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Evaluating Use of an Online Intervention for Cancer Patients with Distress

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Evaluating Use of an Online Intervention for Cancer Patients with Distress

by

Amanda Gorlick

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A Thesis submitted in partial satisfaction of
the requirements for the degree
Doctor of Philosophy in Clinical Psychology

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March 2013

Each person whose signature appears below certifies that this thesis in his/her opinion is adequate, in scope and quality, as a thesis for the degree Doctor of Philosophy.

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ABBREVIATIONS

SEER	Surveillance Epidemiology and End Results
NCCN	National Comprehensive Cancer Network
SCL-90	Symptom Checklist 90
BSI	Brief Symptom Inventory
ACOR	Association of Online Cancer Resources
SMART	Sequential Multiple Assignment Randomized Trial
MOST	Multiphase Optimization Strategy
RCT	Randomized Controlled Trial
SCT	Social Cognitive Theory

ABSTRACT OF THE THESIS

Evaluating Use of an Online Intervention for Cancer Patients with Distress

by

Amanda Gorlick

Doctor of Philosophy, Graduate Program in Psychology
Loma Linda University, March 2013
Dr. Jason Owen, Chairperson

Internet-based interventions have been effective in improving cancer survivors' psychosocial functioning. However, low levels of engagement in these interventions have been common. A qualitative interview study was conducted to assess cancer survivors' needs. Semi-structured interviews were conducted with a diverse sample of 25 cancer survivors who were minimally engaged (i.e. spent around 1 hour total on website) with the online intervention created by Owen and colleagues. Interviews were recorded, transcribed, and analyzed using content analysis. Twenty themes were identified from the individual interviews. With an average Kappa in the near perfect range (Kappa= 0.89), the obtained codes were deemed a valid representation of the data. The most common themes included the desire to make connections with other survivors (i.e. sharing, belonging to a group), the structure of the intervention (i.e. ease of use, organization), personal relevance (i.e. perceiving website as a fit, having a need for the website), information provided (i.e. general resources, medical expertise), and the individual's cancer trajectory (i.e. interacting with others with the same cancer type). The data indicate that cancer survivors have diverse needs and preferences. Flexibility should become the gold standard, where interventions could aim to tailor the website based on key variables. 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 current study serves as a starting point for future research to identify and evaluate individual preferences on engagement. Understanding the needs of cancer survivors and implementing interventions that take into account these needs holds promise for increasing engagement and thus improving outcomes.

CHAPTER ONE

BACKGROUND AND SIGNIFICANCE

Cancer Survivorship

Cancer is the second leading cause of death in the United States, expected to have

caused 569,490 deaths in 2010 (American Cancer Society, 2010). The U.S. National

Cancer Institute's Surveillance Epidemiology and End Results (SEER) database for the

year 2007 estimated that over 11 million people in the United States were living with

cancer. According to the American Cancer Society's most recent Cancer Facts and

Figures from 2010, there were over 1 million new cancer cases diagnosed in 2010.

Fortunately, the 5-year survival rate for all cancers diagnosed from 1999-2005 was 68%

which is higher than the 50% survival rate for diagnosed cases from 1975-1977

(American Cancer Society, 2010). Due to advances in cancer diagnosis and treatment,

there are a growing number of survivors in the U. S.

Quality of Life Concerns of Survivors

Extending the life of cancer survivors is not the only marker of successful cancer

treatment, since maintaining and restoring quality of life after treatment continues to be a

major concern for survivors (Baker et al., 2005). Quality of life is defined as an

individual's general well-being, which specifically includes physical well-being,

emotional well-being, social well-being, and spiritual well-being. A cancer diagnosis can

lead to problems in each of these domains. Challenges to physical well-being include

both the acute physical affects of cancer treatment (i.e. hair loss, nausea, and vomiting) as

well as long-term side effects including pain and fatigue. A study assessing 5,605 adult

cancer patients 1 year after diagnosis found that 47.9% experienced sleep difficulties and 67.1% were concerned with fatigue (Baker et al., 2005). Even though sleep disturbance, pain, and fatigue are not considered life threatening, both disrupt survivors' daily functioning (Ferrell & Dow, 1997). Problems related to emotional well-being include: anxiety, fear of recurrence, second malignancies, concern over future tests, and rumination over the previous cancer episode. In the same study by Baker et al. (2005) which assessed adult cancer patients 1 year after diagnosis, 68.1% were concerned about their illness returning, 59.8% feared developing a disease recurrence, and 57.7% had fears about the future (Baker et al., 2005). Issues of social well-being have referred to family issues (i.e. sexual problems, marital problems, children's adjustment to parent's cancer), employment issues, health insurance issues, discrimination, and financial issues. Lastly, spiritual well-being encompasses challenges related to spiritual distress, grief, and finding meaning and purpose in their survivorship (Ferrell & Dow, 1997). Unfortunately, quality of life concerns have generally been neglected in survivors since encounters with the healthcare system lessen as the disease enters remission.

Psychological Distress in Survivors

The National Comprehensive Cancer Network (NCCN; 2002) defined cancer distress as "an unpleasant emotional experience of a cognitive, behavioral, emotional, social, and/or spiritual nature that may interfere with the ability to effectively cope with cancer symptoms and treatment." Distress encompasses normal feelings of vulnerability and fear through depression, anxiety, panic, social isolation, and spiritual crisis. Common symptoms include: worry and fear about the future, concern about illness,

sadness for loss of health, feeling powerless, anger, poor sleep, decreased appetite, difficulty concentrating, and thoughts of illness and death (National Comprehensive Cancer Network, 2002). Medical treatment, functional status, and quality of life all contribute to psychological distress (Sarna, 1993). Distress can be present at any point during the experience, from diagnosis to post-treatment.

Prevalence of Distress

The literature suggests elevated levels of emotional distress in cancer survivors compared to the general population (Vitek et al., 2007; Hoffman et al., 2004). Although distress is considered relatively normal among cancer survivors, the prevalence rates have differed across studies (Stanton et al., 2002). The previous literature highlights three widely cited studies of distress in cancer patients. Derogatis et al. (1983) interviewed newly diagnosed breast cancer patients at various inpatient and outpatient cancer centers using the Symptom Checklist 90 (SCL-90). The SCL-90 is a widely used self-report questionnaire that measures dimensions of psychological distress in both patients and non-patients, including somatization, obsessions and compulsions, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation, and psychoticism. 47% of the sample met criteria for psychiatric illnesses, including depressive and anxiety disorders. Farber (1984) interviewed mostly breast cancer patients using the SCL-90 and found that 34% of the sample reported significant distress. Stefanek et al. (1987) interviewed various oncology outpatients using the Brief Symptom Inventory (BSI) and found that 28% of the sample were endorsing moderate to high distress levels. The BSI is a shortened version of the SCL-90 that also measures the

dimensions of distress. About one-third of outpatients had moderate to severe depression or anxiety. In 2001, Zabora et al. found similar results to these studies. They interviewed 14 cancer types using the BSI and over half of the sample was recently diagnosed patients. Rates differed by cancer site and prognosis, where lung cancer distress prevalence was 43.4% while only 29.6% for genealogical cancers. Carlson (2004) interviewed a variety of outpatients with different cancer types using the BSI. The sample included both newly diagnosed and follow-up patients. The overall prevalence of high distress was 38%, with some cancer types being more severe than others. Lung, pancreatic, and Hodgkin's lymphoma had the highest rates of distress. Later in 2006, the NCCN reported that one-third of cancer patients experience significant distress. In a population-based study of healthy adults and adults with chronic conditions, Kaiser et al. (2010) found a lower estimate of distress in cancer patients (5.7%) using the Kessler 6, a measure of non-specific psychological distress. However, cancer distress was still higher than individuals with other health conditions. The prevalence rates are relatively consistent across studies, but the rates differ slightly by the characteristics of the cancer population (i.e. cancer type, cancer stage, inpatient/outpatient). Regardless of these differences, the advances in diagnostic techniques that increase detection rates of distress will lead to a greater burden of distress overall (Bultz et al., 2006).

Negative Implications of Elevated Psychological Distress

Regardless of the variability in distress found across studies, the distress levels are problematic since they are associated with negative outcomes. Poorer prognoses and higher patient burden were associated with significantly higher distress. Furthermore,

psychological distress has been associated with challenges to managing complex decisions related to treatment options and procedures (Patrick-Miller et al., 2004; Stanton et al., 2002), lengthened hospital admissions (Wein et al., 2010), poor adherence to treatment (Kennard et al., 2004), lower satisfaction with care (Von Essen et al., 2002), lower quality of life (Skarstein, 2000), and poorer survival (Steel et al., 2007). As the initial shock of a cancer diagnosis fades away, levels of distress lower for a proportion of patients, but not all. Perhaps for certain cancer types with higher survival rates and more benign treatments, distress lessens. Ganz et al. found high levels of functioning and quality of life in over 90% of breast cancer participants after treatment both one year past diagnosis all the way up to nine years (1999, 2002). However, in a study by Kaiser et al. (2010), years since first diagnosis was not correlated with distress, implying that distress can occur at any time for survivors. Hanson et al. (2006) suggested that distress has a U-shaped course where distress is high at initial diagnosis, lowers with treatment completion, and raises again as time passes from treatment. The picture is less clear for cancer types not as frequently studied as breast cancer survivors, as well as survivors farther from initial diagnosis. More research is needed on the influences of cancer type, cancer stage, and time since diagnosis on the course of distress.

Face-to-Face Psychosocial Resources for Cancer Patients

Treatments for cancer patients have expanded from medical practices (i.e. chemotherapy, radiation, and proton therapy) to include Complementary and Alternative Medicine interventions (i.e. acupuncture, physical exercise meditation, herbal remedies, meditation, massage, and energy therapies), and psychosocial interventions (Verhoef &

Leis, 2008; Vitek, 2007). There have been hundreds of clinical trials of face-to-face

psychosocial interventions targeting outcomes including quality of life, distress, and

negative affect (Andersen et al., 2009). These psychosocial interventions have typically

been conducted in a community setting under professional facilitation (Klemm et al.,

1999). Interventions have implemented different designs, with the most common

methodologies including education, behavioral training (i.e. relaxation, hypnosis,

meditation, biofeedback), individual psychotherapy, and group psychotherapy. The

literature supports the idea that cancer patients benefit from each of the psychological

intervention types (Fawzy et al., 1994).

Effectiveness of Face-to-Face Psychosocial Interventions

Many studies and reviews have consistently shown face-to-face interventions to

be effective in palliating psychosocial concerns in cancer patients (Edwards et al., 2007,

Andersen et al., 1992, Fawzy et al., 1995, Goodwin et al., 2003). Psychosocial

interventions for cancer patients have led to significant improvements in coping

(Richardson et al., 1997; Telch & Telch, 1986; Antoni et al., 2006), quality of life (Linn

et al., 1982; Institute of Medicine, 2007; Goodwin et al., 2003), social functioning

(Helgeson, 2001; Jacobs et al., 1983), adjustment (Cain et al., 1986; Maguire et al.,

1985), mood and self esteem (Edelman et al., 1999), pain perception (Classen et al.,

2001; Speigel & Bloom, 1983), post-traumatic stress (Arathuzik, 1994), anxiety (Davis,

1986), depression (Rainey, 1985; Pruitt et al. 1993), emotional well-being and positive

mindset (Antoni et al., 2001), suppression of negative affect and aggressive behaviors

(Geise-Davis et al., 2002), and distress (Goodwin et al., 2001; Fawzy et al., 1990; Forester et al., 1985; Institute of Medicine, 2007; Antoni et al., 2006).

There is also evidence of the effectiveness of face-to-face interventions long-term. A study of breast cancer patients by Speigel et al. (1989) found improved survival although results failed to be replicated years later in 2007. Similarly, Fawzy et al. (1993) found a significantly lower rate of death compared to controls 6 years after participation in a psycho-education intervention for melanoma patients. At 10 year follow-up, participants who attended the intervention had higher survival than participants who did not attend (Fawzy et al., 2003). Andersen et al. (2007) found decreases in distress and increases in immune function that after 11 years, decreased the rate of recurrence and death in breast cancer participants (Andersen et al., 2008). For participants that had a recurrence, reductions in distress were maintained (Andersen et al., 2010). Antoni (2001) found increased emotional well-being, positive mindset, positive lifestyle change, and positive affect one year after the intervention for breast cancer patients ended.

Some reviews have been far less enthusiastic about the effectiveness of psychosocial interventions for cancer patients. Newell et al. (2002) critiqued the overly positive results of previously published reviews arguing that interventions lacked methodological vigor. The efficacy of these interventions for reducing distress and increasing quality of life was found to be inconclusive, and a lack of evidence was found for improvements in social functioning. They tentatively recommended group therapy, psycho-education, and structured counseling, however, these suggestions were based on only a few studies that reached their level of methodological vigor. Lepore & Coyne (2006) and Coyne & Lepore (2006) reached similar conclusions to Newell et al (2002)

based on methodological soundness of review studies. They predicted that the more rigorous the review, the less likely positive outcomes of psychosocial interventions for cancer would be found.

