space.net, was a 12-week Internet-based support group facilitated by trained doctoral students in clinical psychology. The components of the website included an asynchronous discussion board, facilitated synchronous chats where participants could interact in real time, weekly coping-skills training exercises, personal profile pages where participants could post pictures and information about themselves, and private email messaging to other members or facilitators. Facilitators sent introductory emails to all new participants, sent messages encouraging engagement with the intervention, lead chat room discussions, posted topics to the discussion board, and responded to participants' postings to the site. Participants completed a baseline questionnaire and were then immediately randomized into an existing group or to a waitlist control group. All participants had access to the group for 12 weeks.

Procedure

After receiving IRB approval, all eligible Minimally-Engaged users were contacted by telephone. Interested users provided verbal consent to participate and then scheduled a time to complete the qualitative interview. Semi-structured, individual telephone interviews were conducted and audio recorded, transcribed, and coded. The semi-structured interview assessed participants' experiences with the website as well as their general preferences for

online support. The interviews lasted approximately 60 minutes and participants were compensated for their participation.

Data Analysis

The current study relied on interpretive descriptive qualitative methods for identifying themes associated with participants' lived experiences with the health-space intervention [21]. Interviews were digitally recorded, transcribed, and reviewed for accuracy. The transcripts were initially reviewed by the principal investigators. Interviews were reviewed independently to identify all potential instances in which barriers to engaging with the intervention were discussed. A consensus-building process was used to create a dictionary of 18 codes, and each potential code was defined in a codebook.

Multiple coders were used to ensure consistency, and all coders were provided with thorough training to use the codebook. All transcripts were double-coded, and inter-rater reliability was calculated to ensure reliable coding. Inter-rater reliability was in the near perfect range (mean Kappa = 0.88). Frequencies and percentages of participants who identified each theme were calculated. Since participants could endorse multiple themes, percentages did not always round to 100%. To assess participants' opinions regarding specific intervention components (i.e., professionally-facilitated chat, discussion board, coping-skills training exercises, personal pages, etc.), interview text related to each intervention component was coded as “liked”, “disliked”, or “neutral”.

RESULTS

Seventy-five potential participants were identified. Twenty-five (33.3%) participants agreed to be interviewed (Table 1). The average age of interviewed subjects was 52.8 years. The majority of subjects were white, married females. Over half of participants had a Bachelor's degree or higher as well as a moderate to high income. The most common cancer types were breast (28.0%), prostate (20.0%), thyroid (16.0%), other (16.0%), and multiple (12.0%). Other cancers included mouth, thymus, and leiomyosarcoma, while multiple cancers included prostate and bladder, breast and kidney, and kidney and prostate. Fifteen (60.0%) participants were randomized to immediate access to the intervention, while 10 (40.0%) participants were randomized to the waitlist group. However, there was no significant difference between randomization groups on time spent engaged in using the website, $t(23) = -.22, p > .05$. Participants' time using the website ranged from 10–179 minutes, with an average of 64.2 minutes over the 12-week intervention. There were no significant differences between those who agreed to be interviewed and those who did not on age, distress level, gender, cancer type, income, education, ethnicity, or marital status. Similarly, there were no significant differences among all of the engagement groups on these variables.

Categories of User Experiences

Three over-arching categories (comprised of 18 specific themes) were identified: Connecting with similar others, individual expectations, and problems with the site.

Connecting with similar others—This category captured the importance of participants being able to interact with relatable participants (Table 2). Specific themes in this category reflected that participants tended to have a difficult time relating to others or feeling like they were unable to contribute to the conversation due to marked individual differences (72.0% of participants). These differences related to a participants' cancer trajectory, including a different cancer type (56.0%), phase of treatment (24.0%), or cancer stage (20.0%). Also, some participants desired more group connection and interaction than they received (36.0%). To illustrate the themes in this category, one participant stated during the interview “I was hoping that I would find more of my cancer on there”. Another participant reported “I wasn't having pain and losing my hair and I was reading stuff from lots of folks that said they had just undergone chemotherapy. They had gone through their last session of radiation and stories of people's hair finally coming back and the vomiting had stopped, and how do I fit in to something like that? It just -- I just didn't feel like I fit, I didn't even have any room to say anything well, you know, keep your hope up, things will get better because I can't relate to the throwing up and the hair falling out, hair loss and losing weight and losing a job, can't work and so forth”.

