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### Use of an Enhanced Engagement Approach to Increase Engagement in an Online Support Group

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LOMA LINDA UNIVERSITY  
School of Behavioral Health  
in conjunction with the  
Faculty of Graduate Studies

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Use of an Enhanced Engagement Approach to Increase Engagement in  
an Online Support Group

by

Ketlyne Sol

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

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September 2015

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

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## ABBREVIATIONS

EI	Engagement Intervention
TAU	Treatment as Usual
OSG	Online Support Group
CES-D	Center for Epidemiological Studies-Depression Scale (depression)
FACT Total	Functional Assessment of Cancer Therapy Total (quality of life)
IOES Total	Impact of Events Scale-Revised Total (anxiety)
POMS TMD	Profile of Mood States-Total Mood Disturbance (mood disturbance)
QWB	Quality of Well-Being Scale of the EuroQoL-5D (overall health)
SS	Social Support Index (social support)

## ABSTRACT OF THE DISSERTATION

Use of an Enhanced Engagement Approach to Increase Engagement in  
an Online Support Group

by

Ketlyne Sol

Doctor of Philosophy, Graduate Program in Clinical Psychology  
Loma Linda University, September 2015  
Dr. Jason E. Owen, Chairperson

Online support groups (OSGs) are potentially useful resources for individuals with chronic health problems who often face challenges in receiving desired support from similar others. Barriers such as limited mobility, time, distance, and desire for anonymity limit access to this support in traditional face-to-face groups. However, engagement in OSGs are well documented to have low user activity, despite the barriers they help to overcome. Several reasons for this low engagement are discussed. Study into engagement is limited by the fact that there are many different ways of measuring engagement, which are not consistent across studies. Furthermore, interventions to specifically improve engagement are limited and varied.

Breast cancer is a chronic, potentially fatal, health problem that is the most frequently reported cancer among women. Because of the distress experienced by many women with breast cancer, several OSGs exist to help meet the support needs of people with breast cancer. Although participants report experiencing improvements in psychosocial outcomes, these OSGs also suffer from low engagement. This randomized control longitudinal study seeks to improve engagement by increasing contact and utilizing different methods of contacting participants (e.g., postal mail, email, and phone call) to help improve engagement in a small sample of breast cancer survivors in an OSG.

Various methods for measuring engagement are also utilized. Results indicate that the intervention was successful in improving engagement in the intervention group. However, the intervention did not decrease the amount of time to engage in the website. Furthermore, although there was a significant improvement in psychosocial outcomes in both groups over time, the intervention did not result in significantly more improvements on these measures. Limitations and directions for future study are also discussed.

# CHAPTER ONE

## INTRODUCTION

Engagement in online support groups (OSGs) is a well-documented problem (Donkin, Christensen, Naismith, Neal, Hickie, & Glozier, 2011; Eyesenbach, 2005). Given the potential isolation- and distress-reducing benefits of OSGs to users with chronic health problems, like cancer, further study into the improvement of OSGs is important. Various factors affect engagement in OSGs, however, lack of consistency in measuring engagement across studies limits our understanding of the extent of the problem. Furthermore, there are limited studies on interventions that test multiple ways to increase engagement in order to better generalize these interventions for replication. Continued study into the factors affecting engagement as well as more consistent use of engagement measures will help to improve OSG engagement.

The salutatory effects of social support on physical health are well-documented. (Penley, Tomaka, & Wiebe, 2002). Studies have also reported that both giving and receiving social support can positively affect mental health (Pfeiffer, Heisler, Piette, Rogers, & Valenstein, 2011). When individuals have a chronic illness, they may experience specific stigmas associated with their condition, disability, disfigurement, or other psychosocial sequelae that members of their primary support network may have difficulty understanding (Davison, Pennebaker, & Dickerson, 2000). Having cancer is no exception to this and there are many psychological consequences of cancer that are extremely common in survivors. As such, cancer survivors stand to benefit from adequate social support to help them in their adjustment to cancer, and many studies have documented the positive effects of social support for those living with cancer.

Cancer diagnosis, treatment, and survivorship is often a challenging experience contributing to problems with anxiety, depression, fear of recurrence, poor quality of life, and other symptom complaints such as fatigue, pain, and cognitive difficulties (Gottlieb & Wachala, 2007; Hewitt, Herdman, & Holland, 2004). Furthermore, having cancer often is often a stigmatizing and isolating experience that contributes to additional distress experienced by survivors (Cho et al., 2013; Leung, Pachana, McLaughlin, 2014; Roland, Rodriguez, Patterson, & Trivers, 2013). These aspects of the experience of cancer as well as additional psychosocial aspects of diagnosis and treatment contribute to the overall burden of distress experienced by many cancer survivors. As a result, cancer survivors are more likely to use mental health services than those without a history of cancer or even those with other chronic health issues (Hewitt & Rowland, 2002).

There are several well-established psychological interventions for these psychological sequelae of cancer. One of these interventions is group counseling whereby a professional facilitates discussion between individuals experiencing some distress. Support groups (often used interchangeably with the term ‘group counseling’ in the literature) are helpful because individuals facing chronic illness often find their need for mutual understanding met in talking with others with similar conditions (Davison, Pennebaker, & Dickerson, 2000; Hoey, Ieropoli, White, & Jefford, 2008). Support groups can be found for various conditions including depression (Bright, Baker, & Neimeyer, 1999), multiple specific types of cancer (e.g., breast cancer, Setoyama, Yamazaki, Nakayama, 2011; lung cancer, Xu et al., 2014; colon cancer, Campbell et al., 2001), chronic pain (van Uden-Kraan, Drossaert, Taal, Smit, Moens, & Van de Laar, 2011), and neurological disorders such as Parkinson’s disease (Lieberman, 2008).

Studies on support groups have also indicated their effectiveness in alleviating some of the distress symptoms often experienced by cancer survivors. For example, a meta-analysis of the effects of peer-directed support group participation for depression found significant reductions in depressive symptoms, with effect sizes comparable to those of professionally-led group cognitive behavioral therapy and more effective than treatment as usual (Pfeiffer, Heisler, Piette, Rogers, & Valenstein, 2011). Additionally, Hewitt, Herdman, and Holland (2004) reviewed various studies reporting that cancer survivors benefit from engaging in group therapy, with findings supporting a variety of improvements including mood, coping, trauma symptoms, and quality of life (Hewitt, Herdman, & Holland, 2004).

### **Utilization of and Barriers to Support Group Attendance**

While beneficial, some of the psychosocial resources provided to aid patients in their adjustment are not well-utilized. A population survey study conducted by Hewitt & Rowland (2002) found that cancer survivors were still more likely to report using mental health services compared to healthy individuals and those with other chronic health conditions in the general population. Yet, Hewitt and Rowland's study also found that among these three categories of patients, cancer patients reported having the greatest unmet needs for mental health services. This may be due, in part to the different factors that contribute to overall distress in cancer survivors. These include trait anxiety (Ando, Iwamitsu, Kuranami, Okazaki, Nakatani, Yamamoto, Watanabe, and Miyaoka, 2011) as well as state anxiety and depression (Goebel, Stark, Kaup, von Harscher, and Mehdorn, 2011). So while the relatively greater use of psychosocial resources by cancer survivors

may indicate a larger level of distress that leads them to seek these support groups among other psychosocial resources, significant barriers continue to limit these patients' use of these resources. There are various reasons for this.

A study conducted by Eakin & Strycker (2001) of the resources of an HMO for cancer patients found that while 68% of their patients reported being aware of the HMO's Cancer Counseling Center (which provided both individual and group counseling), only 9% of patients reported using the Counseling Center. Furthermore, while 33% of patients were aware of community-based cancer support groups, only 7% ever used them. The authors examined patients' reasons for not using the support resources available to them and the majority (32%) reported that they already had the support that they needed, while 11% reported that the location or time of meetings was inconvenient, another 4% reported that they did not have transportation, and 1% were too sick to use these resources.

Other reasons for low support group use by cancer survivors have been examined (Ieropoli, White, Jefford, & Akkerman, 2011). In this paper, the authors addressed physical barriers to support group attendance through a qualitative study of 53 colorectal cancer survivors examining peer support delivery preferences (between face-to-face and telephone support groups). They found that 55% of participants reported that feeling sick was a barrier to attending face-to-face support group meetings, while another 33% reported that travel complications were a barrier to attendance.

A report by the Institute of Medicine (Hewitt, Herdman, & Holland, 2004) addressed a variety of other factors that may contribute to low support group use. At the patient level, the report stated that a majority of women did not utilize support groups



because they did not feel that they needed them (Hewitt, Herdman, & Holland, 2004). These patients reported that that the support resources that they had available such as their own coping skills as well as the support of family and friends were enough for them. Other patient-level factors included lack of health insurance, which affects one's access to these services due to cost. Some patients reported that they were not aware of the availability of support services. The authors also suggested that other patients may have rejected support group use due to additional stigma by the general public about mental health service use. At the institution level, the report identified poor screening of patients in distress that prevents them from receiving the care they need to address their distress. Furthermore, according to the report, oncologists and surgeons did not regularly refer patients to these services. These physicians were also often unaware of community-based resources to which they may refer patients. Inadequate coordination among providers to ensure that patients' distress was being adequately addressed served as another barrier indicated in the report. Additional institution-level factors identified by the report included inadequate amounts of professional therapists to treat patients also contributed to patients' not receiving adequate psychosocial care, as well as decreased funding for psychosocial resources has been another factor that contributed to the lack of services offered by institutions.

By offering other modalities for delivering empirically-supported psychosocial services, we have the potential to enhance our ability to meet the unmet psychosocial needs of patients with chronic health issues, by reaching those who would otherwise be unable to access such care. Online support groups are one of these modalities that may help meet the psychosocial needs of patients.