The results are mixed regarding the effectiveness of psychosocial interventions. However, there is convincing evidence of psychosocial interventions increasing psychological functioning, specifically distress, anxiety, and pain. Studies of depression and survival have been less clear. Interventions delivered by experienced therapists that last a minimum of 12 weeks have repeatedly shown to be effective (Stanton, 2006). Also, reviews have recommended various intervention components that have continually shown to be useful. Interventions with an educational component, stress management component, problem solving, coping skills training, relaxation, and group support have been recommended to maximize benefit for distressed, anxious, and poorly coping cancer patients (Fawzy et al., 1994; Jacobsen et al., 2008; Stanton, 2006). Studies have found educational components more effective than peer support, purportedly due to increased structure (Rehse & Pukrop, 2003; Hoey et al., 2008; Stanton, 2006). Effect sizes for psychosocial interventions have ranged from .30-.54, suggesting a small to medium effect (Jacobsen et al., 2006). Effect sizes were largest in studies with highly distressed patients (Andrykowski & Manne, 2006; Goodwin et al., 2001; Stanton, 2006; Gordon et al., 1980). There are still important gaps in the literature, including few studies of all cancer types, few studies of long-term survivors, and few studies of ethnically diverse samples.

Prevalence of Use of Face-to-Face Resources

Although there has been a growth in the number of available and effective

psychological services for cancer patients, including the large number of psychosocial intervention trials, the percentage of those who elect to participate is low. Studies have identified a range of psychological therapy use between 28-41% (Burstein et al., 1999; Richardson et al., 2000; Lee et al., 2000). These therapies included relaxation, self-help groups, spirituality, imagery, biofeedback, and hypnosis. Participants from these studies were primarily breast cancer patients. Hewitt et al. (2002) found 23.7% cancer survivors to use a support group, but only 11.2% used a cancer-specific support group. Higher prevalence of use was found in leukemia, Hodgkin's, and breast cancers, while lower use was found in lung, skin, and female reproductive cancers (Owen et al., 2007). Ganz et al. (2002) reported a prevalence rate of 30% for breast cancer patients who used face-to-face support. Specifically, 13% used psychological therapies and 6% used support groups. Other cancer types had a prevalence of 14.2%. In a study of outpatients, VandeCreek et al. (1999) reported 21% of participants used relaxation techniques, 21% used self-help groups, and 19% used mental imagery. Pascoe et al. (2000) assessed the use of support resources in Sydney, Australia. Psychological resources included patient support groups, information services, hospital-based counseling services by social workers, psychologists, and psychiatrists, as well as private counseling services. Sixteen percent of patients had attended a cancer support group, 6.5% of the sample was currently in a support group, and 17% received individual counseling. Twenty-nine percent of counseling was delivered by general practitioners, 23% by social workers, 23% by counselors, 15% by psychologists, and 10% by psychiatrists. Regardless of the variety of effective resources for cancer patients, they are irrelevant if patients fail to make use of them.

Factors Contributing to the Underutilization of Face-to-Face

Interventions

The process of seeking psychological services commonly begins with distress screening. Although awareness of the importance of the psychosocial needs of cancer survivors has been growing, attention to distress by oncologists has remained low. Despite the high prevalence of distress, routine screening for distress is rarely part of cancer care (Cleeland et al., 2000; Bultz et al., 2006). Typically, the patient seeks out psychosocial resources instead of the medical team (Carlson et al., 2004). A large percentage of unreported distress is due to the lack of recognition and inquiry on the part of healthcare providers. One study found that physicians did not recognize nonverbal distress signals or follow up with distress-related statements made by cancer patients (Ryan et al., 2005). Oncologists have been shown to have difficulty in identifying distress due to factors including: the belief that distress is normal with cancer, concern that the patient could be uncomfortable discussing the topic, feelings of incompetence, and limited time with the patient (Wein et al., 2010). In a study of 12 oncologists classifying 1109 cancer patients, only 13% of cases were correctly identified with severe depression, while 79% of cases were correctly identified as not depressed. These results could be due to oncologists discounting distress as a normal consequence of cancer (Fallowfield et al., 2001). Distress screening has not been protocol at every cancer facility. Screening for distress has only been useful for identifying distressed patients, but without psychosocial follow-up, the screening procedure is not productive. Healthcare providers, including oncologists, nurses, rehabilitation specialists, radiation specialists, and social workers must make a referral and initiate the psychosocial

treatment process. Miller et al. (2003) found that 57% of participants reported desiring help with emotional issues during their cancer episode, but only 35% received care. Seventy-three percent of the total sample thought that the physician should offer emotional services to their patients. In another study by Detmar et al. (2000), 94% of patients had a desire to discuss emotional issues with their doctor, but 39% said they would discuss this topic only if the doctor initiated the conversation.

Patient attitudes also contribute to the low levels of distress identification and treatment. Patients could be too distressed to go through the effort to seek psychosocial care, lack the resources to find care, be so preoccupied with the physical aspects of their cancer that they fail to notice their level of distress, lack the knowledge of available psychosocial resources, and/or assume that their doctors are too busy to deal with distress or are unskilled in the area of emotional issues (Carlson et al., 2004; Institute of Medicine, 2004). Patients often do not perceive the relevance of psychosocial treatments to their primary medical treatment course (Adler & Fosket, 1999; Holland, 1999).

In addition to patient and physician factors, significant barriers associated with face-to-face interventions have been identified. Common barriers include an unwillingness to go to regular meetings, the time commitment, scheduling, stigma and embarrassment, and geographically undesirable locations for treatment (Owen et al., 2004; Fukui et al., 2001; Cunningham et al., 1998; Andrykowski & Manne, 2006). These barriers have been potent enough to prevent people from seeking psychosocial services. Cancer patients might be more susceptible to the barriers of face-to-face interventions. In a study by Hewitt et al. (2002), only 7% of cancer patients sought out face-to-face psychosocial services despite the large number experiencing significant psychological

distress. These systematic barriers lead to the underutilization of psychosocial services, especially by those who would likely benefit the most.

The Internet Addressing Underutilization of Face-to-Face
Psychosocial Interventions

Internet-based interventions have been useful for individuals who would not seek face-to-face therapy (Owen et al., 2004; Gustafson et al., 1993). The Internet could eliminate barriers related to patient factors as well as face-to-face methodological factors. The Internet provides 24-hour convenience and anonymity which serves as an equalizer for appearance, socioeconomic status, gender, and age. Internet-based interventions provide the same psychosocial services as face-to-face therapies but are much easier for individuals to access at the convenience of the individual. While some research has argued that Internet-based interventions are less effective than face-to-face interventions, other studies show no significant differences in outcome or therapeutic alliance between the two delivery methods (Day et al., 2002; Cook et al., 2002). Online resources increase the availability of credible health information (Wang et al., 2008), increase social interactions between patients with similar conditions (Owen, 2004), and facilitate opportunities to express emotions and process experiences (Lieberman & Goldstein, 2006; Owen et al., 2005).

Internet access has typically been associated with higher socioeconomic status, higher education level, lower age, and Caucasian ethnicity. In 2007, the Pew Internet & American Life Project reported that the demographic divide between those who have access and who do not is steadily declining. As a follow-up, the Pew Internet &

American Life Project conducted another survey in 2009 and determined that the

generation gap between Internet users has been decreasing further. Approximately 85%

of adults in their 20's reported using the Internet, 80% of adults in their 30's, 80% of

adults in their 40's, 70% in their 50's, 55% in their 60's, and 45% in their 70's and older.

The survey also suggested that older adults use the Internet less for social networking and

more for health information. Similarly, a 2007 Harris poll was conducted to determine

the number of "cyberchondriacs" or individuals who seek health information online and

identified over 160 million Americans who used the Internet for this purpose. With

increasing levels of interest and use of the Internet, a concomitant increase in the

dissemination of services over the Internet will follow.

Use of Online Psychosocial Resources

Internet-based interventions could be especially encouraging for cancer patients.

Cancer patients reported comparable or increased interest in Internet-based interventions

as face-to-face therapies (Owen et al., 2005; Owen et al., 2004). In a study of almost

7,000 Americans with chronic illnesses including cancer, Owen et al. (2010) found 54%

of online support group users never having attended a face-to-face group prior to seeking

online support, implying a desirable alternative. Approximately 39-58% of cancer

patients used the Internet for a variety of reasons, including communication, community

support groups, and health education information (Eysenbach, 2003). A study by Basch

et al. (2004) found that 42-49% of participants used the Internet to obtain cancer-related

information and to communicate with other cancer patients. Another study found higher

rates of Internet use with 84% using the Internet for cancer information, 2% emailed their

primary care physician, 8% emailed their oncologists, and 6% emailed survivors from

support groups (Poll-Franse & Eenbergen, 2008). Rimer et al. (2005) found that 41% of

cancer survivors used mailing lists from the Association of Online Cancer Resources

(ACOR) between 1-3 hours a day to obtain cancer information, support, and to help

others. Another survey found smaller numbers, with 11% of participants using the

internet for mental health information and 1% using chat rooms to discuss mental health

concerns (Powell & Clarke, 2006). Owen et al. (2010) found a prevalence of 1.5% of

people using online support groups, with cancer patients having a higher likelihood of

participating among other groups. The use of online psychosocial resources has been

significantly lower than educational resources. Limited research on the use of online

support groups has been conducted, but the current literature suggests low use.

Demographic differences in the use of online psychosocial resources have been

consistently found. Increased use of the Internet to obtain health-related information was

associated with younger age (Lieberman & Huang, 2008; Owen et al., 2010), women

(Lieberman & Huang, 2008; Murray et al., 2003), higher income and education (Murray

et al., 2003; Owen et al., 2010), Caucasian ethnicity (Murray et al., 2003; Owen et al.,

2010), and lower health status (Houston & Allison, 2002, Owen et al., 2010). These

differences warrant additional attention to these unrepresented groups to determine what

could be done to better involve them in online interventions. Although the disparity in

Internet use based on age, low income, education, socio-economic status, and ethnicity

has been declining, it is still relevant (Smith, 2010). Data from Disparities Policy Project

and Public Opinion and Survey Research (2011) has found improvements in ethnic

disparities with 87% of Caucasians, 80% of Blacks, and 72% of Hispanics currently

using the Internet. According to the Pew Research Center's Internet & American Life

Project (2010), the 18-30 age range has the highest percentage of Internet users, but other

age groups are not far behind. The digital divide has decreased and additional initiatives

are being implemented to continue to bridge the gap of online resource use based on

these demographic differences (Pew Research Center's Internet & American Life Project,

2011). Both the presence of demographic differences as well as how cancer survivors

have been shown to use the internet are influential for increasing use of online resources.

Effectiveness of Internet-based Psychosocial Interventions

A variety of Internet-based interventions have been implemented to target

psychotherapy outcomes and behavior change, including smoking cessation and physical

activity change. In a meta analyses of 92 Internet-based psychotherapy interventions

conducted by Hen et al. (2008), the average weighted effect size was 0.53, which is

considered a moderate effect (Cohen, 1988). The presence of moderate effect sizes in

Internet-based behavioral interventions is promising for the future detection of positive

intervention effects.

Few randomized control studies using Internet-based interventions have been

conducted addressing psychosocial issues in cancer patients; however, the literature is

growing. Internet-based interventions have been implemented to target various

psychosocial issues, including depression (Winzelberg, 2003; Lieberman, 2003), distress

(Salzer, 2010, Owen et al., 2005, Hoybye, 2010), and quality of life (Hoybye, 2010;

Owen et al., 2004; Gustafson et al., 2001). In a randomized study with 72 breast cancer

patients using a 12 week Internet-based support group (Bosom Buddies), reductions were

found in depression, stress, and cancer-related trauma at post-assessment, with effect

sizes ranging from 0.37-0.45 (Winzelberg et al., 2003). Owen et al. (2005) assessed 62

breast cancer patients randomized into a 12-week support group. A trend for higher

emotional well-being relative to controls was found as well as significant improvements

in quality of life and emotional well-being for participants with higher distress at baseline

(Owen et al., 2005). This result was consistent with face-to-face psychosocial

interventions, where more distressed individuals gained the most benefit (Helgeson et al.,

2006). Lieberman et al. (2003) conducted a non-randomized 16-week study with 32

breast cancer patients using a support group from The Wellness Community. At post-

assessment, significant reductions in depression were found.

There have been several breast cancer studies from the research team at the

University of Wisconsin using the CHESS system, an interactive computer program with

information, social support, and problem solving components. One study by McTavish et

al. (1995) assessed CHESS in a 15-week, non-randomized pilot study of eight breast

cancer patients and found the intervention to be viable, useful, cost effective, and

efficient for cancer care. Another study by Shaw et al. (2006) conducted a 20-week

randomized trail using CHESS and found that the information and social support services

contributed to higher health information competence. The CHESS intervention also lead

to significant improvements in healthcare participation, information competence, social

support, doctor relationships, breast cancer related concerns, and negative emotions in

related studies conducted by the research group (Shaw et al., 2008; Wise et al., 2008;

Gustafson et al., 2001).

Not all Internet-based interventions have found significant improvements in psychosocial functioning in cancer patients. Hoybye et al. (2010) conducted a 1-week randomized self-guided Internet support group study assessing mood disturbance and cancer adjustment. No intervention effects were found on mood disturbance and at 6-month follow up, the intervention group exhibited less improvement in depression than the control group. A limitation of the study was that no therapeutic intervention was administered besides encouraging participants to use the non-facilitated discussion board. Salzer et al. (2010) conducted a randomized study of 78 women with breast cancer assigned to either an online peer support group or educational control group. Participants in the peer support condition endorsed higher distress at 12-month follow-up than the education-only group, which was contrary to hypotheses. However, participants in the peer support condition endorsed high levels of satisfaction. The intervention was un-moderated and unstructured, which could have been a limitation. Therefore, the null and negative findings from the Hoybye et al. (2010) and Salzer et al. (2010) articles could be reflective of the minimal level of participant exposure to the intervention.