Individual expectations—The Individual Expectations category captured the importance of participants' expectations about using Internet-based interventions (Table 3). Participants tended to express that the intervention was not relevant to their personality and preferences for online support (84.0%). Specifically, participants reported that the information was not relevant to them, that the intervention was not a high priority in their life at the time, or that they were not interested in communicating with others since they were more introverted. Participants also reported that they desired information on various topics, including cancer treatments, recipes and exercises, finances, spirituality, and family concerns (84.0%). The intervention provided information within the weekly guidance modules, but not all topics were included (i.e., financial and recipes). Many participants wished that the intervention had a more positive tone of communication where topics would emphasize positive and uplifting aspects of cancer survivorship and recovery (64.0%). Participants tended to prefer facilitators who were knowledgeable about cancer as well as more involved in the intervention (64.0%). In terms of familiarity with computers, participants reported that they did not like using the computer or communicating with others online (24.0%). Lastly, participants reported having a negative experience with a previous support group, either face-to-face or online (12.0%). To illustrate the themes within this category, one participant reported “I was being a voyeur, I like to read what they're up to. I might chime in now and then and might not, but I guess I wasn't looking for a lot”. Another participant mentioned “If a facilitator would've reached out to me personally, not a phone call but just like ... I'm the facilitator for your group, just curious if there's anything we can do to get you engaged or hey do you have a thought on x, y, z?”.

Problems with the site—This category captured the main idea that minimally-engaged participants found the site to be difficult to use (Table 4). Participants often reported that the site was not intuitive to use (92.0%). Furthermore, many participants noted that they had time constraints, including a busy schedule and previous engagements that prohibited them from being able to attend the designated weekly chat group times (64.0%). Participants also

reported that there was inadequate instruction and that a printed manual for the website would be helpful for learning how to use the site and what is available on the site (52.0%). The intervention included email reminders to encourage participation, but some participants reported that these reminders were too frequent and led participants to feel guilty about not engaging with the site (32.0%). Participants also had to answer questionnaires throughout the 12-week intervention and expressed that they were too long and time-consuming (24.0%). Furthermore, participants reported that if they were to spend time answering the questionnaires, they would prefer feedback about their responses. Participants who were randomized into the waitlist also mentioned their dislike for having to wait and wanted help for their distress at the time of sign-up (24.0%). Lastly, participants stated that they disliked the appearance of the site and provided suggestions to increase its appearance, including additional pictures (24.0%). To further illustrate the themes in this category, one participant mentioned the following in response to why they did not engage more with the site: “My own time because I don't have a lot of it.” Another participant mentioned “I just needed the first time you go on, do this. Then subsequent visits, here's what you're going to do. I guess that's what I was looking for and I didn't really find. So I never gave it a good chance because I didn't understand it and I just didn't have the energy to try to delve into it and figure it out.”

Intervention components

Minimally-engaged users' attitudes about specific intervention components are shown in Figure 1. The majority of participants liked the idea of the discussion board (60%, n=15). One participant mentioned “That was nice. It drew you in ... it gave you some place to start. You know, not knowing what you're getting into and to see the messages and everything, that helped”. Fourteen (56%) participants mentioned a general positive regard for the personal pages. One participant stated “I really liked the opportunity to get to know people a little more, it just helps you be a little more open and have some background on them and know what their experience was and it also helps you gauge what their saying. To give a little more weight or to just kind of oh they are having a bad day today because they are in the middle of chemo. And to have a sense of where they are in the situation”. Thirteen (52%) participants liked the idea of the guidance modules and one participant reported “I think the idea is good, having supplemental information or stuff to think about or do during the week, I think the philosophy behind it makes sense.” However, many participants disliked the idea of the chat room (40%, n=10). One participant stated “I didn't ever want to try it... I'm basically not a chat kind of person.”