## **Online Support Groups' Utility in Overcoming Barriers to Psychosocial Treatment**

Patients with chronic illnesses have begun to make use of online support groups (OSGs) as reports have suggested that the benefits of using OSGs are comparable to those of face-to-face groups (Lewandowski, Rosenberg, Parks, & Siegel, 2011). In OSGs, patients make contact with similar others to share their experiences with their illness (Rains & Young, 2009) and are able to do so without the need to travel to a specific location at a specific time. An additional benefit to using OSGs among those with chronic illnesses is that of anonymity, which allows patients to speak more openly about their experience with similar others (Wiljer, Urowitz, Barbera, Chivers, Quartey, Ferguson, To, & Classen, 2011; Malik & Coulson, 2008). In a study by Malik & Coulson (2008) on the OSG experiences of individuals struggling with infertility, participants indicated that other benefits of the OSG included it being available 24 hours a day, allowing members to post at any time (asynchronously), and permitting members the time to reflect more thoroughly on their responses before posting. Similarly, a systematic review by Griffiths, Lindenmeyer, Powell, Lowe, and Thorogood (2006) found that many participants listed having 24-hour access to the group as a benefit to using internet-based groups. The Griffiths et al. (2006) review also found that users of OSGs reported benefits such as reducing embarrassment or stigma associated with their medical condition through anonymity in their participation, increased convenience in time and travel, and decreased isolation for those who live in rural areas or are limited by disability in their ability to attend face-to-face groups. Other benefits of internet-based interventions listed in this review included decreased cost to obtain services such as group therapy and self-

tailoring of information they received by looking for specific information. Furthermore, in a study by Owen, Boxley, Goldstein, Lee, Breen, and Rowland (2010), individuals with chronic health conditions reported that they were more likely to have used an OSG than healthy individuals. Thus, epidemiological data lends some support to chronically ill individuals preferring OSGs because of barriers that these individuals may overcome to receive peer support by engaging in OSGs.

In a study comparing current users of internet-based therapy and face-to-face therapy on their attitudes towards receiving therapy online, participants were asked five questions about their use of computers to receive therapy, their ability to pick a convenient time for therapy, their ability to concentrate on therapy, and advantages they perceived in being anonymous and invisible (Skinner & Latchford, 2006). Participants in both groups reported that they were willing to seek internet-based therapy due to time convenience, being able to stay anonymous, not being physically observed/seen by their therapist, and being able to concentrate on therapy. Overall, these findings indicate that OSGs may have more appeal for individuals suffering with chronic illnesses and diseases due to convenience and ability to remain anonymous if they choose.

### **Engagement in Online Support Groups**

The mode of delivery of OSGs allows for easier collection of data than is available for face-to-face groups. This is because objective information on participant interactions is readily collected through computer systems (e.g., time spent using the intervention and the content of text-based exchanges). This information has revealed that OSG engagement is actually very low (Eysenbach, 2005). This indicates that despite

benefits in overcoming barriers to face-to-face treatment, usage of support services is still low in individuals facing chronic disease. Similar to other health interventions, exposure to treatment is critical to improving health outcomes. When isolated and distressed individuals do not utilize (e.g., engage in) the OSGs that are provided to help meet their support needs, they limit their exposure to the informational and emotional support that they were likely seeking, potentially complicating their health outcomes.

A better understanding of distressed individuals' activity in and thoughts towards OSGs may help in improving OSG engagement. In a review Preece, Nonnecke, and Andrews (2004) reported that the percentage of those who do not post in an OSG has ranged between 45 and 90% of participants, depending on the type of group (e.g., health-related, computer software-related), with 45% of non-posters being those in health-related OSGs. According to the authors, some of these non-posters have come to be known as "lurkers" (with frequent posters being called "posters"), meaning that while these participants may log in to an OSG they do not ever, or rarely, post to these websites. Instead, they often opt to read what others have posted, if they ever do log in.

In their study, Preece, Nonnecke, and Andrews (2004) sampled from MSN.com open access community forums that included those pertaining to health/wellness, government, sports/recreation, and organizations (not specified by authors), and solicited the participation of lurkers who had never posted on a community forum (Andrews, Nonnecke, & Preece, 2003; Preece, Nonnecke, & Andrews, 2004). Preece, Nonnecke, and Andrews (2004) found that over 87% of lurkers did not feel a need to post because reading was enough, the lurker did not think there was a requirement to post, or the lurker had no intention of posting from the outset. Another 29% of lurkers reported that they

had not posted because they were still getting to know the group, while another 44% reported that shyness or wanting to remain anonymous was a reason for not posting. Forty percent of lurkers felt that others had already posted on something they would have or they had nothing else to say. An additional 19% reported having difficulty with the software, not having enough time, or being overwhelmed by the amount of messages. Other responses appeared to deal more specifically with group dynamics and fit, with over 41% reporting that the forum was not valuable to them, they did not like the low quality of the messages, it was the wrong forum, there were long delays before receiving a response, concerns about aggressive people, fear of commitment, and seeing new members treated poorly. However, when comparing between posters and lurkers, the authors found that both posters and lurkers reported joining for information and support needs. Not surprisingly, significantly more posters than lurkers reported receiving more benefit from their online communities, felt their needs were better met, and perceived a greater sense of membership in their online communities.

Another study compared posters and lurkers in OSGs for breast cancer survivors on five variables: emotional support, emotional expression, informational support, conflict, and insight (Setoyama, Yamazaki, and Namayama, 2011). Among those who posted, higher levels of receiving emotional support and higher levels of receiving informational support were both significantly correlated with lower levels of anxiety. Moreover, a study by van Uden-Kraan, Drossaert, Taal, Seydel, and van de Laar (2008) on OSGs for individuals with breast cancer, arthritis, and fibromyalgia found that lurkers reported significantly more dissatisfaction with their OSGs than did posters. The study also found that lurkers reported feeling less socially-connected as well. While lurkers in

both studies received some of the same benefits that posters did in simply reading posts, they may continue to have difficulty perceiving a sense of community with the members of their OSGs due to their remaining silence in the group. This may compound any sense of isolation that low-engagers may have already been experiencing. Furthermore, they may be limiting themselves from receiving more benefits from their OSGs in remaining silent. It is important that engagement interventions continue to address these individuals to help improve their interactions with peers in OSGs.

However, how readily individuals can join a group may affect their level of activity in the group. For example, a study by Rada (2007) studied group activity of Yahoo! groups in the Illness category. The author categorized the groups as ‘Open,’ where group activity was viewable to anyone on the internet, ‘Register’ where interested parties had to complete a basic Yahoo groups registration to join the group to view group content, and ‘Closed’ which required registration as well as other criteria before group membership would be granted. Contents of the ‘Closed’ group were only viewable to those members who met group entry requirements. Results indicated that the closed group had significantly more postings than the ‘Register’ and ‘Open.’ The ‘Register’ groups had more postings than ‘Open’ groups. These results suggest that more stringent selection processes for group entry may encourage more active participation from group members. A closed group may minimize the presence of lurkers in groups and result simply in non-users and active users of the OSG. This closed group dynamic may have been in place in Health-space.net (the OSG that is the focus of the study for this paper), which is a closed group. Participants were required to report a clinically meaningful level

of distress and complete several baseline questionnaires before being granted entry to the group. Activity of group members tended to reflect non-use and active use.

### **Qualitative Research to Improve OSG Engagement**

Qualitative research has suggested some strategies for improving online interventions. From a user-perspective, a focus group study was conducted with individuals with chronic health conditions and their caregivers (Kerr, Murray, Stevenson, Gore, & Nazareth, 2006). The study surveyed participants regarding their opinions on how online interventions for these populations may be better designed. Results indicated that these users valued both expert and peer forums whereby a trained professional would be available to answer specific questions related to the disease. Participants similarly valued the opportunity to connect with peers who have experienced the disease and could also share their personal experiences of living with a chronic illness. The users in this study also valued information that was carefully tailored to them as an individual. Because their needs are likely to evolve as they go through the program, this type of individual tailoring may be more effective in improving OSG engagement. Similarly, a study by Brouwer, Oenema, Crutzen, de Nooijer, de Vries, and Brug (2008) anonymously surveyed experts in internet-based interventions on their perspectives of how to improve user engagement with an online intervention. Their results indicated that many of the individuals in the study ranked information tailoring and reminders to return to the website as important factors to help improve engagement. They also listed having the website provide information that the user perceives to be useful to him or her as another factor that can help improve user engagement with the website. Although the

study did not specify how that information could be seen as useful, it is likely that basic psycho-education modules, as well as both expert and peer forums will help the individual receive the information he or she perceives to be personally useful. With forums, especially, users will be better able to meet not only their informational but also their support needs.

### **Interactive Elements to Improve OSG Engagement**

As mentioned before, interactive elements of online interventions are thought to be particularly relevant to improving engagement with these kinds of interventions. These include features that allow participants to communicate directly with each other through synchronous and asynchronous forums such as chat rooms and discussion boards, respectively. For example, the Danaher, Boles, Akers, Gordon, and Severson (2006) website offered a peer web forum in the enhanced condition of their intervention, whereby participants who were randomized into the enhanced condition could communicate in an asynchronous fashion. Results indicated that increased use of the peer forum was positively correlated with number of visits to the website and total time spent on the website viewing web pages. Furthermore, a review by Brouwer, Kroeze, Crutzen, de Nooijer, de Vries, Brug, and Oenema (2011) which combined chat room—a synchronous, “live” way of communicating online—and discussion board use into one category they named “peer support” found that, overall, peer support was associated with more time spent on the study website. This review, as well as several others (Bennett & Glasgow, 2009; Fry and Neff, 2009) provided support for promoting participants’ use of



some of the support resources in an OSG in order to help improve their engagement in the OSG over a longer period of time.

Because the medium of communication for OSGs often requires that individuals express themselves in writing, participants may be conferred additional benefits from writing out their thoughts. According to Pennebaker (1997), writing about emotions has positive effects on well-being because the disinhibition involved in writing allows individuals to better explore their emotions and distress and write with more insight. A study by Kim, Han, Moon, Shaw, Shah, McTavish, and Gustafson (2012), which looked specifically at the benefits of written support among breast cancer patients in an OSG, found that receiving more emotional support was associated with having fewer breast cancer concerns after the intervention compared to before the intervention. Those who gave more emotional support also engaged in higher levels of positive reframing. However, OSG participants receiving benefits from writing out their thoughts received minimal support in another study by Lieberman and Goldstein (2006) examining the discussion board posts of breast cancer patients. In the study, the authors recruited individuals who were active in OSGs to complete psychosocial questionnaires on outcomes, and analyzed posts they had already made. The authors found that writing about negative emotions in general had positive effects on depression and quality of life six months after completing the first set of questionnaires. However, when examining specific emotions (anger, sadness, fear, anxiety) they did not find any significant correlations with depression and quality of life. Furthermore, correlations between the types of negative emotions with depression and quality of life were not consistently in the same direction. This indicates that while writing may be helpful to a

certain extent, patients may have added benefit when they are interacting with peers with their writing. This speaks further to the importance of improving engagement in OSGs because with more active participants, patients have increased opportunity to interact with similar others to meet their support needs instead of being one of few posters in their OSGs.