An important limitation of the extant literature on Internet-based interventions for cancer has been a restriction on generalizability. The majority of participants in previous intervention studies have been breast cancer patients, which has constrained the generalization of results (Hoey et al., 2008). Female breast cancer survivors are one of the largest groups of cancer survivors, which has led to their increased use as participants in studies (Ganz et al., 2002). Since other cancer types have different profiles of symptoms and disturbances, these results might be different after including them in the interventions. There is a large amount of support available to breast cancer patients,

which is less common for other cancer types. Peer and professional support could be extremely important for people with types of cancer that have received less attention (i.e. lung and bowel cancers). In addition, since the breast cancer groups involve primarily women, there are fewer studies including men. Very little is known about the effectiveness of internet-based interventions for people with a range of cancer types.

Prevalence of Engagement in Internet-Based Psychosocial

Interventions

Low levels of engagement in Internet-based interventions have been common. This suggests that positive intervention effects from extant studies may not be completely accurate, but rather a floor for future effect sizes due to higher engagement (Eysenbach, 2005; Crutzen et al., 2010; Danaher & Seeley, 2009). The overall prevalence of online support group use was 1.5% in participants from the California Health Interview Survey (Owen et al., 2010). However, use of online support in cancer patients was higher than other chronic conditions such as asthma, lung, heart, hypertension, arthritis (Owen et al., 2010). Regardless, engagement in Internet-based interventions for cancer has been low (Sandaunet, 2008).

Similarly, participant dropout has been characteristic of Internet-based intervention studies for panic disorder (Farvolden et al., 2005), depression (Christensen et al., 2004), weight loss (Verheijden et al., 2007), physical activity (Vandelanotte et al., 2007), and smoking cessation (Strecher et al., 2005). Typical patterns of engagement in psychological interventions have included participants who never accessed the intervention, used the intervention only once, or used the interventions a few times with

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around 1% using the intervention through completion (Christensen et al., 2004; Farvolden et al., 2005; Verheijden et al., 2005). Although dropout in Internet-based interventions has been comparable to face-to-face interventions, it is still problematic (Melville et al., 2010).

Relationship between Engagement and Outcome

Low levels of engagement are undesirable since participation is an important mechanism of action for behavioral modification and symptom reduction in Internet-based interventions (Ritterband et al., 2009; Danaher & Seeley, 2009). In 2002, the World Health Organization suggested that adherence to treatment was the primary factor of treatment effectiveness. Face-to-face intervention studies have found that more psychotherapy sessions were associated with stronger positive outcomes (Crisp et al., 2001). Dose-response relationships have consistently been identified in medical studies, where the dose of treatment is proportionately related to the treatment outcome. In the medical literature, a higher dose of chemotherapy has been associated with better outcome in cancer treatment (Bonadonna & Valagussa, 1981). Dose-response curves have been generalized from medical outcomes to psychotherapy outcomes. One study by Hansen et al. (2002) found that between 13 and 18 therapy sessions were necessary for improvement. Dose-response relationships have also been found in Internet-based interventions (Tate et al., 2001). In physical activity interventions, the number of communications with facilitators, discussion board posts, and chat sessions were positively correlated with more intervention effects (Hillsdon et al., 2005; Vandelonotte et al., 2007).

The dose-response relationship has not always been supported. Brief psychological therapies, ranging from 1 to 12 sessions, have shown to be effective and preferred by various clients (Rosenbaum, 1994; Austad & Berman, 1991). Some participants prefer a limited amount of exposure to the intervention materials. In this case, the participant might be labeled a non-engaged user due to their low dose preference (Christensen et al., 2006). More exposure to an internet-based intervention has not always been found to be beneficial. Glasgow et al. (2007) and Lenert (2009) found that engagement decreased as requirements for participants increased. This smoking cessation intervention found that participation declined with the addition of a mood component to the other components, including education, journaling, tracking cigarette usage, and interacting with facilitators (Lenert, 2009). Glasgow et al. (2007) measured engagement with their main internet-based weight loss intervention compared to their intervention with an additional weight loss intervention. They found that the basic intervention alone had higher engagement then the combined interventions, possibly due to less stringent program requirements. Another study by Christensen et al. (2006) found that some participants, dubbed "one-hit wonders", benefited from a short amount of exposure to the intervention. Engagement could also be confounded by personal motivation. The more motivated person will use the intervention as opposed to less motivated participants. The relationship between engagement and outcome is complicated, and positive treatment outcomes could be achieved through a range of engagement levels and not just the highest level. Since dose-response relationships in psychosocial Internet-based interventions for cancer have not been completely evaluated, the maximum reach of outcomes for these interventions is still unknown. Intervention

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affects could be more potent when adequate intervention doses are administered to participants.

Measuring Engagement in Internet-Based Interventions

Data on participant engagement has become an expected component in published studies since it has many useful functions (Ritterband et al., 2003), including assessing the program's usability, determining what aspects of the interventions are most popular, and identifying what components explain the observed intervention effects (Frenn et al., 2005; Eysenbach, 2005). Although most Internet intervention trials for cancer have reported at least one measure of engagement, measurement has been inconsistent. Studies measured general (i.e., logins and time on site) and specific (i.e., uses per intervention component) engagement measures. In the Bosom Buddies intervention by Winzelberg et al. (2003), engagement was measured by the number of logins, message posts, and journal entries. The intervention by Owen et al. (2005) measured the number of visits to specific intervention components, word count, and the percentage of words in discrete, emotional categories. The CHESS intervention group measured a variety of engagement variables, including number of messages, word count, the percentage of users who wrote more than three messages, time on site, time per component, number of uses per component, total uses, and uses per week (Shaw et al., 2006; McTavish et al., 1995; Wise et al., 2008; Gustafson et al., 2001; Shaw et al., 2008; Shaw et al., 2007; McDowell et al., 2010; Shaw et al., 2006). The intervention by Hoybye et al. (2010) measured total posts and the number of posts per participant, while Lieberman (2003) measured the number of meetings attended. The most commonly reported engagement

measures were the number of messages written, word count, posts, time on site, and uses per intervention component. The metric of these measures were inconsistent across studies, with studies reporting totals, means, medians, maximums, and percentages. More uniform measures of engagement across Internet-based interventions could improve the understanding of engagement as a mechanism of action.

Measuring the Association Between Engagement and Outcome in Cancer

Only a few cancer studies have assessed the relationship between engagement and outcomes, but most found a positive relationship. One study of Norwegian breast cancer patients found that participation was associated with group bonding, empowerment, peer support, uncertainty reduction, and receiving information related to treatment decision making (Coreil, 2004). The intervention by Owen et al. (2005) evaluated the relationship between linguistic variables and quality of life, emotional well-being, and cancer-related thoughts in a randomized trial. Greater expression of sadness was associated with greater quality of life, greater expression of negative affect was associated with higher emotional well-being, and greater expression of sadness and anxiety were related to fewer cancer-related thoughts. Shaw et al. (2007) found that more time spent on the interactive components (i.e., discussion board) of the CHESS intervention was associated with higher health information competence. Another study by Wise et al. (2008) using the CHESS intervention found higher use of the educational materials and personal accounts of cancer associated with higher healthcare participation. Winzelberg et al. (2003) correlated the number of logins and postings with depression, perceived stress, and post-

traumatic stress symptoms, but none were significant. Importantly, no Internet-based

interventions for cancer patients have shown negative effects of engagement on outcome

measures. A dose-response relationship likely exists, but before more studies assess this

relationship, efforts to increase engagement to reach maximal doses should be made.

Methods to Increase Engagement with Internet-Based Interventions

There have been efforts to increase engagement in current intervention trials. A

suggestion from the literature has been to increase the interactivity of Internet-based

interventions (Ritterband et al., 2003; Leslie et al., 2005; Stout et al., 2001). Studies have

used interactive materials (e.g., chat sessions, activity planning, discussion groups, online

coaches and videos), tailored content to individual needs, and email contact with

participants (Vandelanotte et al., 2007). Several Internet-based interventions applied

interactive elements which have shown some improvements, but overall engagement

remained low.

Focusing more attention on the target population's needs in the development of

intervention materials increases levels of engagement with the interventions (Coulter,

1998; Kaplan & Shaw, 2004). Likewise, existing interventions could be incompatible

with participants' expectations and needs which could lead to low levels of engagement

and high drop out (Melville et al., 2010; Danaher & Seeley, 2009). User-centered

designs have been used to build and evaluate online health interventions. Sequential

Multiple Assignment Randomized Trial (SMART) and Multiphase Optimization Strategy

(MOST) designs have been introduced to potentially increase the reach and effectiveness

of online health interventions (Collins et al., 2007). The SMART design assesses the

ordering of intervention components and creation of tailored variables to maximize

participation. The MOST design has 3 phases: a screening phase where components are

identified for inclusion or exclusion, a refinement phase, and a confirmation phase where

the intervention is evaluated in a randomized control trial. Both models strive to employ

the best intervention strategy for participants. These models are different from manual-

based interventions that do not strongly take into account participant preferences. Even

the most creative, resourceful, visually appealing, and easy to use interventions may not

be valuable to the target population and failure of a project is a time-consuming and

expensive method to learn the importance of user's needs (Kinzie et al., 2002).

Usefulness of Qualitative Designs to Increase Engagement with

Internet-Based Interventions

Randomized controlled trials (RCT's) have long been considered the "gold

standard" of research designs, but they also have acknowledged limitations. RCT's have

external validity threats which restrict the level of generalization. Furthermore, RCT's

contribute to the underutilization of treatments in the real world that have been found to

be efficacious in trials, but are not generalizable (Rothwell, 2005; Sanson-Fisher et al.,

2007). Since intervention trials target populations rather than individuals, the importance

of generalization favors a different methodological approach, such as qualitative designs.

Qualitative studies have a very important use, which is to learn the solution to a

problem by bringing together details to address the larger issue (Rubin & Rubin, 2005).

Even though information is at the level of the individual, collecting a wide variety of

perspectives can generalize to the larger population. Qualitative inquiry has typically

been criticized for its flexible research design and analysis, but qualitative data has become more rigorous which has lead to a more useful and appropriate application (Sandelowski, 1997; Black, 1994). There are validity checks including: stating the importance of the study, using participants with knowledge and direct experience of the problem to make results convincing, calculating inter-rater reliability, ensuring a large variety of responses to avoid bias, and quoting participants to avoid predetermined biases from the experimenter (Rubin & Rubin, 2005).

Qualitative research commonly investigates questions in their natural context using in-depth group or individual interviews. Previous research has shown that individual interviews are comparable to focus groups (Johnston et al., 1995). More recent literature has determined that individual interviews and focus groups are not substitutes, but rather reveal different information. Although both methods allow researchers to investigate people's attitudes and perceptions, focus groups have undesirable group effects, including a focus on shared opinions, hearing only from dominant members, and peer pressure (Levine & Moreland, 1995; Morgan, 1997). Individual interviews have been shown to identify different information, including more controversial and emotional information that might be uncomfortable for participants to share in a group setting (Kaplowitz & Hoehn, 2001). Furthermore, individual interviews are useful when little is known about the problem and the experimenter needs to collect very detailed information from a variety of participants.

The Grounded Theory of qualitative inquiry is a systematic method of developing a theory based on data collection and analysis (Strauss & Corbin, 1990). The theory aims to understand the human experience and the processes involved. Theoretical

frameworks, although more characteristic of quantitative studies then qualitative studies, are used to select research questions and frame subsequent results. Since qualitative data can be combined in a variety of ways to create multiple theories or perspectives, Strauss and Corbin recommend implementing a theoretical framework (1990). However, due to the exploratory nature of qualitative inquiry, researchers should remain open and allow themes and concepts to emerge based on the data and not solely on previous research. Previous studies of both cancer and non-cancer populations have assessed Internet-based interventions through the theoretical framework of Bandura's Social Cognitive Theory (SCT; 1986). SCT has been extensively used to explain the determinants of health-related behaviors and the individual (i.e. expectations, self-efficacy) and environmental mechanisms that influence such behaviors (Williams et al., 2007; Sinicrope 2009). The Theory of Planned Behavior proposed by Ajzen (1991) has also been useful for understanding the relationships between beliefs, attitudes, and behavioral intentions and has been widely used in healthcare settings (Godin & Kok, 1996). Both frameworks have been influential in devising qualitative interview questions.

From the Grounded Theory perspective, Strauss & Corbin (1990) highlighted the importance of examining the biographical, interactional, and organization dynamics within the specific phenomenon being assessed. Interactional questions elicit information regarding personal relationships within the intervention group. Organizational questions relate to the design of the intervention and biographical questions relate to the personal experience with the intervention. These general categories of questions organize the data into individual factors, preferences for social interaction, and preferences related to the intervention.