DISCUSSION

Minimally-engaged participants reported a variety of needs and preferences regarding Internet-based interventions. Three main categories of needs and preferences that are useful for improving users' experiences with these types of interventions were identified, including ways to better promote connecting with similar others, address individual expectations about the intervention, and reduce perceived problems with the website. In terms of connecting with similar others, participants' cancer trajectory emerged as an important barrier to use of the intervention. Specifically, participants preferred interacting with other survivors who

shared the same cancer type, stage, or phase of treatment. Being in a group with similar others has important implications for the composition of Internet interventions. The current intervention included all cancer types, which appeared to serve as a barrier to participation for many. It might be useful for online support groups to be comprised of participants with the same cancer type or trajectory so participants can relate to each other. Given a large enough sample size, sub-groups of similar others could be created, based on cancer type, for example. However, creating and sustaining interventions based on specific cancer types would be difficult for less commonly-diagnosed cancers. A larger online platform, such as that provided by sites like Facebook or the American Cancer Society's Cancer Survivor Network, might be better positioned to deliver highly tailored empirically-supported interventions. Also, approximately 42% of the health-space.net total sample was moderately-to-highly engaged with the intervention despite a group composition that included various cancer types, stages, and trajectories. The similar others category could also extend past cancer-specific information to more specific complaints and problems. The intervention required having a significant distress score, but there was no differentiation among the causes of distress. Some participants' distress was due to fatigue, anxiety, financial concerns, or family troubles. Having more specific inclusion criteria for distress could be an additional way to create a group of more relatable participants.

Participants enrolled into the study without knowing much about what the intervention entailed. Evaluating survivors' expectations during enrollment could help discern whether the intervention is a good fit. Alignment between participants' expectations and intervention-specific expectations would likely promote engagement. Individual tailoring could also help by providing an individual who prefers limited social interaction with the ability to choose which aspects of the intervention to use. Participants stated that they desired an intervention that was easy to use, easy to navigate, and organized. Various suggestions that would make the website more accessible and intuitive were provided, e.g., making it easier to link to specific pages on the site. Similarly, participants suggested categorizing information into threads (i.e., threaded by topic, cancer type, gender, etc.). Though costly, usability testing and emphasis on the user experience could certainly improve the degree to which e-health interventions are perceived by users as approachable and user-friendly. It would also be helpful for facilitators to be vigilant for minimally-engaged users and to be as proactive as possible in helping these users learn how to best make use of these types of online interventions and to take initial steps towards becoming socially connected with other survivor participants.

In regards to the specific intervention components of health-space.net, the majority of participants reported a general positive regard for the discussion board, personal pages, and guidance exercises. However, the majority of participants in the current study of minimally-engaged users endorsed a general disregard for the chat room feature. These opinions have important implications for online interventions for cancer survivors. It is important to determine what components participants would and would not use. It would be necessary to determine if participants disliked the chat room because they were not open to that mode of communication or if they were unfamiliar with how to use it. Interestingly, the chat room was a very popular feature for participants who were moderately-to-highly-engaged with the intervention. It is possible that participants who use the chat room are more outgoing and

interested in social-networking. However, many participants reported that they prefer to read additional information instead of networking. It might be possible for facilitators to talk more directly about the chat room with participants and assuage any anxieties about that mode of communication. It appeared that some participants in this minimally-engaged group equated the chat room with other online chat rooms that have typically been seen as unsafe and inauthentic. The chat room most closely resembles the face-to-face support group format that has been shown to be helpful for cancer survivors so it is imperative to assist participants in becoming more comfortable with the chat feature.

There are several noteworthy limitations of the present study. First, although we made every effort to sample a group (minimally-engaged users) that is inherently difficult to study, there are potential limits to the generalizability of the study findings given the relatively small sample size. However, it is worth noting that the sample size is comparable to that reported in similar studies and was sufficient to obtain saturation of the observed qualitative codes. Additionally, the current sample was not representative of the larger population of cancer survivors, but instead was mostly female, higher income, higher education, and Caucasian ethnicity. However, these characteristics are reflective of the demographic of survivors who tend to use the Internet for support. Also, the obtained themes were tied to the current intervention and may not generalize to other types of Internet-based interventions for cancer survivors. Another limitation was that the interviews were conducted after participants completed the intervention, so the elapsed time since using the intervention varied among participants. Participants who had more recently used the intervention may have had a more detailed recollection of their personal experience.