### **Testing Specific Methods for Improving OSG Engagement**

While the former studies examined improving engagement by improving interaction among participants, others have sought to improve engagement by improving overall use of website tools. In order to better address low engagement in OSGs, health behavior change intervention websites have increasingly included various features within the interventions themselves aimed at improving engagement by encouraging increased use of the website. One of these techniques are elements within the intervention that promote specific engagement in the website as well as the target behavior of the intervention overall. One type of these elements is a behavior tracking tool, such as the one used in a study by Robroek, Lindeboom, and Burdorf (2012) on online interventions to promote healthy lifestyle changes in an employee population. The intervention incorporated self- monitoring tools that generated graphs of fruit and vegetable intake, physical activity, and weight as part of their randomized intervention condition to promote user engagement with the website. In examining engagement data for their intervention, the authors found no significant difference between the control group (which largely received psycho-educational materials) and the intervention group on website visit frequency in the first three months. The authors did find that significantly

more intervention condition participants accessed the website during the fourth through twelfth months than did those in the control condition. However, for the following thirteenth through fifteenth months during which time email prompts were sent to participants to complete one of a series of questionnaires throughout the study, control group participants accessed the website significantly more often. Thus, employing specific elements such as behavior tracking tools to promote website use did not appear to be effective in increasing user engagement with the website in this study.

The Danaher, Boles, Akers, Gordon, and Severson (2006) study was specifically designed to improve engagement in an internet-based intervention to promote chewing tobacco cessation. The randomized control group in this study received basic psycho-education about chewing cessation within the intervention website as well as links to websites with information. In the enhanced condition of their study, they used specific elements which included: asking users to list specific social supports for their quit process, testimonial videos of former quitters and videos of experts providing information for quitting, a peer forum, an ask-the-expert forum, information tailored to the participant's cessation needs, email prompts encouraging participants to set a quit date, periodic emails to support participants in meeting their cessation goals after setting a quit date, and periodic emails to encourage regular website logins for those who did not log in on a regular basis. The authors found that those in the enhanced condition visited the website more often, spent more total time on the website, and spent more total time viewing website content than did those in the basic condition. Forum postings by participants in the enhanced condition were also positively correlated with total website visits and page views. Additionally, survival analysis results (with "survival" defined as

amount of days spent on the website before ceasing use) indicated that participants in the enhanced condition had a median of 11 days spent on the website, compared to 0 days for participants in the basic condition. Enhanced condition participants also exhibited less dropout (non-usage attrition) over time than did those participants in the basic condition. The authors reported that email prompting to complete periodic assessments was related to decreased website activity. However, examination of the graph revealed that participants in the enhanced condition had a more stable decay after peaks in these assessment periods compared to basic condition participants whose curves would peak and return back to the previous rate of decay. Furthermore, as it relates to the tobacco intervention itself, the author's results indicated that 63% of enhanced condition participants set a quit date while 41% reported quitting. However, they did not provide information on how many of the basic condition participants set quit dates and indeed quit their usage of chewing tobacco. Furthermore, because the enhanced condition utilized several tools to improve engagement (e.g., email prompts, forums, videos), it is unclear which of these was most effective in improving engagement in this study.

### **Increased Moderator Contact to Promote OSG Engagement**

As demonstrated by the Danaher, Boles, Akers, Gordon, and Severson (2006) study, sending emails is one technique that can be used to help improve engagement with a website. According to Schneider, de Vries, Candel, van de Kar, and van Osch (2013) sending periodic emails is a proactive effort in reducing low engagement and attrition when it is sent to all participants from the time they have been granted access to a website. This implies that strategies to improve engagement after engagement has

declined, or to initiate contact after an extended period of time has passed since participant entry into the website, would not be recommended by the authors. Thus in this lifestyle intervention study, Schneider, de Vries, Candel, van de Kar, and van Osch (2013) attempted to prevent low engagement and attrition by focusing on sending periodic email prompts from the outset, instead of only when users' engagement had decreased. Results indicated that users who were sent an email at two weeks following access to the website were significantly more likely to log back in to the website than those who were sent the prompting email at six weeks. However, no significant difference was found in login likelihood of those participants who were sent the prompting email at four weeks and those participants who received it at two or six weeks following entry to the website. These results imply that timing of the first email to engage participants on the website is an important factor to consider when encouraging continued engagement.

Another technique that can be used to improve participant engagement is to contact the participant on the telephone. A study by Greaney, Sprunck-Harrild, Bennett, Puleo, Haines, Viswanath, and Emons (2012) examined the effect of daily, automated emails versus emails plus phone calls to increase participants' engagement in an internet-based self monitoring tool to track physical activity, meat intake, fruit and vegetable intake, and daily multivitamin intake. Participants were randomized to one of the two groups and asked to monitor a minimum of three behaviors for at least one category each week. In this study, two phone calls were made to treatment group participants in addition to receiving daily emails reminding them to log into the website to track their progress. The phone calls were to focus on providing participants with technical

assistance, such as those related to difficulties with logging on to the website and using the self monitoring tool. Their results indicated that participants in the condition receiving emails and phone calls met the minimum behavior tracking requirements for significantly more weeks than did participants in the email only condition. Furthermore, these results indicate that adding a phone call to the engagement intervention may help participants better engage with specified parts of the web-based intervention, compared to sending reminder emails alone.

### **Review of Measures of Engagement**

Evaluating the impact of these different techniques for improving engagement requires reliable measures of engagement to determine their effectiveness. However, there have been a myriad of ways in which engagement is measured, and this has not yet been fully settled in the literature. A review by Brouwer, Kroeze, Crutzen, de Nooijer, de Vries, Brug, and Onema (2011) on characteristics of internet interventions that were related to increased engagement in lifestyle change interventions found that frequency of logging in to a website was the most commonly reported measure of engagement. While this helps give some information on whether users are visiting the website and acknowledging the importance of users logging in to the website to receive the benefits of the intervention, this is still a fairly unsophisticated way of measuring engagement. Another way of measuring engagement has been the percentage of users who returned to a website (Brouwer et al., 2011). The other most frequently reported measure of engagement reviewed was average time (minutes) spent by users in visiting the website. This is a somewhat more sophisticated measure of engagement because it not only

inherently speaks to whether a user logged into the website, but it also reports on how long a user may have engaged in the website, thereby increasing his or her chances of receiving the information presented on the website. Other more sophisticated measures of engagement reported in this review include average number of pages visited and percent of participants who completed all modules in multiple visits. Still another potentially sophisticated measure of engagement reported in the review was percent of users completing modules during their first visit. However, measuring engagement in this way may lead to overly positive results on the level of engagement of a website because it does not report on long term use. Also, as previously reviewed in the discussion of no, low, and high engagers, the number of postings in a website may speak to a participant's level of engagement in a website. However, this would also require information on other measures of engagement to attempt to differentiate between these three categories of participants.

Text analysis is another way engagement may be measured. For example, word count has been used as a basic text-based measure of engagement (Joyce & Kraut, 2006; Kramer, Fussell, Setlock, 2004). Text analysis may also include more complex analysis into the content of the text for word patterns that may better reveal the individual's mood and various other psychological experiences (Pennebaker, Mehl, & Niederhoffer, 2003). Using word count and more complex text analysis procedures as measures of engagement may give more information into the individual's level of engagement than other measures, such as number of postings or time spent on website. For example, someone may make many individual posts on a website, but these could be short replies to other posts such as "I agree." On the other hand, a person may post with significantly more text

when talking about medical procedures, options for treatment, or giving other advice, but not disclose much about their own emotional experiences with cancer. Without the additional information that text-based analysis provides, such posters would likely rate highly in level of engagement. Using additional computer programs allows for these more complex text analyses (Pennebaker, Mehl, & Niederhoffer, 2003). Better understanding these patterns of word usage may also help to improve interventions to better address specific areas of participants' experience with cancer, which may also help improve interactions among participants to promote engagement.

Nonetheless, basic word count, which is arguably the simplest of text analysis options, is still a useful tool for measuring engagement. Joyce and Kraut (2006) studied return postings in a six month period by members in a variety of peer-led OSG groups, including one for open-source developers (Mozilla), support groups for baldness, weight management, and breast cancer, as well as a group for those interested in gun rights. The authors found that increased word count resulted in a significantly more likelihood of receiving a reply from members. Response rates were the lowest in the open-source group (54%) and highest in the breast cancer support group (74%), with an average of 70% among the four non-Mozilla groups. After controlling for group type and characteristics of the first post the authors found that participants who received a reply were significantly more likely to post again.

Although there is a lack of agreement among studies about the best measures of engagement, combined with a lack of strong trials to better draw conclusions, it appears that time spent on website, amount of postings, and word count may together speak to the amount and the quality of a participant's engagement in an OSG. Combined, these may



indicate how much exposure the participant may have had to the website's resources, receiving and providing support of his or her peers on the website. Nonetheless, this review of the various methods of measuring engagement indicates that consistent engagement is low in OSGs, objectively demonstrating this critical problem with OSGs.

### **Theories**

The low engagement in OSGs shows that the extrinsic motivation of a cancer diagnosis is not sufficient to help the large majority of individuals in OSGs actively engage in these communities. Theory suggests other strategies for improving online interventions to help individuals better engage in OSGs.