Qualitative Studies of Internet-Based Interventions

Qualitative studies have been conducted assessing how cancer patients use the Internet. Studies have assessed the content of messages posted on online discussion boards. Klemm (1998, 2008) interviewed participants and identified the following themes in the messages: information, opinions, support, personal experiences, thanks, humor, prayer, symptomology, and frustration with healthcare providers. Henderson (2003) conducted interviews to determine how cancer patients cope with a cancer diagnosis. Patients use prayer, avoiding negative people, developing a positive attitude and will to live, and receiving support. Studies have assessed patient's experiences with obtaining cancer information over the Internet. Ziebland et al. (2004) found that patients use online information to seek information and second opinions, learn about symptoms and treatments, interpret consultation, and develop questions for doctors. Sharf (1997) found that cancer patients use online discussion forums to exchange information, receive social support, and find empowerment. Gray (1997) assessed participant opinions of online self-help groups and found that emotional, informational, and practical support about cancer treatment and decision making were most important. Another qualitative study conducted by Clayman et al. (2008) interviewed health professionals to determine important topics of discussion for cancer patients. These topics included: understanding diagnoses, what treatment will be like, what types of health professionals will be involved in treatment, and seeking information and support. Although Internet resources have multiple benefits, Rozmovits (2004) reported that patients believed a large amount of information on the Internet was contradictory, patchy, and haphazard, preferring experimental information from universities and cancer centers.

Qualitative studies of gender differences have been conducted. Klemm (1999) found that women wrote more about personal experience and support, while men wrote about medical information. Furthermore, studies have found that the experience of cancer was more holistic in women, while limited to the physical body in men (Seale et al., 2006, Klemm, 1999). Blank & Adams-Blodnieks (2007) found that men used the Internet to access information about treatment and sexuality, while women used online resources for emotional expression and support. These studies are consistent with previously found gender differences in Internet use.

There have only been a couple qualitative studies assessing the barriers and motivators of Internet-based interventions, to date. Sandaunet et al. (2008) conducted qualitative interviews of participants from their Norwegian online cancer self-help group and found the following barriers to use: avoiding painful details about cancer, not being sick enough to participate compared to the rest of the group, establishing a legitimate position in the group, everyday schedules, and illness phases. Lieberman et al. (2003) conducted interviews to assess patient's positive and negative experiences with the online support group they previously participated in. Themes included barriers to participation (i.e., procrastination and different expectations), motivators to participation (i.e., trust in the intervention and value), as well as the purpose of the intervention (i.e. confusion of the goal and what is expected of participants). Both studies used participants with breast cancer which is not generalizable to all cancer patients. More qualitative inquiries should be conducted for all cancer types to assess the motivators and barriers to engagement. The Grounded Theory of qualitative inquiry could alter the intervention design to better fit the needs of cancer survivors.

Summary and Statement of the Problem

Psychosocial Internet-based interventions for cancer patients have shown promising results, but use of the interventions has been relatively low. Interventions might exhibit a dose-response relationship, where higher engagement with the intervention materials leads to better outcome. Before these associations can be tested, engagement levels must be increased to ensure adequate doses of intervention (Figure 1). Arguably the most effective way to increase engagement is to ask the participants who have direct experience with the intervention. Individual interviews of participants will shed light on the motivators and barriers to engagement in the current intervention. It is important to ask survivors about their experience with the various components of the intervention, their interaction with facilitators and group members, as well as the individual values, intentions, and expectations of the intervention. Based on responses, the intervention will be altered to better reflect the needs of cancer survivors. The current study is specific to the Internet-based intervention created by Owen et al. (2005). The intervention is representative of other online interventions for chronic illness populations. In terms of components, the intervention implements social support components (i.e. discussion board, chat room, and email), informational components (i.e. guidance modules), facilitation, and technological support. Results of the current qualitative inquiry could generalize to other online resources for cancer survivors, better suiting their needs.
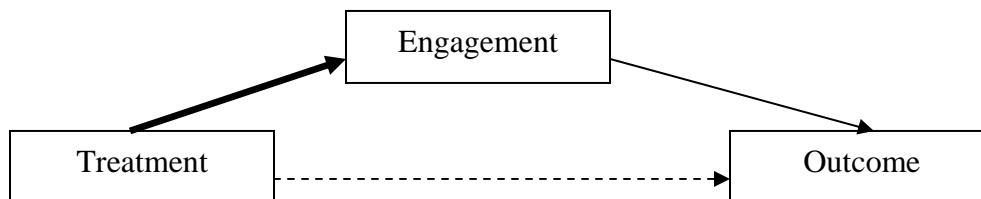
Figure 1. Theoretical framework of the current study.

Specific Aims

<u>Specific Aim 1</u>: To identify the motivators and barriers of engagement within an Internet-based intervention to better inform a user-centered intervention design.

Hypothesis 1. Potential themes of motivators and barriers will be indentified based on the previous literature and theoretical frameworks of the current qualitative inquiry: Individual factors (i.e. sickness phase, time, informational needs, level of positivity), Social factors (i.e. communicating with other patients and health professionals, helping others, receiving support, hearing other's experiences), and attitudes regarding the structure and components of the intervention (i.e. trust in intervention, confusion). However, given the qualitative nature of the design, the data collected will drive the categories of motivators and barriers if responses differ from hypothesized categories.

Hypothesis 2. Potential motivators and barriers will differ between individuals randomized into the support group and individuals randomized into the wait-list group.

<u>Specific Aim 2</u>: To assess the general usefulness of each intervention component.

CHAPTER TWO

METHODS

Intervention

The intervention is a 12-week internet-based support group based at Loma Linda University (www.health-space.net). The support group was designed by a clinical psychologist and facilitated by graduate students in the psychology department of Loma Linda University. The components of the website include an asynchronous discussion board, facilitated synchronous chats, weekly coping and guidance exercises, personal profile pages, and private email messaging to other members or facilitators. The discussion board displayed posts from participants in chronological order. The chat room allowed participants to communicate with each other in real time. The guidance exercises consisted of readings and exercises on 12 diverse topics, including relationships, relaxation, and communication. The profile pages allowed participants to post pictures and personal information about themselves as well as the ability to look at other participants' pages. After consenting to participate in the support group, participants completed a questionnaire about relevant demographics and psychosocial information. After completing the questionnaire, participants were either immediately randomized into the support group or to a waitlist group for 12 weeks. All participants had access to the group for 12 weeks.

Participants

Participants have been recruited into the intervention through the Loma Linda University cancer registry or online recruitment strategies, including posts on facebook

(www.facebook.com) and craigslist (www.craigslist.org). 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). Baseline questionnaires were completed and then participants were randomized into the intervention or a 12-week waitlist group. For the current study, participants had already consented, enrolled, and completed the intervention. 174 participants have completed the intervention and demographic information is provided in Table 1.

Gender significantly differed among the engagement groups. Specifically, the low engagement group had significantly more males than the other groups. There were no other significant differences among the engagement groups.

Table 1

Demographics for participants who completed the intervention protocol (n=174).

	Total	No use	Low	Moderate	High	Significant?
Distress m(sd)	5.2 (2.8)	3.5 (3.3)	5.3 (2.7)	5.7 (2.3)	5.7 (2.7)	No[a]
Age m(sd)	54.6 (11.6)	56.2 (9.4)	53.7 (12.8)	54.2 (10.6)	57.7 (9.6)	No[a]
Randomized f(%)						No[b]
Waitlist	57 (32.8)	12 (21.1)	28 (49.1)	29 (50.9)	5 (8.8)	
OSG	117 (67.2)	13 (11.1)	62 (53.0)	12 (10.3)	13 (11.1)	
Gender f(%)						Yes[b]
Male	52 (32.9)	7 (13.5)	32 (61.5)	11 (21.2)	2 (3.8)	
Female	106 (67.1)	12 (11.3)	52 (49.1)	27 (25.5)	15 (14.2)	
Cancer Type f(%)						No[b]
Breast	38 (21.8)	6 (15.8)	22 (57.9)	7 (18.4)	3 (7.9)	
Prostate	37 (21.3)	6 (16.2)	20 (54.1)	9 (24.3)	2 (5.4)	
Female Reproductive	12 (6.9)	1 (8.3)	5 (41.7)	3 (25.0)	3 (25.0)	
Other	41 (23.6)	5 (12.2)	19 (46.3)	12 (29.3)	5 (12.2)	
Melanoma	6 (3.4)	1 (16.7)	2 (33.3)	1 (16.7)	2 (33.3)	
Blood	5 (2.9)	0 (0.0)	3 (60.0)	2 (40.0)	0 (0.0)	
Thyroid	13 (7.5)	0 (0.0)	10 (76.9)	2 (15.4)	1 (7.7)	
Colon	8 (4.6)	2 (25.0)	3 (37.5)	3 (37.5)	0 (0.0)	
Multiple	14 (8.0)	4 (28.6)	6 (42.9)	2 (14.3)	2 (14.3)	
Income f(%)						No[b]
0-20,000	15 (8.7)	3 (20.0)	2 (13.3)	4 (26.7)	1 (6.7)	
21,000-40,000	34 (19.8)	6 (17.6)	16 (47.1)	8 (23.5)	8 (23.5)	
41,000-60,000	31 (18.0)	3 (9.7)	20 (64.5)	9 (29.0)	4 (12.9)	
61,00-80,000	26 (15.1)	3 (11.5)	22 (84.6)	5 (19.2)	2 (7.7)	
> 80,000	66 (38.4)	10 (15.2)	30 (45.5)	15 (22.7)	3 (4.5)	
Ethnicity f(%)						No[b]
White	137 (86.7)	16 (11.7)	75 (54.7)	32 (23.3)	14 (10.2)	
Black	9 (5.7)	1 (11.1)	5 (55.6)	1 (11.1)	2 (22.2)	
Hispanic	5 (3.2)	0 (0.0)	2 (40.0)	3 (60.0)	0 (0.0)	
Other	7 (4.4)	2 (28.6)	2 (28.6)	2 (28.6)	1 (14.2)	
Marital f(%)						No[b]
Married	125 (71.8)	16 (12.8)	64 (51.2)	31 (24.8)	14 (11.2)	
Single	19 (10.9)	3 (15.8)	9 (47.4)	4 (21.1)	3 (15.8)	
Divorced/ Widowed	30 (17.2)	6 (20.0)	17 (56.7)	6 (20.0)	1 (3.3)	
Education f(%)						No[b]
Some High School	3 (1.7)	1 (33.3)	2 (66.7)	0 (0.0)	0 (0.0)	
High School grad	29 (16.7)	7 (24.1)	16 (55.2)	5 (17.2)	1 (3.4)	
Some College	43 (24.7)	5 (11.6)	20 (46.5)	10 (23.3)	8 (18.6)	
Bachelors	45 (25.9)	7 (25.6)	22 (48.9)	13 (28.9)	3 (6.7)	
Post-Bachelors	54 (31.0)	5 (9.3)	30 (55.6)	13 (20.1)	6 (11.1)	

Note: OSG= Online support group
    Excluded missing values
    a= One-way Analysis of Variance
    b= Chi-square test

Participants were categorized by their level of engagement with the intervention determined by Owen et al. (American Psychosocial Oncology Society Presentation, 2011). Cut-points were logically created based on the number of participants in different clusters. The distinct categories included use of the intervention less than 10 minutes, from 10 minutes to 3 hours, 3 to 12 hours, and more than 12 hours. The 10 minute cutoff was created since it was expected that a portion of participants look around to get a feel for the website, but do not participate the recommended amount. The suggested amount of engagement was one hour each week resulting in at least 12 hours total. Although 12 hours was recommended, few participants actually adhered.

For the current investigation, only the low engagement group was sampled to gain a comprehensive understanding of the barriers to using the intervention. Participants who engaged with the intervention less than 10 minutes were not included since participants were not expected to have enough knowledge and experience with the website to provide thorough information. Subjects were sampled from the pool of participants who have been given access to the intervention and have completed the 12-week protocol. Participants originally randomized into the waitlist group were included in the study to increase the sample size, gain information about the barriers associated with waitlist groups, and gain insights on methods to prevent participants from falling through the cracks during the transition into the study. To ensure accurate responses, participants must have completed the intervention within two years. 90 participants completed the study protocol within the duration (Table 2).

Table 2

Demographic information of participant pool (n=90).

	Participant characteristics
Distress m(sd)	5.3 (2.7)
Age m(sd)	53.7 (12.8)
Randomized f(%)	
OSG	62 (68.9)
Waitlist	28 (31.1)
Gender f(%)	
Female	52 (61.9)
Male	32 (38.1)
Cancer Type f(%)	
Breast	22 (24.4)
Prostate	20 (22.2)
Other	19 (21.2)
Thyroid	10 (11.1)
Multiple	6 (6.7)
Female Reproductive	5 (5.6)
Blood	3 (3.3)
Colon	3 (3.3)
Melanoma	2 (2.2)
Income f(%)	
0-20,000	2 (2.2)
21,000-40,000	16 (17.8)
41,000-60,000	20 (22.2)
61,00-80,000	22 (24.4)
> 80,000	30 (33.3)
Ethnicity f(%)	
White	75 (89.3)
Black	5 (6.0)
Hispanic	2 (2.4)
Other	2 (2.4)
Marital f(%)	
Married	64 (71.1)
Divorced/Widowed	17 (18.9)
Single	9 (10.0)
Education f(%)	
Some High School	2 (2.2)
High School grad	16 (17.8)
Some College	20 (22.2)
Bachelors	22 (24.4)
Post-Bachelors	30 (33.3)

The majority of potential participants were Caucasian, married females with an average

age of 53.7 years. Over half of participants had a Bachelor's degree or higher and were

middle class or higher. The most represented cancer types included breast (24.4%), prostate (22.2%), other (21.2%), thyroid (11.1%), and multiple (6.7%). Other cancer types included tongue, lymphoma, leiomyosarcoma, bladder, thymoma, and chordoma. Multiple cancers included the following combinations: breast and kidney, appendix and cervical, prostate and kidney, and prostate and bladder.