The findings of the current study have important implications for researchers and others developing Internet-based interventions for cancer survivors. Internet-based interventions should be designed and built using a bottom-up approach where participants' opinions and preferences inform website development. Once the needs of survivors are better understood, interventions could be more carefully tailored to improve efficacy. For example, a survivor could choose the type of information they would like to receive, the type of survivors they would like to interact with, and the topics of conversation applicable to their experience. The need for flexibility in Internet-based interventions should become the new standard. Using qualitative methodologies is imperative in developing more effective interventions that keep participants engaged. Understanding barriers to engagement is critical for the effectiveness of psychosocial interventions in the digital era.

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Figure 1.
Participants opinions of intervention components.

Table 1

Characteristics of interview participants

Interview Subjects (n=25)	
Distress M (SD)	5.84 (2.43)
Age M (D)	52.8 (12.78)
Randomized n (%)	
OSG	15 (60.0)
Waitlist	10 (40.0)
Gender n(%)	
Male	9 (36.0)
Female	16 (64.0)
Cancer Type n (%)	
Breast	7 (28.0)
Prostate	5 (20.0)
Thyroid	4 (16.0)
Other	4 (16.0)
Multiple	3 (12.0)
Female rep	1 (4.0)
Blood	1 (4.0)
Cancer Stage n (%)	
No spread	7 (28%)
Spread to lymph tissue	5 (20%)
Regional metastasis	4(16%)
Distant metastasis	4 (16%)
Unknown	5 (20%)
Income M (SD)	
0–20,000	1 (4.0)
21,000–40,000	5 (20.0)
41,000–60,000	5 (20.0)
61,00–80,000	6 (24.0)
> 80,000	7 (28.0)
Ethnicity n (%)	
White	21 (84.0)
Hispanic	3 (12.0)
Other	1 (4.0)
Marital Status n (%)	
Married	19 (76.0)
Divorced/Widowed	5 (20.0)
Single	1 (4.0)
Education n (%)	
Post-Bachelors	8 (32.0)
Bachelors	6 (24.0)

Interview Subjects (n=25)	
High School grad	7 (28.0)
Some College	4(16.0)

Table 2

Specific themes associated with Connecting with Similar Others.

Theme	<i>n</i> (%)	Description
Connect with similar others		
Unable to relate	18 (72.0)	Not being able to relate to others, not able to contribute to the conversation, feeling like the group was not a fit
Cancer type	14 (56.0)	Dislike being in a group with people of different cancer types, prefer people with the same cancer type
More connection	9 (36.0)	Wanting more group interaction and communication
Phase of treatment	6 (24.0)	Dislike being in a group with people of different treatment phases, prefer people with the same treatment phase
Cancer stage	5 (20.0)	Dislike being in a group with people of different cancer stages, prefer people with the same cancer stage

Table 3

Specific themes associated with Individual Expectations about the Site.

Theme	<i>n</i> (%)	Description
Individual expectations		
Personal relevance	21 (84.0)	Feeling like topics were not relevant, being introverted and not wanting to interact with others, not a high priority
Desire for information	21 (84.0)	Wanting additional information about improving lifestyle, treatments
Tone of communication	16 (64.0)	Wanting the tone of communication to remain positive, prefer not to speak about the negative
Facilitation	16 (64.0)	Prefer more communication with facilitators, prefer facilitators who are knowledgeable about cancer
Internet experience	6 (24.0)	Dislike using the computer, dislike communicating online
Previous support group	3 (12.0)	Having a negative past experience in either a face-to-face or Internet support group

Table 4

Specific themes associated with Problems Using the Site.

Theme	<i>n</i> (%)	Description
Problems with site		
Structure of website	23 (92.0)	Found site difficult to use, not intuitive
Time commitment	16 (64.0)	Having a busy schedule, unable to attend scheduled chats and needing additional chat times
Inadequate instruction	13 (52.0)	Needing a manual for how to use site, confused about what to do and how to do it
Email reminders	8 (32.0)	Receiving too many email reminders, feeling guilty about not using the site and receiving the reminders
Problem with questionnaires	6 (24.0)	Questionnaires were too long and time consuming, wanting feedback based on responses to questions
Problem with waitlist	6 (24.0)	Dislike having to wait 12 weeks for access to the site, needed help at the time of sign up
Problem with site appearance	6 (24.0)	Dislike appearance of the site