One of the ways in which theory is useful is to apply it to the design of behavior change interventions. At this stage, different theoretical models may help to address the individual, social, and/or societal factors that affect behavior change (as well as their underlying factors), in order to help improve the interventions' success in changing behavior (Rimer & Glanz, 2005). Furthermore, with psychological research in particular, it becomes especially important to ground research in sound theory, as many of the concepts studied in psychology are not directly observable. OSG engagement is a specific behavior whereby increases in such behavior have been associated with positive health outcomes within specific groups of individuals. Therefore, theories for health behavior change may be utilized to address OSG engagement.

The transtheoretical model of behavior change (TTM; Prochaska, DiClemente, & Norcross, 1992) is one way to address OSG engagement at the individual level. According to the TTM, when individuals engage in a problematic behavior, their

readiness to change that behavior lies on a fluid spectrum that includes not believing that the behavior is problematic, taking active steps to improve that behavior, and consistently maintaining the improved behavior. As it pertains to OSG use, if the problematic behavior were operationalized as a lack of OSG use, the TTM can be used to understand and work to correct individuals' lack of OSG engagement. Therefore, individuals who sign up for OSGs yet do not use the resources provided in the website itself and/or do not interact with other individuals on the website are likely to be in the precontemplation and contemplation stages of the TTM. Along with motivational interviewing, which is a useful complement to the TTM (Miller & Rollnick, 2002), individuals' aversions to increasing their engagement may be explored so that they may be helped to resolve their conflicts with and ambivalence about engagement to help them reach a resolution to engage in the OSG.

Social cognitive theory (SCT; Bandura, 1971; 1989) helps to address the interpersonal aspects of behavior change by taking into account how an individual's behavior affects others in their social network and how these others' behaviors affect the individual. As summarized by Rimer and Glanz (2005), five concepts contribute to SCT's utility in behavior change including reciprocal determinism, behavioral capability, expectations, self-efficacy, behavioral modeling, and reinforcements. The demographic factors of the types of individuals that are more likely to benefit from OSGs (such as distance to face-to-face groups and physical disability) are directly addressed in the provision of an OSG and thus overcoming those physical barriers to receiving support. Providing psycho-education on how to use the OSG as well as psycho-education on the skills that contribute to the positive health outcomes of increased engagement may help

to increase individuals' sense of self-efficacy to successfully utilize the resources provided in the OSG. By having distressed individuals with a wide range of skill in coping with their distress in the OSG, modeling of more healthy behavior may be demonstrated by certain individuals in the OSG to further promote peer interaction by those who are less skilled in these healthy coping techniques. Praising healthy interactions among OSG members as well as active use of other resources on the website will likely reinforce positive engagement behavior to help individuals continue to return to the website. Finally, with reciprocal determinism, members receive support from their peers through validation of their experiences and personal disclosure. Therefore, in receiving benefits from interacting with their peers and utilizing other resources on the website, individuals are more likely to return to the website and provide the support that they themselves received of their peers.

Overall, the previously mentioned theories address specific intra- and inter-individual factors that may be addressed to help improve OSG engagement. In better addressing these factors, we may help individuals return to the website, and once on the website, use it and return to it for more than just informational needs so that they may receive and provide support to their peers.

### **Overview of Study**

Based on the theory and research cited in this review, this study seeks to test a specific method for improving engagement in a randomized fashion. This would contribute to the literature on engagement interventions because very few studies have tested engagement in this way. Some of these randomized intervention studies have been

reviewed here (e.g., Danaher, Boles, Akers, Gordon, and Severson, 2006; Greaney et al., 2012; Robroek, Lindeboom, and Burdorf, 2012). Furthermore, of the studies testing engagement interventions in a randomized fashion, many pertain to lifestyle changes related to tobacco use, exercise, and fruit and vegetable intake. This study will test particular engagement interventions specifically on a sample of breast cancer survivors.

Breast cancer continues to be the most reported cancer in women (Howlader et al., 2014). Combined with the increasing cost of healthcare, people treated for breast cancer are likely to continue to face several barriers to psychosocial services. This study helped to strengthen the impact of OSGs for these women by addressing engagement in OSGs designed to meet their support needs in a cost-efficient way that also allows for flexibility in time and anonymity. This study was part of a larger study on OSG use in cancer survivors, which provided various professionally facilitated resources such as weekly psycho-education modules, a personal blog to respond to the weekly topics as well as other topics the participant chooses, a discussion board for asynchronous discussion, and a weekly synchronous chat discussion. In the larger study, levels of engagement were noted to be lower than desired, and we sought to evaluate ways to more rapidly identify those at risk for non-engagement attrition to better meet their support needs. This study sought to improve engagement by targeting users' engagement in chatting or blogging by specifically encouraging personal disclosure and mutual support in both of these website tools to help enhance social support given and received. If bidirectional interaction and disclosure between participants occurred, then a participant may be more likely to perceive a greater sense of community, as previously reviewed.

This may result in the participant returning to the website and increase engagement in other parts of the website as well, such as the discussion board and guidance modules.

After participants had been randomly assigned to either the treatment or control condition, the engagement intervention will seek to improve engagement by contacting the treatment group participants in a series of messages that includes postage mail, emails, and phone communication. All participants received contact via postage mail and an initial email. Participants may receive additional emails or a phone call if they do not post a blog or join a chat for a predetermined amount of time. This is described in more detail below in the Procedures.

### *Aims and Hypotheses*

The aims of the present study were as follows:

Aim 1: To determine whether an enhanced engagement intervention would increase engagement in an OSG for cancer survivors.

Hypothesis 1a: An enhanced engagement intervention, would increase the level of engagement in an OSG such that intervention group participants would post more blogs, post more discussion board comments, and join more weekly chats compared to those who receive no additional contact. Furthermore, the amount of words typed into blogs, the discussion board, and chats, as well as total time (in minutes) spent in weekly chats, in the psycho-educational modules, and on the website overall, would be higher in the enhanced engagement intervention.

Hypothesis 1b: Contacting enhanced engagement participants within the first two weeks of joining the OSG, would decrease the amount of time that passes before they make their first posting to the chat or the blog in the OSG.

Aim 2: To explore whether an enhanced engagement intervention resulted in improved psychosocial outcomes.

Hypothesis 2: Participants in the enhanced engagement intervention group would report significantly more improvements in depression, anxiety, distress, quality of life, overall health, mood disturbance, and social support.

## **CHAPTER TWO**

### **METHOD**

#### **Participants**

The participants were incoming participants of a larger online study on cancer survivors in an OSG. The participants in the larger study varied in age, gender, cancer diagnosis, and cancer stage. For this study, all incoming participants were women with breast cancer diagnoses of various stages. Participants were referred to the website through an email list of a large national group for women.

#### **Materials**

##### *Email Messages*

After being granted entry to the website, treatment group participants were sent a personalized introductory email from a research assistant, welcoming them to the website. The letter encouraged them to post to the website and gave tips to help them stay motivated based on some of their initial questionnaire responses. Templates were created for second (Appendix B), and fourth (Appendix D) email messages to be sent to participants based on their level of activity in the chat and in the blog. A template was created for a generic third email message (Appendix C). Whether participants would be sent the second, third, and fourth email messages would depend on whether they joined a weekly chat group or posted a blog within 10-14 days of the last contact attempt.

### ***Mailed Packet***

A personally addressed welcome packet was also mailed to participants' physical home address (Appendix A). It consisted of frequently asked questions (FAQ) to the website as well as a series of screenshots of the website to help participants navigate the website.

### ***Phone Call Points of Focus***

A template (Appendix E) was created outlining various points of focus for conversations with participants, based on their activity level in the chat or blog. Phone calls were attempted after the participant was sent a first and second email, and had not engaged in the chat, posted a blog, or both.

## **Procedure**

### ***Brief Description of Larger Study Procedures***

The larger study, of which this smaller study is a part, was IRB approved by Loma Linda University. Participants of the larger study were recruited via a secure cancer registry from which participants were sent recruitment flyers; they also received follow up phone calls to these recruitment messages. Additionally, participants were recruited from Facebook, Yahoo! groups, and blogs that targeted cancer survivors. Furthermore, a large national women's empowerment organization assisted in recruitment efforts by emailing their members about the study and provided a link to the study website where interested members could gain additional information and sign up to participate in the study.



Upon going to the study's website, participants were asked several questions pertaining to their level of distress, ability to read and write in English, and ability to access the internet. Participants were granted access to the group if they met recruitment requirements. Recruitment requirements were as follows: participant distress rating of 4 or higher (on a scale of 0-10, with 10 being the highest level of distress), read and write English, and have regular access the internet. Participants were then randomized into the immediate access group or to a wait list control group where they would be able to join the website after twelve weeks. Participants in the immediate access group were asked to complete a questionnaire upon joining the study that would grant them access to the website. Wait list participants would be allowed to complete this same questionnaire twelve weeks after being randomly assigned to the wait list group. Upon joining the website, all participants were sent an automatically generated message from the website welcoming them to the website with brief tips to get started. Participants would have access to a variety of services including, private mail, a profile page for describing themselves and their cancer experience, discussion board, weekly psychoeducational guidance pages, as well as the aforementioned facilitated chat room and personal blog.

Details about outcome measures used and the larger study itself can be found in Owen, Bantum, Criswell, Bazzo, Gorlick, and Stanton (2013). Briefly, these instruments were the Distress Thermometer (Distress), Impact of Events Scale-Revised Total (IOES Total; anxiety), Center for Epidemiological Studies-Depression Scale (CES-D; depression), Functional Assessment of Cancer Therapy Total (FACT Total; quality of life), Quality of Well-Being Scale of the EuroQoL-5D (QWB; overall health), and Profile

of Mood States-Total Mood Disturbance (POMS TMD, mood disturbance), and Social Support Index (SS; social support).

### ***Sub-study Procedures***

For this IRB-approved sub-study, after being granted access to the website, participants were randomized into the treatment as usual (TAU) group or into the enhanced engagement intervention (EI) group. The following procedures would proceed with participants in the EI group. Within one week of joining the website, participants would be sent Email Message #1 from a research assistant's personal email account, rather than the generic email address for the larger study, to better personalize the email message. Within one week of joining the website, participants were also sent a welcome packet via postal mail which contained screenshots of the website to help them navigate the website and a list of frequently asked questions about the website. If participants had not engaged in the chat, blog, or both within 10-14 days of being sent the Email Message #1, they would be sent Email Message #2 to encourage their participation in the targeted activity in which they had not engaged. If the participant still had not engaged in that activity within 10-14 days of Email Message #2, they were contacted via phone. If the participant was not reached, a voicemail was left indicating the next time a call would be attempted. The message also included times when the research assistant would be in the lab if the participant wished to call back instead. A second call would be attempted in seven days. If the participant had not engaged in that activity within 10-14 days of the second phone call attempt, she was sent Email message #3. Finally, Email Message #4

would be sent if, after beginning activity in the chat, blogging, or both, the participant stopped engaging in one or both of these activities for one month.