All 90 potential participants were attempted to be contacted to maximize diversity in the sample. The pool of potential participants (n=90) was representative of individuals who have been shown to use the internet, specifically Caucasian, younger women with high income and education. However, in order to gain information regarding barriers of use, individuals who were part of the demographic that tended not to use the internet, including men, older age, other ethnicities, and lower incomes and education, were included as well. The investigator attempted to capture the variability in these relevant demographic variables, including age, gender, marital status, ethnicity, education, and income. However, comparisons based on these characteristics were not within the scope of the current investigation. Recruitment of subjects ceased once no new categories were found and identified categories were dense and validated.

Data Collection

The current study was reviewed and approved by the LLU Institutional Review Board. Potential participants were contacted over the phone. The process and purpose of the study was explained over the phone to potential participants and verbal consent was given by participants before investigation continued. Individuals who did not agree to participate were tracked to identify the presence of response bias. Interviews were

scheduled after verbal consent was provided by the participant. Written consent was not required since the current study is an extension of the previous intervention they consented to and completed.

In depth guided one-on-one sessions using phone interviews were conducted and audio recorded, transcribed, and coded. Qualitative interviews are extremely common in qualitative research and have been compared to "night goggles", since they allow researchers to examine phenomenon that are not readily apparent (Rubin & Rubin, 2005). The interviews lasted approximately 60 minutes and participants received a $10 gift card for their participation in the telephone interview. The moderator conducted all of the interviews. However, the initial interviews were overseen by the principle investigator of the research team, to ensure the interview process proceeded as planned.

The interview process followed the Responsive Interview Model proposed by Rubin & Rubin (2005), where the moderator listens carefully to the participant and asks questions until they have a complete understanding. At the beginning of each interview, the moderator introduced the interview, mentioned the duration of the interview as well as the ground rules (i.e. no right or wrong answers and the importance of hearing the participant's full input). The moderator had important roles in the interview including, asking open ended questions, probing for detailed responses, keeping the conversation on topic after it drifts on a tangent, and moving the conversation forward when a conclusion has been reached on a question. At the same time, moderators should take a more passive role in the conversation by avoiding showing approval for certain responses or providing suggestions or personal opinions that could bias responses (Krueger, 1988). Although questions were asked one at a time by the moderator, the goal was for the participant to

speak more than the moderator and direct the conversation more than a question-answer session. The semi-structured format allowed the interview to be more flexible and participant-driven. Although each interview was guided by the same questions, each conversation was unique since participants have different opinions and perceptions of the intervention.

Semi-structured Interview

A semi-structured interview was used since it is flexible and driven by the participant. The interview assessed the research question of interest: How can we build a better intervention for cancer patients with distress? The interview included broad categories of questions that Strauss and Corbin recommended, including interactional, organizational, and biographical questions (1990) to elicit information related to personal factors, social factors, and intervention-specific factors. Questions were also influenced by previous research and important theoretical concepts from previous qualitative inquiry. Borrowing factors from SCT and the Theory of Planned Behavior, the current study employed concepts such as intentions, expectations, and perceptions of value to influence interview development.

The interview questions are presented in Appendix 1. Open-ended questions were used since they stimulate discussion (Krueger, 1988). Overall, researchers have recommended using as little as two questions to as many as 12, depending on the time allotted (Krueger, 1994). The first question was designed to be relatively simple and neutral to ease the participant into the discussion. More sensitive questions were asked after rapport has been established and participants were more comfortable (Côté-

Arsenault, 1999). The primary questions followed an appropriate flow and follow up and

probing questions were used to elicit more thorough information. Primary questions

represented topics that must be addressed, follow up questions were used to expand

understanding and richness, and probing questions were standardized ways to increase

the depth of topics (Rubin & Rubin, 2005). The language of the interview was

intentionally at a relatively easy reading level to account for differences in participants'

education levels. Intervention-specific items, such as 'discussion board', 'personal

pages', and 'facilitators', were explained in further detail when necessary, especially for

participants who did not actively participate and thus were unfamiliar with those words.

Analysis

Interviews were recorded using a device that attached to the telephone.

Completed interviews were transferred to a secure database in the Behavior Oncology

Lab and played back through iTunes. The audio-taped interviews were transcribed into

written scripts using Express Scribe and Dragon Dictate. Express Scribe is a foot pedal

software used to control the playback of the interviews so they can be spoken into

Dragon Naturally Speaking's speech recognition software. The transcriptions were then

read over for accuracy.

Coding followed the content analysis method of open and axial coding. Open

coding facilitated the decomposition of the data into properties and dimensions. The

sentences were examined and compared for similarity to identify categories. Since

categories were not predetermined, but data driven, a line by line analysis of every phrase

was the best method for capturing detailed categories (Strauss & Corbin, 1990). Similar

properties from the written content were placed in the same category. The process of axial coding combined the data according to the categories and relationships that arose during open coding line by line analysis. Subcategories were combined into more general categories or themes.

Coding began immediately after the first interviews were conducted to assess the relevance of the interview questions and to determine coding procedures. The transcripts were initially read over by the moderator and principle investigator of the Behavioral Oncology Lab. For the first nine interviews, both the moderator and principle investigator independently highlighted text from the interviews that represented barriers or motivators. A barrier was loosely defined as anything that prevented someone from using the site, while a motivator was defined as anything that would encourage someone to use the site. However, no differentiation between motivators or barriers was made within the highlighted sections. The highlighted transcripts were also assigned a tentative code or theme that was discussed between the moderator and principal investigator. Involving both raters led to a more thorough coding scheme. Overlap of highlighted text was good between the two raters, with a Kappa over 0.70 on two randomly identified transcripts. After the moderator and principal investigator agreed on the final set of codes, the user-friendly code book was created (Appendix 2). The code book was comprised of 20 general codes and 84 specific codes, where the general codes represented over-arching categories, while sub-categories represented more specific examples of general categories. The overarching themes included information exchange, social interaction, individual factors, and the structure of the intervention. Each highlighted section received one code.

The moderator taught two research assistants in the Behavioral Oncology lab how to apply the code book to the transcripts. Multiple coders were used to ensure consistency. Coding began in the presence of the moderator to ensure that confusion from raters was adequately addressed. If coding transcripts took more time than the allotted lab meeting, the research assistants could finish coding the de-identified interviews at a later time. Coders met weekly with the moderator to review the coded transcripts and continue training. The research assistants together coded all of the transcripts, while the moderator coded all the transcripts as well. Consequently, 100% of the data was double coded in order to calculate reliability (Marques, 2005). Inter-rater reliability between coders was calculated to ensure validity of the code book. Cohen's Kappa (1960) measures the number of concordant ratings compared to the number of non-concordant ratings while taking into consideration differences due to chance. Values range from 0 to 1, with Kappas of .40-.60 representing moderate agreement, higher than .60 representing solid agreement, and .80 and above representing near perfect agreement (Everitt, 1996). For the current investigation, a minimum Kappa of .70 was determined to be acceptable.

Once all interviews were coded, the number of themes was calculated per participant as well as the average number of themes across participants. To compare across individuals, data were clustered across participants. Frequencies and percentages of participants who indentified each theme were calculated. Based on the obtained frequency distribution, it was plausible to determine which themes were more or less prominent in the sample. Within each general theme, the more specific sub-categories were characterized across participants. Themes were compared across randomized status

(i.e., immediate access or waitlist) to determine if there were key differences on themes

between the two groups. To assess participants' opinions regarding the intervention

components, text related to the components was coded as "liked", "disliked", or

"neutral".

CHAPTER THREE

RESULTS

Sample Characteristics

Ninety potential participants were identified for participation (Figure 2).

65 (72.2%) participants did not join the study. Of those 65, 3 (4.6) participants declined

due to not remembering the Health-space website and being too busy, 36 (55.4)

participants were unable to be reached after 3 phone calls, 1 (1.5%) participant was

deceased, 5 (7.7%) participants had the wrong contact information, 15 (23.1%)

participants were not contacted because it has been 2 years they graduated the study, and

5 (7.7%) participants elected to participate in the interview, but were unable to be reached

after the initial phone call.
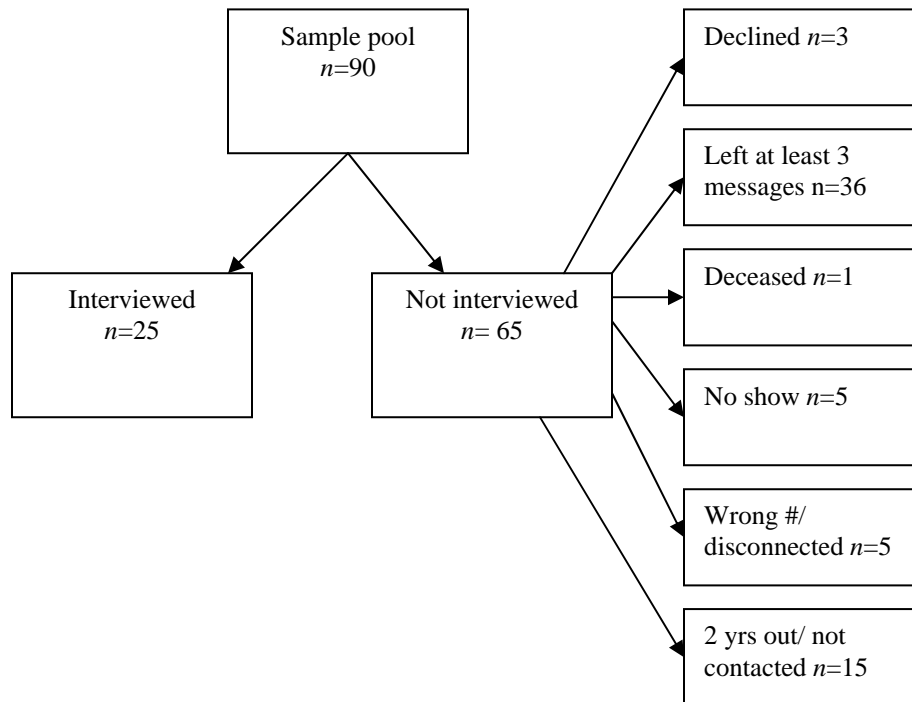
Figure 2. Flowchart of study participants.

Twenty-five (24.7%) participants agreed to be interviewed (Table 3).

Table 3

Characteristics of interview participants.

	Interview Subjects (n=25)	Participant Pool (n=90)	Significant?
Distress M(SD)	5.84 (2.43)	5.3 (2.7)	No[a]
Age M(D)	52.8 (12.78)	53.7 (12.8)	No[a]
Randomized f(%)			No[b]
OSG	15 (60.0)	28 (31.1)	
Waitlist	10 (40.0)	62 (68.9)	
Gender n(%)			No[b]
Male	9 (36.0)	32 (38.1)	
Female	16 (64.0)	52 (61.9)	
Cancer Type n(%)			No[b]
Breast	7 (28.0)	22 (24.4)	
Prostate	5 (20.0)	20 (22.2)	
Female Reproductive	1 (4.0)	5 (5.6)	
Thyroid	4 (16.0)	19 (21.2)	
Colon	0 (0.0)	2 (2.2)	
Melanoma	0 (0.0)	3 (3.3)	
Blood	1 (4.0)	10 (11.1)	
Other	4 (16.0)	3 (3.3)	
Multiple	3 (12.0)	6 (6.7)	
Income M(SD)			No[b]
0-20,000	1 (4.0)	2 (2.2)	
21,000-40,000	5 (20.0)	16 (17.8)	
41,000-60,000	5 (20.0)	20 (22.2)	
61,00-80,000	6 (24.0)	22 (24.4)	
> 80,000	7 (28.0)	30 (33.3)	
Ethnicity n(%)			No[b]
White	21 (84.0)	75 (89.3)	
Black	0 (0.0)	5 (6.0)	
Hispanic	3 (12.0)	2 (2.4)	
Other	1 (4.0)	2 (2.4)	
Marital Status n(%)			No[b]
Married	19 (76.0)	64 (71.1)	
Single	1 (4.0)	9 (10.0)	
Divorced/Widowed	5 (20.0)	17 (18.9)	
Education n(%)			No[b]
Some High School	0 (0.0)	2 (2.2)	
High School grad	7 (28.0)	16 (17.8)	
Some College	4 (16.0)	20 (22.2)	
Bachelors	6 (24.0)	22 (24.4)	
Post-Bachelors	8 (32.0)	30 (33.3)	

Note: Excluded missing data

    OSG= online support group

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 middle class or higher. 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 leiomyoscarcoma, 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 online support group, while 10 (40.0%) participants were randomized to the 12-week waitlist group. However, there was no significant difference between the time spent on the website and whether the participant was randomized into the support group or waitlist group, $t(23) = -.22$, $p > .05$. Time spent on the website ranged from 10-179 minutes, with an average of 64.2 minutes. Demographic information was compared between participants who elected to be interviewed and those who did not. There were no significant differences between those participants who did not partake in the interviews or those who did participate on age, distress level, gender, cancer type, income, education, ethnicity, or marital status.

Reliability

Kappas were calculated for both general and specific codes. For general codes, Kappas ranged from .75-1.0, with an average of .89. For specific codes, Kappas ranged from .71-.93, with an average of .82. Since Kappas were in the acceptable to near perfect ranges, the obtained codes were deemed a valid representation of the data.

Themes
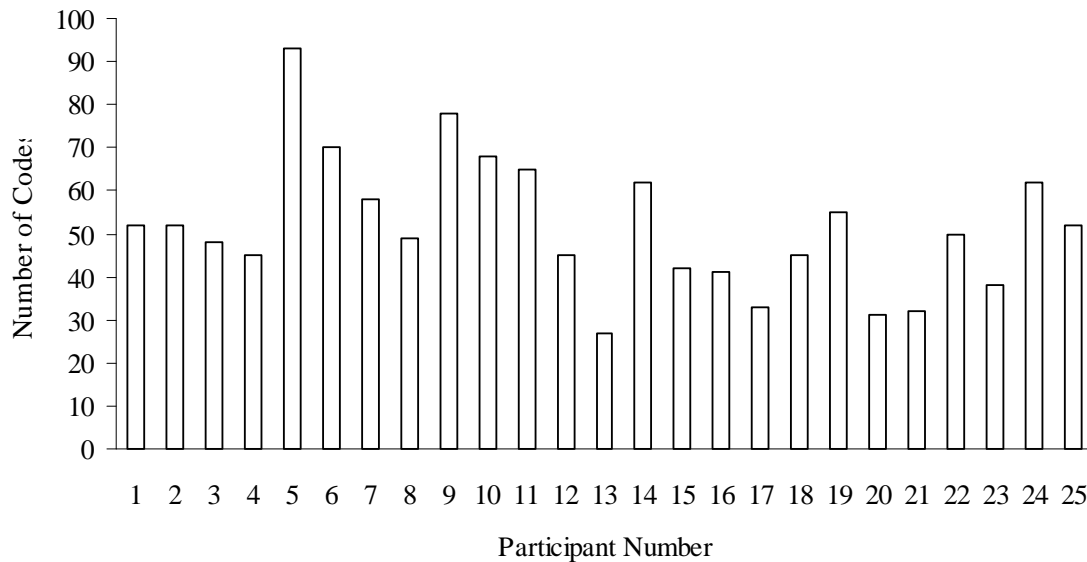
Figure 3. The total number of codes endorsed by participant.

The number of codes per interview ranged from 27-93, with a mean of 52 (*sd*=16)

codes per interview. Figure 3 displays the distribution of the number of codes per

participant. 20 general themes were indentified in the interviews (Figure 4). Themes

were clustered around the following categories: information exchange, social interaction,

individual factors, and the structure of the intervention. In terms of the information

exchange category, the general theme of information and resources was obtained. Within

the social interaction category, the general themes included making connections and

preferences for social interaction. In terms of individual factors, the endorsed themes

included the individuals' cancer trajectory, personal relevance of the intervention, time

considerations, tone of communication on the website, previous experience with support

groups, experience with the computer and Internet, and the Internet format of delivering

support. Within the intervention specific category, the general themes included website

structure, opinions of the facilitation, general positive regard for the website, getting

started on the website, opinions of the email reminders, the appearance of the site,

opinions regarding the questionnaires, the external incentives, study procedures, and

general regard for the institution. Tables 4-7 show the frequency and percentage of each

general and specific code.
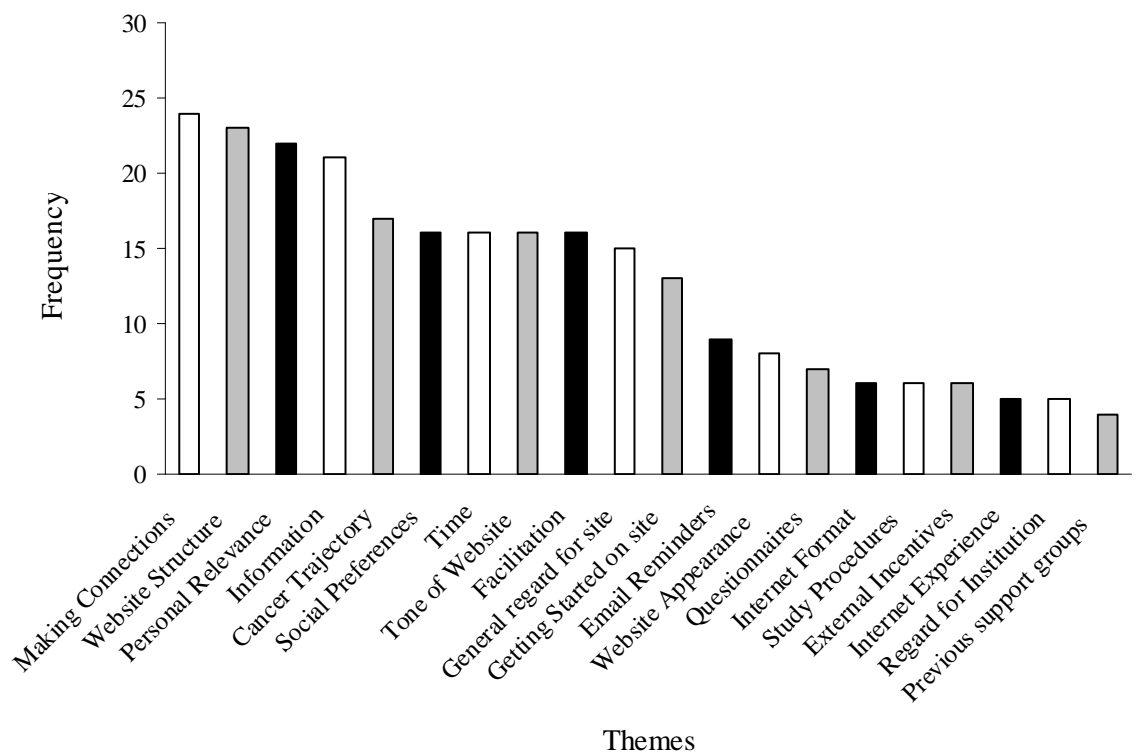
Figure 4. Number of participants endorsing general themes.

Table 4

Frequencies and percentages of participants endorsing general and specific codes within the information exchange category.

Informational Resources	N	%
Information Exchange	**21**	**84**
General information (1i)	16	64
Medical information (1f)	16	64
Lifestyle information (1a)	8	32
Psychological information (1b)	7	28
New information (1g)	7	28
Credible information (1h)	6	24
Social information (1e)	4	16
Spiritual information (1d)	3	12
Financial information (1c)	2	8

Table 5

Frequencies and percentages of participants endorsing general and specific codes within the social interaction category.

Social Interaction	N	%
Making connections	**24**	**96**
Connecting with survivors (2a)	22	88
Sense of community (2b)	17	68
Desire to help others (2c)	12	48
More group interaction (2d)	9	36
Social Preferences	**16**	**64**
Introverted (3a)	9	36
Liked ability to lurk (3d)	6	24
Extroverted (3e)	5	20
Not interested in social (3c)	5	20
Uncomfortable jumping in (3b)	4	16

Table 6

Frequencies and percentages of participants endorsing general and specific codes within the personal category.

Personal	N	%
Personal Relevance	**22**	**88**
Not a fit (5d)	17	68
No need for site (5e)	13	52
Unable to contribute (5i)	8	32
Did not give site a chance (5f)	8	32
Need for site (5c)	7	28
Relevant/interesting topics (5b)	6	24
Not a high priority (5h)	6	24
No pressure (5g)	5	20
Mood (5a)	3	12
Cancer Trajectory	**17**	**68**
Cancer type (4a)	14	56
Phase of treatment (4c)	6	24
Cancer stage (4b)	3	12
Cancer severity (4d)	2	8
Time Considerations	**16**	**64**
Busy (6b)	12	48
Needing more chat times (6c)	9	36
No more time on computer (6a)	5	20
Tone of Communication	**16**	**64**
Remaining positive (7a)	12	48
Warm and welcoming (7d)	8	32
Fun and light-hearted (7b)	3	12
Serious conversation (7c)	1	4
Internet Format	**6**	**24**
Like internet format (10b)	5	20
Dislike communicating online (10a)	3	12
Internet Experience	**5**	**20**
Dislike computer (9a)	4	16
Uncomfortable with computer (9b)	4	16
Previous support group experience	**4**	**16**
Negative experience (8a)	3	12
Positive experience (8b)	2	8
No experience (8c)	1	4

Table 7

Frequencies and percentages of participants endorsing general and specific codes within the intervention specific category.

Intervention Specifics	N	%
Website Structure	**23**	**92**
General characteristics (12a)	20	80
Dividing into threads (12e)	14	56
Quickly finding information (12b)	9	36
Label posts (12c)	7	28
Issues logging on (12g)	6	24
Summaries of topics (12d)	5	20
More personalized (12f)	3	12
Facilitation	**16**	**64**
Not enough contact (13e)	12	48
Knowledgeable facilitators (13c)	10	40
Encouraging facilitators (13a)	7	28
Facilitators connect group (13g)	6	24
Impersonal communication (13h)	2	8
Flexible facilitators (13b)	1	4
Pushy facilitators (13d)	1	4
Facilitators act like counselors (13f)	1	4
General positive regard	**16**	**64**
Liked idea of site (11a)	15	60
Liked that we are trying to help (11b)	5	20
Getting Started/Introduction	**13**	**52**
Having a manual (15d)	12	48
Confused at beginning (15c)	10	40
Knowing overall goal (15b)	7	28
Facilitators introduce themselves (15a)	3	12
Email Reminders	**9**	**36**
Too many email reminders (17a)	8	32
Liked email reminders (17b)	6	24
Feeling guilty/embarrassed (17c)	2	8
Appearance of site	**8**	**32**
Concern about appearance (14b)	6	24
Liked appearance (14a)	2	8
Questionnaires	**7**	**28**
Too long of questionnaires (16a)	6	24
Feedback from questionnaires (16b)	3	12
Enjoyed questionnaires (16c)	3	12
Less specific questionnaires (16d)	1	4
External Incentives	**6**	**24**
Liked gift cards (19a)	5	20
Want more external incentives (19b)	2	8

Study Procedures	6	24
Dislike waitlist (18c)	5	20
Paranoia about being in a study (18a)	1	4
Confused about waitlist (18b)	1	4
Dislike time limit (18d)	1	4
Regard for Institution	**5**	**20**
Positive regard for LLU (20a)	4	16
Negative regard for LLU (20b)	1	4

Making Connections

As participants mentioned barriers and motivators to use of the intervention, the most commonly endorsed theme was related to making connections. 24 (96%) participants mentioned that they would like use the intervention for making connections with other survivors. Within the general theme, participants specifically reported that they would like to share with other cancer survivors (n=22), find survivors who have been through the same experiences (n=17), have a desire to help others (n=12), and have abundant interactions with survivors (n=9).

> I mean the whole reason for me to be interested was to get into it and share with other people. (F-49y)
>
> I mean it's not a club you want to be in, but once you're in it, you want to know what it's like for other people who are in it. (F-56y)
>
> One of my greatest resources was being able to speak to someone who had gone through the same thing (F-36y)

Website Structure

23 (92%) participants reported that the structure of the website was an important factor in their use of the intervention. Specifically, participants mentioned the desire for

an easy to use and straightforward website (n=20), organizing the topics of discussion

into categories or threads (n=14), being able to quickly find relevant information (n=9),

and labeling posts by the topic or participant information (i.e. gender, age, cancer type,

geographic location) (n=7). 6 participants reported having difficulties logging onto the

website due to the website address or password. Lastly, participants stated that receiving

summaries of topics or newsletters would be helpful to remain involved in the group

(n=5) as well as tailoring the website to make it more personalized to a survivors' needs

(n=3).

> I didn't like the way that it was just thrown in there. There was no sense of order to it and so it was just like reading one of those magazines that gives you short saying here and there (F-60y)

> It just doesn't feel accessible enough to me. It's not easy enough for me to want to pursue it. I have to do too much work to pursue it. (F-53y)

Personal Relevance

22 (88%) participants mentioned that the intervention was not personally

applicable to them. Specifically, participants reported that the intervention was not a fit

with their needs (n=17), that they did not have a current need for the intervention or that

they have moved on from actively dealing with their cancer (n=13), that they did not give

the intervention a chance (n=8), and they felt unable to contribute to the conversation or

help other survivors (n=8). However, 7 participants endorsed a current need for the site.

Six participants mentioned that the topics were not relevant or interesting to them, six

participants stated that their participation in the site was not a high priority in their lives

at the time and that there were more important issues, five participants reported that they

did not want to feel pressure from facilitators to participate, but would rather use the

intervention on their own terms, and three participants mentioned that their desire to

participate depended on their mood at the time, which was variable from day to day.

> I realized I don't think I really fit in with what you're all trying to do because I don't have those concerns. I don't have any problems and I don't think cancer will ever kill me, not the prostate cancer, I mean. (M-78y)

> 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. (M-59y)

Information

21 (84%) participants endorsed the need for informational resources on an online

intervention for survivors. Specifically, participants sought general cancer information,

including links and a list of frequently asked questions (n=16), medical information

(n=16), lifestyle information on nutrition and exercise (n=8), information about

psychological functioning and coping (n=7), updated research and information (n=7),

information from credible sources and institutions (n=6), information for family members

(n=4), information on faith and wellness (n=3), and financial information (n=2).

> Linking to things that are available because sometimes I want to know where I can go participate in relay for life, I want to know where I can become part of the American Cancer Society and that would be really useful also for those organizations because it connects the doctors and the patients. So when you're at the doctors office, it would be nice to know that there is a resource because it's hard (F-32y)

> Even physicians that would be willing to do a group support type talk for things that people are very interested in as a cancer patient or survivor. (F-60y)

Cancer Trajectory

17 (68%) participants mentioned their preference for interacting with survivors who had similar experiences with cancer as themselves. Participants stated that they preferred to interact with survivors with the same cancer type (n=14), the same phase of treatment (i.e. in treatment, survivorship, remission) (n=6), the same stage of cancer (n=3), and a similar severity and impact of the cancer (n=2).