### **Assumption Testing**

Seventy-one participants were randomly assigned to the treatment as usual (TAU) and engagement intervention (EI) groups ( $n = 35$  and  $36$ , respectively). Six of the participants declined further participation in the study when being contacted as part of the EI group intervention. None of the participants in the TAU group declined further participation. This resulted in a final count of  $n = 35$  and  $30$ , in the TAU and EI groups, respectively, for analyses ( $N = 65$ ; Figure 1).

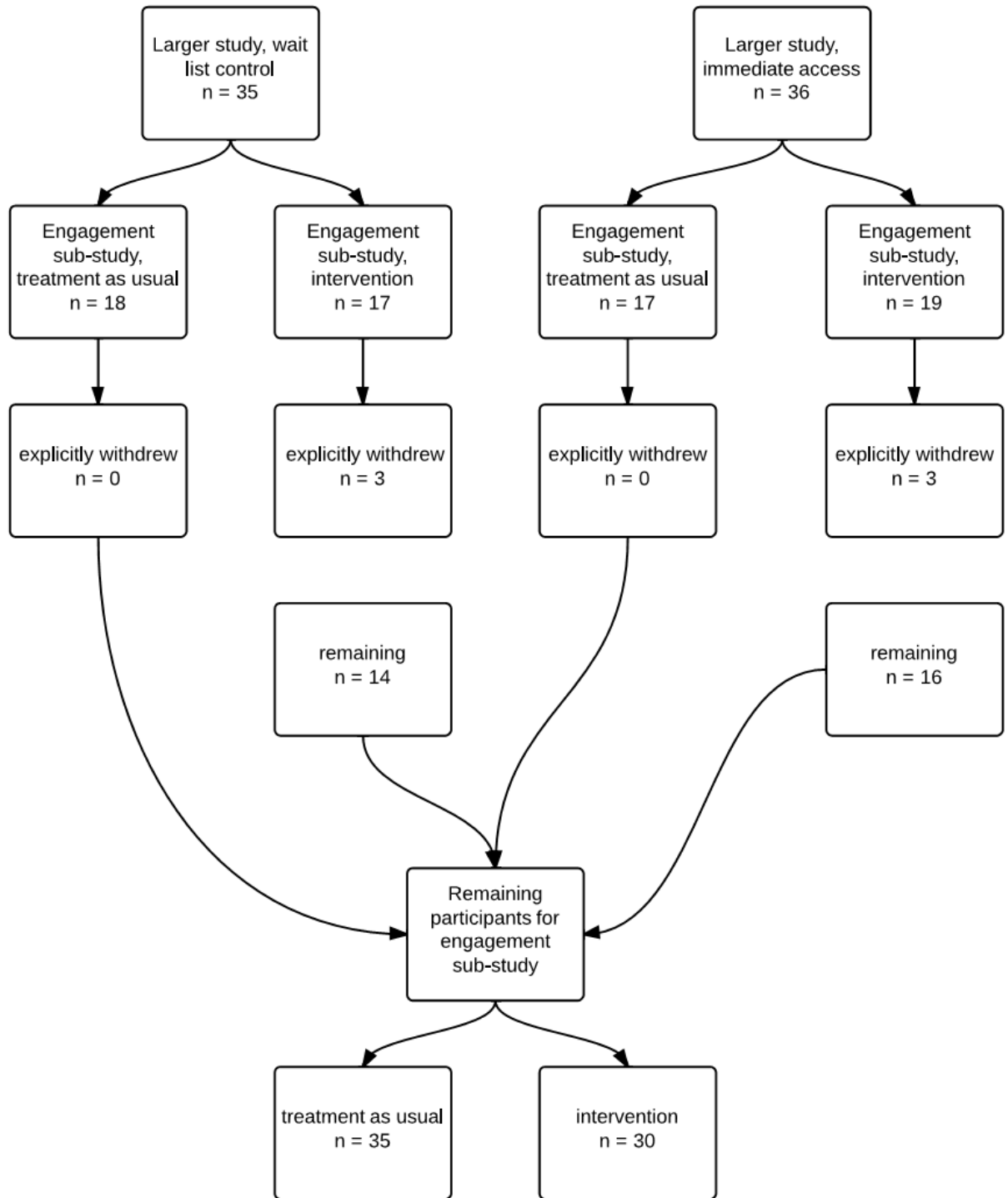


Figure 1. Flow chart of participants included for analyses.

After withdrawn participants were removed, the TAU group began with 35 participants and the EI group had 30 participants available for analysis at pre-test of psychosocial measures. However, only 21-22 were available to be analyzed for post-test measures in the TAU group, and 22 for the EI group. Missing variable analysis was conducted on the data set, grouping by Engagement Intervention, after removing participants who had withdrawn. Little's MCAR was not significant for any of these (TAU:  $\chi^2(195) = 17.44, p = 1.00$ ; EI:  $\chi^2(134) = .00, p = 1.00$ ), suggesting that there were no meaningful patterns in the missing data. Furthermore, comparisons between explicitly withdrawn participants ( $n = 6$ ) and those remaining ( $n = 65$ ) in the study had no significant differences with respect to age (withdrew  $M = 51.00, SD = 6.97$ ; remained  $M = 51.38, SD = 8.6$ ;  $t[69] = -.11, p = .92$ ), years since diagnosis (withdrew  $M = 3.03, SD = 2.16$ ; remained  $M = 4.80, SD = 4.57$ ;  $t[69] = -.94, p = .35$ ), years of education (withdrew  $M = 17.80, SD = 3.03$ ; remained  $M = 16.36, SD = 2.92$ ;  $t[67] = 1.06, p = .29$ ), or frequency of days accessing the internet in a week (withdrew  $M = 6.50, SD = 1.23$ ; remained  $M = 6.49, SD = 1.39$ ;  $t[69] = -.01, p = .99$ ). Furthermore, using Fisher's exact test for test of homogeneity, there were no significant differences between the distributions of withdrawn and remaining participants on marital status (statistic = 5.82,  $p = .13$ ), cancer stage (statistic = 2.72,  $p = .84$ ), tumor spread (statistic = 1.78,  $p = .66$ ), and ethnicity (statistic = 2.49,  $p = 1.00$ ).

### ***Screening for Analysis 1: Did Intervention Increase Engagement?***

The remaining 65 participants' engagement with the website was compared using total website time, chat time, chat word count, number of chats attended, number of

discussion board posts, discussion board word count, number of blog posts, blog word count, and time spent in the psychoeducational modules on the website. Outliers were detected by standardizing scores and identifying those with absolute value z-scores greater than 3.3. Outliers were found on website time (1 in each group), discussion board word count (1 in each group), number of blog posts (1 in each group), blog word count (1 in each group), and psychoeducation time (1 in treatment as usual group). Winsorizing outliers did not lead to skew and kurtosis within acceptable limits, in at least one group on each of these variables. All variables were subsequently transformed using inverse, square root, and log 10 transformations. The transformation in each variable that led to the least discrepant skew and kurtosis values within acceptable ranges for both groups was used to conduct independent samples t-tests (sqrt website time, sqrt chat time, log 10 chat word count, sqrt number of chats attended, sqrt discussion board posts, log 10 discussion board word count, sqrt number of blog posts, log 10 blog word count, sqrt guidance time in mins). All transformed variables met the assumption of homogeneity of variances. However, because Shapiro-Wilks tests indicated significant deviations from normality within most groups for all transformed variables used in the analysis, and examination of their normal curves continued to indicate significant deviations from normality for most groups, a Mann Whitney U test was also conducted on the untransformed original variables.

An additional analysis was conducted for comparison with the participants who had withdrawn included, for a total of 35 participants in the TAU group and 36 participants in the EI group. Outliers were found on website time (1 in each group), discussion board word count (1 in each group), number of blog posts (1 in each group),

blog word count (1 in each group), and psychoeducation time (1 in treatment as usual group). Winsorizing outliers did not lead to skew and kurtosis within acceptable limits, in at least one group on each of these variables for this full sample as well. Similarly, significant skew and/or kurtosis was found in at least one group for each of the variables. Again, various transformations conducted improved skew and kurtosis in these variables. For consistency, mean comparisons were conducted with the type of transformation that was conducted with the same variable in the analysis that did not include participants who had withdrawn (sqrt website time, sqrt chat time, log 10 chat word count, sqrt number of chats attended, sqrt discussion board posts, log 10 discussion board word count, sqrt number of blog posts, log 10 blog word count, sqrt guidance time in mins). Furthermore, because Shapiro-Wilks tests continued to indicate significant deviations from normality for the transformed variables of the full sample, additional nonparametric mean comparisons (Mann-Whitney U test) were conducted on the untransformed variables.

In order to determine whether to include the larger study randomization variable in the main analysis, the same procedures were followed. Mean comparison analyses were conducted, grouped by the larger study randomization condition (wait list control vs immediate access). Because there were no significant differences found between these groups, this variable was not included in the main analyses for engagement variables.

*Screening For Analysis 2: Did Intervention Decrease Time to  
Engage in Different Parts of Website?*

Assumptions for Cox proportional-hazards survival analysis were evaluated for time to first chat, time to first blog activity, time to first discussion board activity, and time to first website activity. Missing values were censored, as they indicated that activity had not occurred by the time the participant graduated from the study. Thus, missing values were replaced with the total number of days or weeks that the participants was in the study, as appropriate for the unit of measurement of the variable (days = 84, weeks = 12). This resulted in a final  $N = 71$  for analysis, which is adequate for the analysis given that no covariates were included in the survival analysis. Participants who withdrew were also censored. Previously reported MVA indicated no systematic differences in missing values. Furthermore, there were no significantly meaningful differences between participants who withdrew and the rest of the participants in the study, besides being in the intervention group.

Outliers were screened by standardizing scores and looking for cases in each variable with absolute z-scores greater than 3.3. No cases met this criterion, indicating no outliers were present in any of the target variables. All variables were within acceptable limits for skew. However, time to first DB post was significantly kurtotic while time to first chat, blog post, and website post neared significance for kurtosis. Furthermore, Shapiro-Wilks tests indicated significant deviations from normality for all variables, and inspection of their curves revealed significant flatness of their respective curves. However, because assumptions of normality are not required for survival analysis the variables were not transformed.



Because procedures of the intervention did not change during the course of the study, it is assumed that no systematic changes occurred over the course of the study that would affect the results of survival analysis. Examining statistics of a time-dependent covariate to test the proportionality of hazards assumption indicated no significant interactions thus meeting this assumption.

Mean comparisons of time to post variables were also conducted on those participants who had engaged in a variable. For all variables except time to join chat, screening indicated significant skew and/or kurtosis within at least one group for most variables, however none of these were due to outliers. Furthermore, Shapiro-Wilks test indicated significant deviations from normality for two variables, and inspection of curves confirmed this. Therefore, Mann Whitney U tests were conducted for significance testing on all variables for uniformity in reporting results.

Time to post variables were also analyzed grouped by the larger study randomization condition (wait list control vs immediate access). Because there were no significant differences found in time to post between these groups as well as no significant results in the survival analyses, this variable was not included in the main analyses.

### ***Screening For Analysis 3: Did Intervention Improve Psychosocial***

#### ***Outcomes?***

Screening of Pre and Post measures of Distress, QWB, IOES Total, CES-D, POMS TMD, FACT Total, and SS was conducted for two separate analyses of a mixed design ANOVA. This was conducted on measures of psychosocial functioning with

missing Post data dropped and as an intention to treat analysis with missing Post data replaced as described below. However, because results were similar for significance values and effects sizes in both analyses, only the screening for the intention to treat analysis results are reported here.

For the intention to treat analyses missing Post-test values in a variable were replaced with the Pre-test value for that same case. This resulted in a complete data set, with 35 participants in the TAU group and 36 participants in the EI group. Screening of Pre and ITT Post measures of Distress, QWB, IOES Total, CES-D, POMS TMD, FACT Total, and SS indicated that all but IOES ITT Post had skew and kurtosis within acceptable limits. Outliers were detected by standardizing scores and looking for those with  $|z\text{-scores}|$  greater than 3.3. There were no cases in all but one variable (again, IOES ITT Post) in each group with  $z\text{-scores}$  greater than 3.3. For IOES ITT Post, both skew and kurtosis were outside of acceptable limits in the EI group. The one outlier that was detected was also in the EI group. Winsorizing corrected the skew and kurtosis in this group. Running the repeated measures ANOVA with the winsorized variable did not produce results that were much different than the results produced with the original IOES ITT Post variable. With the winsorized variables, significance values were only .01 point less and effect size was only .01 larger. Thus, analyses proceeded with the original IOES ITT variable. Although Shapiro-Wilks tests indicated significant deviations from normality for Distress Pre and Post, QWB Pre and Post, IOES Pre and Post, and SS Pre and Post, visual examination of the distribution curves appeared to be normally distributed. The assumption of sphericity is assumed to have been met since there were only two groups being compared. The assumption of homogeneity of variance for

between subject tests was also met for all variables. Analyses proceeded with the original, untransformed variables.

Psychosocial variables were also analyzed grouped by the larger study randomization condition (wait list control vs immediate access). A significant interaction of treatment condition and time were found for ITT Distress and ITT IOES Total. Repeating the analyses with the interaction term of the two treatment conditions (larger study randomization condition x engagement intervention randomization condition) indicated no significant effects of this interaction term. Furthermore, covarying for larger study randomization condition did not lead to any major changes in significance and effect size values. Thus, the original study randomization variable was not included in the main analyses.

## CHAPTER THREE

### RESULTS

All participants included in analyses were women with breast cancer diagnoses who had completed treatment. There were no significant differences between TAU and EI groups on age ( $t[69] = -.29, p = .77$ ), years since diagnosis ( $t[69] = -.38, p = .71$ ), years of education ( $t[67] = .35, p = .73$ ), and frequency of days accessing the internet in a week ( $t[60.99] = -1.25, p = .22$ ). Summary of means are found in Table 1. Furthermore, using Fisher's exact test for test of homogeneity, there were no significant differences between the distributions of TAU and EI on ethnicity (statistic = 3.96,  $p = .52$ ), marital status (statistic = 1.53,  $p = 1.00$ ), cancer stage (statistic = 2.81,  $p = .79$ ), and tumor spread (statistic = 1.17,  $p = .84$ ). Summary of cell counts and percentages are found in Table 2.

Table 1

*Group Comparisons of Continuous Demographic Variables*

	TAU		EI		<i>p</i>
	<i>n</i> = 35		<i>n</i> = 30		
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	
Age	51.06	9.37	51.77	7.78	0.77
Years since diagnosis	4.45	4.4	5.22	4.8	0.71
Internet frequency (days/week)	6.29	1.58	6.73	1.11	0.22
Years of education*	16.59	2.75	16.1	3.13	0.73

*Note.* TAU (treatment as usual), EI (engagement intervention)

\*TAU  $n = 34$

Table 2

*Group Comparisons of Frequency Distributions of Categorical Demographic Variables*

		TAU		EI		<i>p</i>
		<i>N</i>	%	<i>n</i>	%	
Ethnicity	Asian	0	0	1	3.3	0.52
	Black	2	5.7	0	0	
	Hispanic	0	0	1	3.3	
	Other	2	5.7	1	3.3	
	White	31	88.6	27	90	
Marital status	Divorced	3	8.6	4	13.3	1.00
	Married	30	85.7	25	83.3	
	Single	2	5.7	1	3.3	
Cancer stage	1	14	40	7	23.3	0.79
	2	10	28.6	11	36.7	
	3	3	8.6	4	13.3	
	4	6	17.1	6	20	
	In situ	2	5.7	1	3.3	
	Not sure	0	0	1	3.3	
Tumor spread	Lymph spread	7	20	7	23.3	0.84
	Metastases	6	17.1	6	20	
	No spread	21	60	14	46.7	
	Regional spread	1	2.9	3	10	

*Note.* TAU (treatment as usual), EI (engagement intervention)

### **Analysis 1: Did the Intervention Increase Engagement?**

An independent samples t-test conducted on the transformed variables (sqrt website time, sqrt chat time, log 10 chat word count, sqrt number of chats attended, sqrt discussion board posts, log 10 discussion board word count, sqrt number of blog posts, log 10 blog word count, sqrt guidance time in mins) indicated that group differences were significant and favored the EI group on website time ( $t[63] = -2.36, p = .02, d = .59$ ), chat time ( $t[63] = -2.18, p = .03, d = .55$ ), blog word count ( $t[63] = -2.03, p = .047, d = .51$ ), and psychoeducation time ( $t[63] = -2.19, p = .03, d = .55$ ). Group differences approached significance, again favoring the EI group, on chat word count ( $t[63] = -1.97, p = .05, d = .50$ ) and number of chats attended ( $t[63] = -1.98, p = .05, d = .50$ ). There were no significant differences between groups on discussion board posts ( $t[63] = -.28, p = .78, d = .07$ ), discussion board word count ( $t[63] = -.59, p = .56, d = .15$ ), and number of blog posts ( $t[63] = -1.75, p = .09, d = .44$ ). See Table 3 for a summary of these values.

As mentioned before, Shapiro-Wilks tests indicated significant deviations from normality within most groups for all transformed variables used in the analysis, and examination of their normal curves continued to indicate significant deviations from normality for most groups. Thus, a Mann Whitney U test was conducted on all original, untransformed engagement variables being analyzed. Results of these analyses largely confirmed results indicated by the independent samples t-test. Group differences were significant and favored the EI group on website time ( $U = 344.00, p = .02, r = .30$ ), chat time ( $U = 369.00, p = .03, r = .27$ ), and psychoeducation time ( $U = 363.50, p = .03, r = .26$ ). Group differences approached significance, again favoring the EI group, on chat word count ( $U = 393.50, p = .058, r = .24$ ) and number of chats attended ( $U = 395.50, p =$

.061,  $r = .23$ ). There were no significant differences between groups on discussion board posts ( $U = 490.50$ ,  $p = .64$ ,  $r = .06$ ), discussion board word count ( $U = 484.50$ ,  $p = .58$ ,  $r = .07$ ), number of blog posts ( $U = 393.00$ ,  $p = .07$ ,  $r = .22$ ) and blog word count ( $U = 391.00$ ,  $p = .07$ ,  $r = .23$ ). These results are summarized in Table 4.