> Still feel like I'm getting a little bit beyond the panicky new people to the diagnosis into the more in depth people who have experienced it a couple times and are beyond the first level of oh what do I do kind of panicking questions. I don't mean this to be a knock on the people who first are diagnosed because I remember when I was like that but you get to different levels. The first time it's really scary and the 3rd time it's like eh (F-49y)

> I was hoping that I would find more of my cancer on there (F-38y)

Social Preferences

6 (64%) participants reported various preferences related to social interaction with other survivors in the group. Specifically, participants mentioned that they were introverted and did not wish to disclose personal information with other survivors (n=9), that they appreciated the choice to share as much or as little as desired (n=6), that they were not as interested in the social aspects of the intervention as the informational aspects (n=5), and that they were uncomfortable jumping into the group from the beginning (n=4). However, 5 participants reported that they were extroverted and interested in hearing other survivors' experiences.

> It's not that I'm an introvert, but I guess with my personal stuff, I don't really like to post it all out.

> 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. (F-53)

Time Considerations

16 (64%) participants mentioned that a lack of time contributed to their low use of the intervention. Participants stated that they were busy for a wide variety of reasons (n=12), would have participated in the chat room, but were unavailable at the time it was offered (n=9), and did not want to spend more time on the computer than they already do for other reasons outside of the intervention (n=5).

> I never got to do any of your chats because I have another form of cancer support on Wednesday when you were having them and so I'm on a Boat Team for breast cancer survivors which is a sport. It's physical activity, but it's also a place to get support. And so those practices were on Wednesday evenings when you were having your chat. So I never got to do those. (F-56y)

> My own time because I don't have a lot of it. (F-56y)

Tone of Communication

16 (64%) participants reported that the tone of communication of the website was an important determinant of their use of the intervention. Twelve participants mentioned the desire to remain positive and avoid negative topics, eight participants stated that they would like the intervention to foster a warm and welcoming environment, and three participants reported the desire for fun and light-hearted conversation. Only one participant reported a preference for a more serious tone of communication in the group.

> It's just, to me, it is that we got to keep other women positive when we go into these support groups, regardless of what the circumstances are. (F-44y)

> I noticed that there were a lot of people that were dedicated to this site and they used it and they were very welcoming. I loved that. (F-57y).

Facilitation

16 (64%) participants mentioned that their interaction with facilitators impacted their use of the intervention. Specifically, twelve participants would have liked more interaction with the facilitators than they received. Also, for the facilitators to be knowledgeable about cancer (n=10), to provide encouragement (n=7), to actively connect survivors with similar backgrounds and experiences (n=6), to be flexible to the survivors' needs and topics of conversations (n=1), and to act more like a counselor (n=1). Two participants preferred a more personal style of communicating, instead of a more generic style. Lastly, one participant preferred less communication with the facilitators than they received.

> I think they were very encouraging with the e-mails. (M-40y)

> If a facilitator would've reached out to me personally, not a phone call but just like, hey this is [XX], 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. (M-44y)

General Regard for the Intervention

15 (60%) participants had positive opinions about the intervention from a general perspective. Specifically, participants reported that they appreciated the general idea of the website and that it was available to survivors (n=15) and that they were pleased that researchers were trying to develop helpful interventions for survivors (n=5).

> I believe what you are trying to create and do is a really great thing. I believe that a support group is excellent therapy (M-66y)

> I did like the set up and idea of it. I think it's great. (F-47y)

Getting Started on the Website

13 (52%) participants mentioned the importance of a thorough introduction and available guidance upon entering the intervention. Specifically, participants mentioned the necessity of having a manual that dictates what is available on the site and specific instructions of use (n=12), feeling confused about what was expected of being a participant in the intervention (n=10), needing to know the overall goal of the study (n=7), and having the facilitators initially introduce themselves and their role on the site (n=3).

> I don't know whether it was my computer or the system or what. Or me. Probably me. I guess maybe a set of directions on how to participate would be handy, one that's always there every time you go to get into it. (M-73y)

> 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. (F-57y)

The remainder of themes were identified by less than half of the sample. The themes included opinions regarding the email reminders (i.e. appreciating the site reaching out to survivors with email reminders, disliking the constant email reminders), the physical appearance of the website (i.e. making suggestions for improving the website appearance), the online questionnaires required for participation (i.e. disliking the lengthy questionnaires, appreciating the thought provoking nature of the questionnaires), the Internet as a mode of delivery of psychosocial services (i.e. liking anonymity of the site, feeling uncomfortable communicating online), study procedures (i.e. disliking the idea of a waitlist group), external incentives for participation in the group (i.e. appreciating the gift cards, preferring additional incentives), experience using the computer and Internet

(i.e. uncomfortable using the computer), general regard for the institution (i.e. trusting

Loma Linda University), and previous experience with support groups, either face-to-face

or online (i.e. having a positive or negative experience).

Themes across Randomized Status

Comparing the cluster of themes between participants randomized into the

immediate access group and to the waitlist, only the study procedures theme was

significantly different between groups, X^2 (1)= 6.18, p=.013. More waitlist participants

reported Study Procedures as a barrier of use than participants randomized into the

immediate access group. Since the theme explicitly stated the idea of disliking the

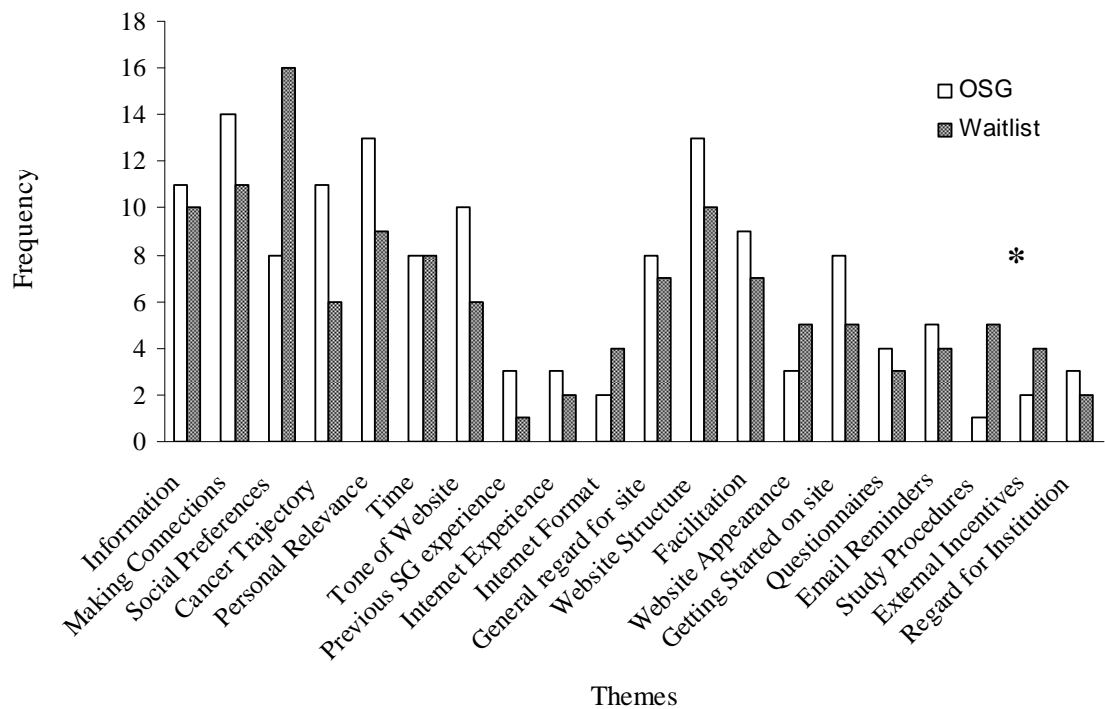waitlist group, this finding was not surprising (Figure 5).

Figure 5. Number of participants endorsing general themes by randomization status.

Intervention Components

The majority of participants liked the idea of the discussion board (60%, n=15).

In relation to the discussion board, one participant mentioned:

> That was nice. It drew you in. Well 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. (F-79y)

14 (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. (F-49y)

13 (52%) participants liked the idea of the guidance modules. In relation to the

educational modules, 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. (M-67y)

However, the majority of participants disliked the idea of the chat room (40%, n=10).

One negative opinion of the chat stated that:

> I didn't ever want to try it… I'm basically not a chat kind of person. (M-78y)

The breakdown of opinions of the intervention components are shown in Figure 6.
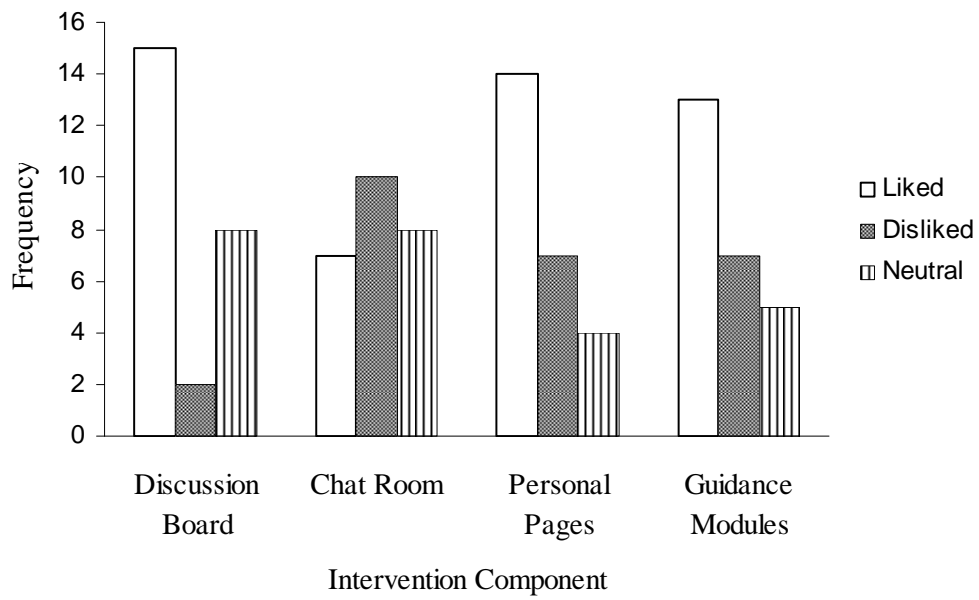
Figure 6. Number of participants who liked, disliked, or had neutral opinions regarding the intervention components.

CHAPTER FOUR

DISCUSSION

Main Findings

The qualitative study assessed the motivators and barriers of engagement in an online intervention for cancer survivors. Minimally engaged participants were interviewed in order to capture their needs and preferences for online support that have been otherwise unknown. The overarching theme that emerged was the desire to make connections with other survivors. Within the general theme, many subthemes emerged, including the desire to share with other survivors and hear their experiences, the desire to belong to a group of survivors who share similar experiences, and the desire to help other survivors. This finding is consistent with the previous literature on the use of online support groups for meeting cancer survivors' social support needs (Basch et al., 2004).

Another prevalent theme related to the structure of the intervention. Participants stated that they desired an intervention that was easy to use, easy to navigate, and organized. Regardless of the participants' specific needs and preferences, a website that is not intuitive or straightforward would pose a large barrier to engagement. This theme has important implications for website developers. Creating a user-friendly website requires time and resources that may be unavailable to researchers. However, it is necessary to create interventions that are organized and easy to use.

The personal relevance of the intervention to the survivor was also a common theme. Various subthemes emerged, but participants most commonly reported that the intervention was not a match, that participants were unable to relate to other participants in the group, and that participants did not have a current need for the site. Individual

preferences appear to play a large role, which underscores the importance of tailoring

aspects of interventions to match the participants' needs and expectations. An online

questionnaire could assess the individuals' informational and social preferences. Another

possibility is to organize the intervention into different sections. For example,

informational resources could be separated into the identified domains, including

medical, social, emotional, and financial information. It would also be possible to

separate group members by cancer type or trajectory, so an individual could chose which

individuals they would like to interact with. However, it may not be plausible to address

each need endorsed by participants.

In terms of information and resources, participants mentioned the importance of

updated, credible information related to various domains, including nutrition, exercise,

finances, emotional functioning, social functioning, and treatments. The importance of

information acquisition has been consistently shown in the literature of how cancer

survivors use the internet for support. Meier et al., (2007) found that informational

support was the most common topic across 10 Internet resources for cancer survivors. It

is important for developers to be able to tailor information and resources to the specific

needs of the participants.

A participants' cancer trajectory also emerged as an important barrier to use of the

intervention. Specifically, participants preferred interacting with other survivors who

either shared the same cancer type, severity, stage, or phase of treatment. The idea of

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. It might be useful for online support groups to be

comprised of participants with the same cancer type or trajectory. Other identified themes included the frequency of email reminders, the physical appearance of the website, the lengthy online questionnaires required for participation, the Internet as a delivery method of psychological services, dislike for the waitlist, the appeal of external incentives for participating, a lack of experience using the computer, general positive regard for the institution, and having positive or negative experiences with support groups. Taken together, the emergent themes reflected individual factors, social factors, and factors related to the structure of the intervention.