Table 3

*Means and Standard Deviations for Transformed Engagement Measures (N = 65)*

Engagement Measure	TAU <i>n</i> = 35		EI <i>n</i> = 30		Btwn. group sig.	Effect size ( <i>d</i> )
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>		
Sq. root Total chats attended	.80	1.22	1.43	1.36	†	.50
Log10 Chat word count	1.19	1.70	2.06	1.85	†	.50
Sq. root Chat time (mins)	6.82	10.70	13.11	12.57	*	.55
Sq. root Total blog activity	1.45	1.78	2.29	2.07	†	.44
Log10 Blog word count	1.49	1.61	2.29	1.52	*	.51
Sq. root Total discussion board activity	1.46	1.71	1.57	1.56	ns	.07
Log10 Discussion board word count	1.41	1.40	1.61	1.33	ns	.15
Sq. root Website total time (mins)	15.98	15.88	25.39	16.24	*	.59
Sq. root Psycho-education time (mins)	5.55	5.09	8.37	5.23	*	.55

*Note.* TAU (treatment as usual), EI (engagement intervention)\**p* < .05, †*p* < .10



Table 4

*Means and Standard Deviations for Untransformed Engagement Measures and Significance Test Results Using Mann-Whitney U Test (N = 65)*

Engagement Measure	TAU <i>n</i> = 35		EI <i>n</i> = 30		Btwn. group sig.	Effect size ( <i>r</i> )
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>		
Total chats attended	2.09	3.54	3.83	4.11	†	.23
Chat word count	1675.37	3243.42	2975.37	3361.22	†	.24
Chat time (mins)	157.65	278.53	324.53	362.04	*	.27
Total blog activity	5.20	8.26	9.37	13.27	†	.22
Blog word count	1184.69	2246.31	2489.03	4601.94	†	.23
Total discussion board activity	5.00	7.89	4.83	6.62	ns	.06
Discussion board word count	530.71	1024.51	455.03	793.51	ns	.07
Website total time (mins)	500.25	768.85	899.56	959.86	*	.30
Psycho-education time (mins)	56.08	77.65	96.53	84.55	*	.26

*Note.* TAU (treatment as usual), EI (engagement intervention)

\**p* < .05, †*p* < .10

Another independent samples t-test was conducted on the full sample, whereby withdrawn participants were included in analyses for a total sample size of 71 participants. Transformed variables for this full sample were utilized (sqrt website time, sqrt chat time, log 10 chat word count, sqrt number of chats attended, sqrt discussion board posts, log 10 discussion board word count, sqrt number of blog posts, log 10 blog word count, sqrt guidance time in mins). With the full sample, there were no significant differences between the TAU and EI group on any of the transformed variables (website time ( $t[69] = -1.28, p = .20, d = .31$ ; chat time  $t[68.24] = -1.16, p = .25, d = .28$ ; number of chats attended  $t[68.30] = -1.13, p = .26, d = .27$ ; chat word count  $t[68.78] = -.85, p = .40, d = .21$ ; blog word count  $t[69] = -.85, p = .40, d = .20$ ); number of blog posts  $t[69] = -.60, p = .55, d = .14$ ); discussion board posts  $t[69] = -.39, p = .70, d = .09$ ; discussion board word count  $t[69] = -1.19, p = .24, d = .29$ ; psychoeducation time ( $t[69] = -1.25, p = .22, d = .30$ ). See Table 5 for a summary of these values.

Again, as previously mentioned, Shapiro-Wilks tests indicated significant deviations from normality within most groups for all transformed variables used in the analysis. Examination of their normal curves continued to indicate significant deviations from normality for most groups. Thus, a Mann Whitney U test was conducted on the original, untransformed engagement variables. Results of these analyses confirmed results indicated by the independent samples t-test with no significant differences found between the TAU and EI groups on all variables when the full sample was included (website time  $U = 494.00, p = .12, r = .19$ ; chat time  $U = 513.00, p = .14, r = .17$ ; number of chats attended  $U = 534.50, p = .23, r = .14$ ; chat word count  $U = 534.50, p = .22, r = .15$ ; number of blog posts  $U = 549.00, p = .33, r = .12$ ; blog word count  $U = 547.00, p =$

.32,  $r = .12$ ; discussion board posts  $U = 617.50$ ,  $p = .88$ ,  $r = .02$ ; discussion board word count  $U = 622.50$ ,  $p = .93$ ,  $r = .01$ ; psychoeducation time  $U = 518.50$ ,  $p = .20$ ,  $r = .15$ ).

These results are summarized in Table 6.

Table 5

*Means and Standard Deviations for Transformed Engagement Measures (N = 71)*

Engagement Measure	TAU $n = 35$		EI $n = 36$		Between group sig.	Effect size ( $d$ )
	$M$	$SD$	$M$	$SD$		
Sq. root Total chats attended	.79	1.22	1.19	1.36	ns	.27
Log10 Chat word count	1.19	1.70	1.72	1.85	ns	.21
Sq. root Chat time (mins)	6.82	10.70	10.92	12.47	ns	.28
Sq. root Total blog activity	1.45	1.78	1.90	2.07	ns	.14
Log10 Blog word count	1.49	1.61	1.90	1.63	ns	.20
Sq. root Total discussion board activity	1.46	1.71	1.38	1.33	ns	.70
Log10 Discussion board word count	1.41	1.40	1.38	1.33	ns	.24
Sq. root Website total time (mins)	15.98	15.88	21.99	16.77	ns	.31
Sq. root Psycho-education time (mins)	5.55	5.09	7.23	5.46	ns	.30

*Note.* TAU (treatment as usual), EI(engagement intervention); ns = not significant

Table 6

*Means and Standard Deviations for Untransformed Engagement Measures and Significance Test Results Using Mann-Whitney U Test (N = 71)*

Engagement Measure	TAU <i>n</i> = 35		EI <i>n</i> = 30		Btwn. group sig.	Effect size ( <i>r</i> )
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>		
Total chats attended	2.09	3.54	3.19	4.01	ns	.14
Chat word count	1675.37	3243.42	2479.47	3259.71	ns	.15
Chat time (mins)	157.65	278.53	270.44	351.64	ns	.17
Total blog activity	5.20	8.26	7.81	12.59	ns	.12
Blog word count	1184.69	2246.31	2074.19	4293.30	ns	.12
Total discussion board activity	5.00	7.89	4.06	6.28	ns	.02
Discussion board word count	530.71	1024.51	379.81	742.81	ns	.01
Website total time (mins)	500.25	768.85	757.14	931.92	ns	.19
Psycho-education time (mins)	56.08	77.65	81.17	84.51	ns	.15

*Note.* TAU (treatment as usual), EI (engagement intervention); ns = not significant

## **Analysis 2: Did Intervention Decrease Time to Engage in Different Parts of Website?**

After censoring cases that had withdrawn as well as those who had no activity within a specific engagement variable, a Cox proportional-hazards survival analysis was conducted to determine how effective treatment group was in decreasing time to first activity in four areas: joining a facilitated chat, posting a blog, posting to the discussion board (either new or reply posts), and posting to the website overall (which includes all of the above as well as replies to blogs). There was no statistically significant effect of engagement condition in time to joining the chat ( $G^2 [1] = .69, p = .41$ ), posting to the discussion board ( $G^2 [1] = .03, p = .86$ ), blog activity ( $G^2 [1] = 1.55, p = .21$ ), or posting to the website ( $G^2 [1] = .43, p = .51$ ). See Table 8 for a summary of model effect size, regression coefficients, degrees of freedom, significance values, odds ratios, and 95% confidence intervals for each outcome variable. Survival plots are also displayed in Figures 2 through 5. Furthermore, of participants who engaged in these variables, no significant differences were found between TAU and EI on time to join chat (Mann-Whitney  $U = 64.00, p = .09, r = .31$ ), post to the discussion board ( $U = 162.00, p = .59, r = .09$ ), post within the blog ( $U = 155.00, p = .36, r = .15$ ), or post to website overall ( $U = 163.00, p = .11, r = .24$ ). A summary of means and standard deviations can be seen on Table 7.

Table 7

*Comparison of Time to First Engage in Chat, Discussion Board, Blog, and Website of Participants Who Engaged in Variable*

	TAU			EI			<i>p</i>	<i>R</i>
	<i>n</i>	<i>M</i>	<i>SD</i>	<i>n</i>	<i>M</i>	<i>SD</i>		
Chat (weeks)	12	.94	.71	17	1.6	1.12	.09	.31
Discussion board (days)	19	11.96	26.31	19	7.25	10.17	.59	.09
Blog (days)	17	16.19	14.82	22	13.63	15.45	.36	.15
Website (days)	19	4.26	13.23	24	6.14	7.63	.11	.24

*Note.* TAU (treatment as usual), EI (engagement intervention)

Table 8

*Cox Regression Analysis of Engagement Treatment Condition on Time to Engage in Chat, Discussion Board, Blog, and Website Overall, *df* = 1*

	<i>R</i> <sup>2</sup>	<i>B</i>	<i>p</i>	HR	95% CI for HR
Chat (weeks)	.01	.31	.41	1.36	.65, 2.86
Discussion board (days)	.0004	-.06	.86	.95	.50, 1.79
Blog (days)	.02	-.40	.22	.67	.36, 1.26
Website (days)	.006	.20	.52	1.22	.67, 2.23

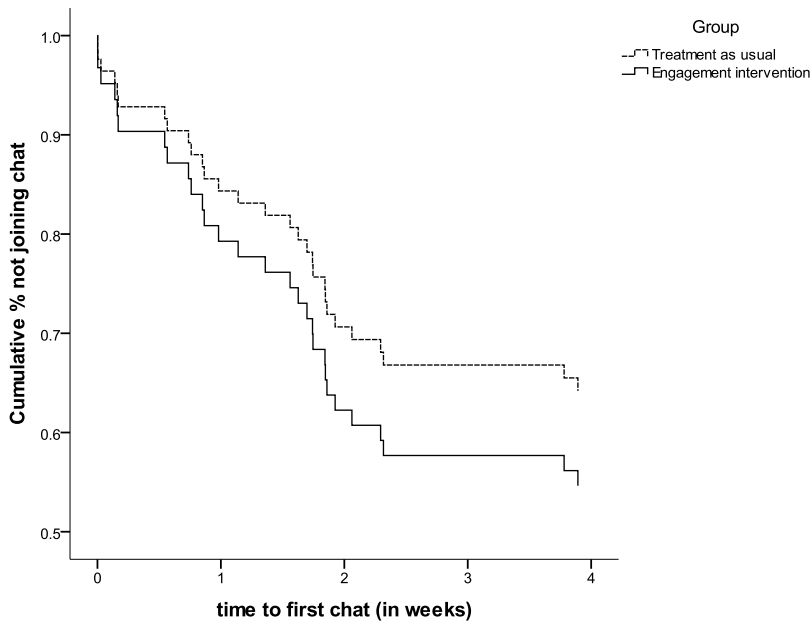


Figure 2. Survival curve of time to first chat.