There were no significant differences in the clustering of themes between participants randomized into the support group and participants randomized into the waitlist group besides the study procedures theme that included the idea of disliking the waitlist. In fact, the most commonly endorsed themes were reported by participants from both groups. It is also interesting that randomized status was not a significant predictor of engagement in the intervention. Past literature has found waitlist participants to engage less in interventions after receiving access, but perhaps the presence of a waitlist group is not a significant barrier of use.

In regards to the specific intervention components of the current intervention, the majority of participants reported a general positive regard for the discussion board, personal pages, and guidance exercises. However, the majority of participants 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. The chat room most

closely resembles the face-to-face support group format that has been shown to be helpful

for cancer survivors, it is imperative to assist participants in becoming more comfortable

with the chat feature. Since participants did not have much exposure to the intervention,

they often were unsure of the specific components. The moderator would explain the

general description of the component and the participant would answer the questions

solely of the idea of the component, without any personal experience with it.

Limitations

The interpretation of the current study should be taken with some precaution. The

overall sample of participants who have joined the intervention were not representative of

the larger population of cancer survivors. The current sample 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. The

researcher also attempted to gather diversity in the sample by attempting to contact each

eligible participant. Another limitation is the relatively low response rate of participants

who elected to participate in the study (24.7%). There are also limitations regarding the

obtained themes and sub-themes. Participant themes tended to reflect more general

recommendations of Internet-based interventions (e.g. connecting with survivors), instead

of specific motivators and barriers of the Health-space intervention (e.g. more group

interaction). It was also difficult to determine the directionality of various themes. Some

themes had a clear direction (e.g. dislike communicating online), while others were more

difficult to discern (e.g. having various types of information). In the latter example of

having various types of information, it was unclear whether participants were generally

reporting types of information that they would like to see in these interventions, whether

these types of information were found in the specific intervention, or whether these types

of information were lacking from the specific intervention. Interviewed participants used

the health-space intervention for a brief duration and it is possible that instead of

remembering specific feedback about the intervention (i.e. motivators and barriers to

Health-space.net), they were only able to provide general recommendations for this type

of intervention. Lastly, it is possible that some themes were missed regardless of the

redundancy of codes or that current themes were not generalizable to other survivors,

especially since only the minimally engaged participants were interviewed. Additional

research is needed to replicate the following themes with a larger and more diverse group

of cancer survivors.

Clinical Implications

The findings of the current study have important implications for researchers

developing Internet-based interventions for cancer survivors. It is a necessary initial step

to assess the support needs of survivors. Qualitative studies are an extremely effective

method for determining what is important to survivors. Assessing the low engagement

group in the current study yielded 20 diverse themes of motivators and barriers to

participation. It is currently unclear if the other engagement groups would have endorsed

similar or different needs. Researchers should interview participants with varying levels

of engagement in order to assess for the presence of unique needs. Once the needs of

survivors have been understood, interventions could aim to tailor the website based on

key variables. 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.

Conclusion

The current study employed a qualitative inquiry to determine the motivators and barriers of engagement in an online intervention for cancer survivors. The findings suggest that cancer survivors, specifically the minimally engaged, have diverse needs when it comes to online support. Generally, survivors' needs included the desire to connect with similar others, based on individual characteristics or similarities in the cancer experience, finding diverse information and resources, feeling like the intervention is personally relevant, and finding the intervention easy to use. It would be useful to tailor these interventions to more appropriately fit the needs of survivors. By more effectively meeting survivors' needs, Internet-based interventions could appeal to more cancer survivors, expanding their reach and outcome.

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SEMI-STRUCTURED INTERVIEW QUESTIONS

Semi-structured interview questions of motivators and barriers to engagement based on behavioral concepts such as value, expectation, and intentions.

Interview Date: _____   **Subject:** _____

Values (Biographical)
1. What is important to you in a website for cancer survivors?
   Follow-up:
   o What would the perfect website look like for you?

Expectations (Biographical)
2. Why did you get involved in the health-space website?
   Follow-up:
   o What motivated you to join?
   o What are some things you think might motivate other cancer survivors
     to join?

3. What were you expecting the health-space website to be like?
   Follow-up:
   o Did health-space meet your expectations?
   o What could we have done to meet your expectations?

4. For waitlist participants: It looks like you had to wait 12 weeks to join health-space after you enrolled. What could we have done to make your transition into the group easier?

Intentions and Behavioral Control
5. It looks like you used health-space (insert time). What did you like about health-space after you enrolled? What were some barriers to using health-space after you enrolled? (Biographical)
   Follow-up:
   o How much would you have liked to use health-space per week?
   o What would have helped you to use health-space more?

Intervention
6. What was your experience with the different components of health-space (like discussion board, guidance exercises, personal pages, blogs, and chats? (Organizational)
  a. What did you think of the Discussion Board?
    Follow-up:
    o What did you like about it?
    o What did you dislike about it?

o What were the barriers that kept you from using it?
o What would make you use it more?

b. What did you think of the Chat?
    Follow-up:
o What did you like about it?
o What did you dislike about it?
o What were the barriers that kept you from using it?
o What would make you use it more?

c. What did you think of the Personal Pages?
    Follow-up:
o What did you like about it?
o What did you dislike about it?
o What were the barriers that kept you from using it?
o What would make you use it more?

d. What did you think of the Guidance Exercises?
    Follow-up:
o What did you like about it?
o What did you dislike about it?
o What were the barriers that kept you from using it?
o What would make you use it more?

7. What was your experience with the facilitators? (Interactional)
    Follow-up:
o What did you like about your interactions with facilitators?
o What didn't you like about your interactions with facilitators?
o What did the facilitators do (or not do) that prevented you from using health-space more?
o What do you think about the importance of facilitators?
o What could the facilitators have done to encourage you to use the health-space website more?
o How much interaction with the facilitators would you have liked?

8. What was your experience with the group members? (Interactional)
    Follow-up:
o What kind of interaction were you looking for?
o How much interaction were you looking for?
o What would have made you interact more with other group members?
o Can you give me an example of a positive experience you had with group members?
o Can you give me an example of a negative experience you had with group members?

9. Have you tried using the alumni group since you finished the 12 weeks of the health-space study?
> Follow-up:
> o   Would you find that useful?

10. Can you tell me anything else that would have helped you to use health-space more? Can you tell me anything else about health-space that prevented you from using it more?

> General probes: Anything else?
> Can you give me an example?
> Can you describe that a little more?
> Tell me more about that.
> What do you like about (insert)?
> What don't you like about (insert)?

Note: Types of intervention questions based on Strauss & Corbin (1990) are in parentheses.

APPENDIX B

CODE BOOK

INFORMATION EXCHANGE

I. INFORMATIONAL RESOURCES FROM AN OUTSIDE SOURCE (NOT SURVIVORS)
    a. Lifestyle (diet, recipes, exercise, info and suggestions for how to move on from cancer, how to get my lifestyle back)
    b. Emotional/Psychological (e.g., coping skills)
    c. Financial
    d. Spiritual (faith, wellness)
    e. Social (testimonials, survivor stories, information for family members, etc.)
    f. Medical information or medical expertise (ask an expert)
    g. New/updated information and research
    h. Credible and clear information
    i. General cancer information (links, available support groups, frequently asked questions, etc.) and resources

SOCIAL INTERACTION

II. MAKING CONNECTIONS
    a. Connecting with other survivors outside of friends and family; hearing others experiences; sharing; talking with others
    b. Sense of community, belonging to a group; not feeling alone; finding others who feel the same way; connecting with similar others
    c. Wanting to help others
    d. Wanting group to be more responsive and to respond more quickly; more interaction in the group

III. PREFERENCES FOR SOCIAL INTERACTION
    a. Not very open, introverted, or don't like talking about self; self-conscious; Not wanting to disclose personal information about themselves
    b. Uncomfortable jumping in; fear of interrupting what's already happening in the group;
    c. Not wanting to use/not as interested in the social components of the website; more interested in reading or getting information;
    d. Liked being able to share as much or as little as I liked; liked being able to lurk
    e. Want more personal information about others and their experience; extroverted

PERSONAL

IV. CANCER TRAJECTORY (PEOPLE IN THE GROUP LIKE ME)
   a. Cancer type
   b. Cancer stage
   c. Phase of treatment/trajectory (i.e., in treatment, survivorship, remission, etc.)
   d. Cancer severity/impact (i.e. recurrence rate, prognosis)

V. PERSONAL RELEVANCE
   a. Mood influences use of the website (e.g., I may not log-on if I'm not in the mood that day)
   b. Topics or postings are relevant and/or interesting to me
   c. Having a current need for site
   d. Whether this would be helpful to me; not what I was looking for; seeing benefit; nothing there for me; not a fit; did not feel a connection; could not relate to others in the group; there was a disconnect; didn't identify with anyone; didn't feel a strong connection with someone
   e. Didn't have any current need for the site; have gotten past my issues or worked through it already; have plenty of existing support; having no concern or problems with cancer or not feeling like cancer is part of one's current life; not feeling like you have cancer; wanting to distance self from cancer or move on; not wanting to be a part of it
   f. Didn't give it a shot; didn't take the time to give it a try
   g. I want it use it how I want to use it; don't want to commit or feel pressured to participate
   h. Bad time in my life to participate; feeling overwhelmed by a loss; other issues going on; not a high priority for me; other important issues besides cancer
   i. Not feeling like I can contribute to the conversation; not able to share anything relevant; not able to help anyone in the group

VI. TIME CONSIDERATIONS
   a. Not wanting to spend any more time on the computer than they already do
   b. Being busy
   c. Needing more chat times; I would have gone to the chat, but it was at a time I couldn't do

VII. TONE OF COMMUNICATION ON THE WEBSITE
   a. Wanting tone of communication to be focused on remaining positive, uplifting or encouraging comments, not wanting to focus on the negative
   b. Fun/humor/light-hearted
   c. More depth/seriousness to conversation
   d. Warmth/friendly/kind/humane/caring/gentle/welcoming

VIII.   PREVIOUS EXPERIENCE WITH SUPPORT GROUPS
     a. Disliked previous experience in a support group or online support group
     b. Liked previous experience in a support group or online support group
     c. No previous experience doing this type of thing; a bit nervous because I have no previous experience

IX. INTERNET/COMPUTER EXPERIENCE
     a. Dislike being on the computer
     b. Not very comfortable using the computer

X. INTERNET FORMAT
     a. Dislike communicating online (don't like interacting with strangers)
     b. Liked privacy/anonymity/not having to travel

<div align="center">INTERVENTION SPECIFIC</div>

XI. GENERAL REGARD FOR WEBSITE
     a. Liked the idea of having a website like this or knowing it was available; nice to be able to reach out to a group
     b. Liked that someone is trying to help

XII.   STRUCTURE OF WEBSITE
     a. General characteristics desirable in a website (e.g., ease of use, straightforward to use, easy to navigate, good design, simple, intuitive, approachable, accessible, professional feel, inviting etc.)
     b. Being able to quickly find relevant information; Links that are easy and direct (e.g., from email reminder messages, links that go directly to the topic); links and buttons did not work
     c. Label posts with themes so you know what it is and who it's from (e.g., tags or keywords)
     d. Providing summaries of topics (e.g., newsletters)
     e. Dividing into categories/threads (topic, medication, treatment, cancer stage, cancer type, problems, gender); group is too broad in scope; needs more organization; needs more structure
     f. Make the website more personalized or tailored
     g. Difficulty remembering web address, password; issues logging in

XIII.   FACILITATION
     a. Facilitators show care and respect, provide encouragement
     b. Facilitator was flexible enough to accommodate needs of the group
     c. Facilitators are knowledgeable about cancer, experts, or have personal experience with cancer; able to provide information
     d. Too much contact with facilitators (e.g., pushy)
     e. Not enough contact with facilitators or facilitators could make more personal contact with me, be more hands on (e.g., messages or phone calls)

f. Facilitator should act more like a counselor
g. Facilitators should be more active in making connections between members
h. Impersonal style of communicating

XIV.   APPEARANCE OF WEBSITE
a. Liked the appearance of the website
b. General or specific concerns about the appearance of the website (e.g., recommendations for color, use of additional pictures, etc.)

XV.   GETTING STARTED ON THE WEBSITE
a. Upon entering group, facilitators need to explain their role on the website; who they are
b. Needing to know the overall point or goal of the website
c. Confusing at beginning about what was expected or what I need to do next (responsibilities of being a member on the site)
d. Needing more and clear information about what is available on the website and how to use it; having a manual

XVI.   QUESTIONNAIRES
a. Too long, too many questions, takes too much time, boring, repetitive questions
b. Would like to receive feedback from questionnaires; thought like I was just providing information for study
c. Liked questionnaires; questionnaires were thought-provoking
d. Make questionnaires less general; more specific; be able to comment

XVII.   EMAIL REMINDERS
a. Too many reminders/ want more control over notifications
b. Liked having reminders/having a site reach out to me and not having to remember/ liked having instant reminder of username & password/have more reminders since they are helpful
c. Feeling guilt or embarrassment about not being more involved after receiving an email reminder

XVIII. STUDY PROCEDURES
a. Paranoia related to being in a study
b. Confusion about nature of the wait-list group
c. Dislike of being in the wait-list group
d. Didn't like that it was time-limited, 12 weeks; not enough time in group

XIX.   EXTERNAL INCENTIVES
a. Liked gift cards, feeling cared about and appreciated for time put into the study
b. Wanting more incentive

XX.	GENERAL REGARD FOR INSTITUTION/LLU
- a. Positive (medical or religious aspects)
- b. Negative (medical or religious)