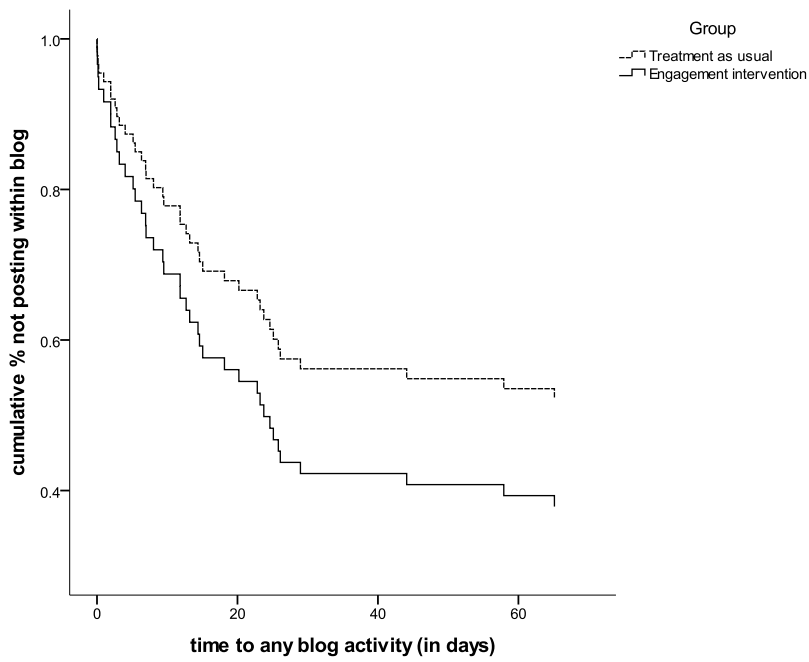


Figure 3. Survival curve of time any blog activity.

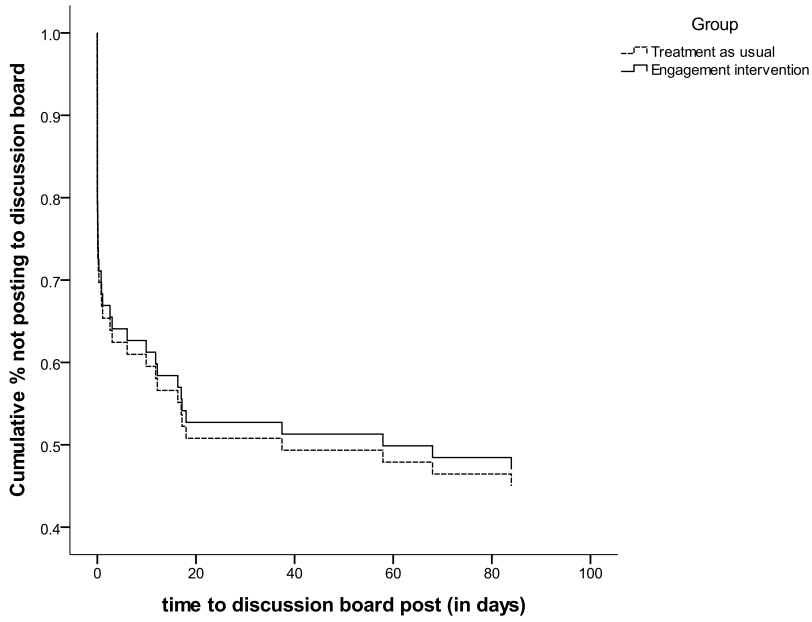


Figure 4. Survival curve of time to first discussion board post.

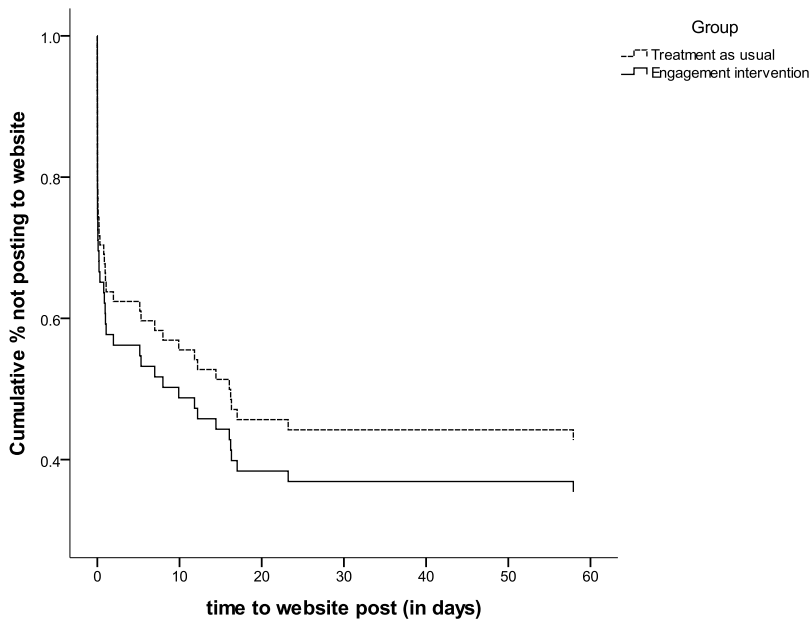


Figure 5. Survival curve of time to first website post.



### **Analysis 3: Did Intervention Improve Psychosocial Outcomes?**

A mixed design ANOVA was conducted on pre and post measures of psychosocial functioning with missing Post data dropped and as an intention to treat analysis with missing Post data replaced as described in the methods section. Because results were similar for significance values and effects sizes in both analyses, only the intention to treat analysis results are reported here.

There was a significant main effect for Distress, indicating a significant decrease in combined scores over time, with a larger combined decrease in the treatment group than in the control group. However, the between-subjects effect of treatment condition (treatment as usual vs enhanced engagement intervention) was not significant. Although the interaction plot of treatment condition x time for Distress suggested a significant interaction, statistical tests indicated that the interaction was not significant. Similar results were found for QWB, IOES Total, and CES-D. For POMS TMD, the only difference is that within-subjects main effect approached significance. Furthermore, the within-subject main effect was not significant for FACT Total and SS. Their interaction plots accurately reflected the non-significant interaction with parallel lines for the two groups. Statistical values of results are summarized in Table 9, with a summary of mean and standard deviations on Table 10. Plots are found in Figures 6 through 12.

Table 9

*Results of Intention to Treat Mixed Design ANOVA,  $df = 1, 69$*

	Time			Between Groups			Time x Group		
	<i>F</i>	<i>p</i>	Partial $\eta^2$	<i>F</i>	<i>p</i>	Partial $\eta^2$	<i>F</i>	<i>p</i>	Partial $\eta^2$
Distress	4.58	.04	.06	.02	.89	<.001	.38	.54	.006
QWB	6.24	.02	.08	.12	.73	.002	.16	.69	.002
IOES Total	5.89	.02	.08	1.30	.26	.02	.97	.33	.01
CES-D	4.74	.03	.06	1.58	.21	.02	.70	.41	.01
POMS TMD	3.94	.05	.05	.14	.71	.002	.49	.49	.007
FACT Total	5.99	.02	.08	.44	.51	.006	.03	.88	<.001
SS	1.20	.28	.02	2.27	.14	.03	.006	.94	<.001

*Note.* QWB (overall health); IOES Total (anxiety), CES-D (depression), POMS TMD (mood disturbance), FACT Total (quality of life), SS (social support). Scale name can be found on page ix.

Table 10

*Means and Standard Deviations for Intention to Treat Outcome Measures*

Outcome Measure	TAU <i>n</i> = 35		EI <i>n</i> = 36	
	Pre	Post	Pre	Post
	<i>M</i> ( <i>SD</i> )	<i>M</i> ( <i>SD</i> )	<i>M</i> ( <i>SD</i> )	<i>M</i> ( <i>SD</i> )
Distress	5.11 (2.27)	4.69 (2.44)	5.36 (2.43)	4.58 (2.82)
QWB	60.71 (21.43)	64.14 (21.64)	58.33 (23.48)	63.06 (22.24)
IOES Total	23.54 (11.67)	21.89 (11.61)	21.81(11.48)	17.89 (11.85)
CES-D	20.23 (9.95)	17.91 (10.59)	16.81 (9.23)	15.78 (9.65)
POMS TMD	32.49 (23.49)	26.97 (24.79)	29.00 (22.73)	26.36 (26.21)
FACT Total	66.60 (11.60)	69.80 (12.97)	68.82 (14.58)	71.64 (15.89)
SS	18.23 (2.67)	18.49 (2.42)	19.11 (2.76)	19.33 (2.47)

*Note.* TAU (treatment as usual), EI (engagement intervention); QWB (overall health); IOES Total (anxiety), CES-D (depression), POMS TMD (mood disturbance), FACT Total (quality of life), SS (social support). Scale name can be found on page ix.

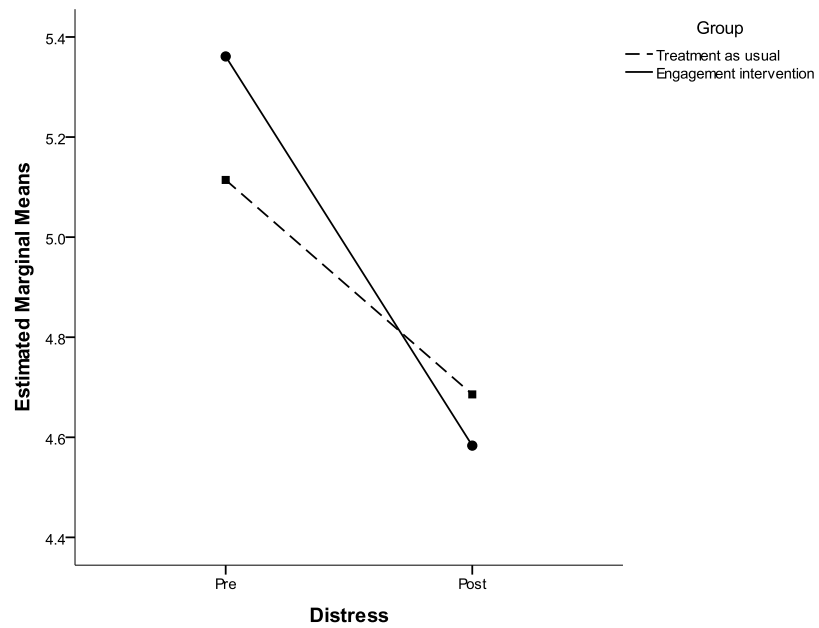


Figure 6. Intention to treat analysis; interaction of engagement intervention and time, for Distress scores.

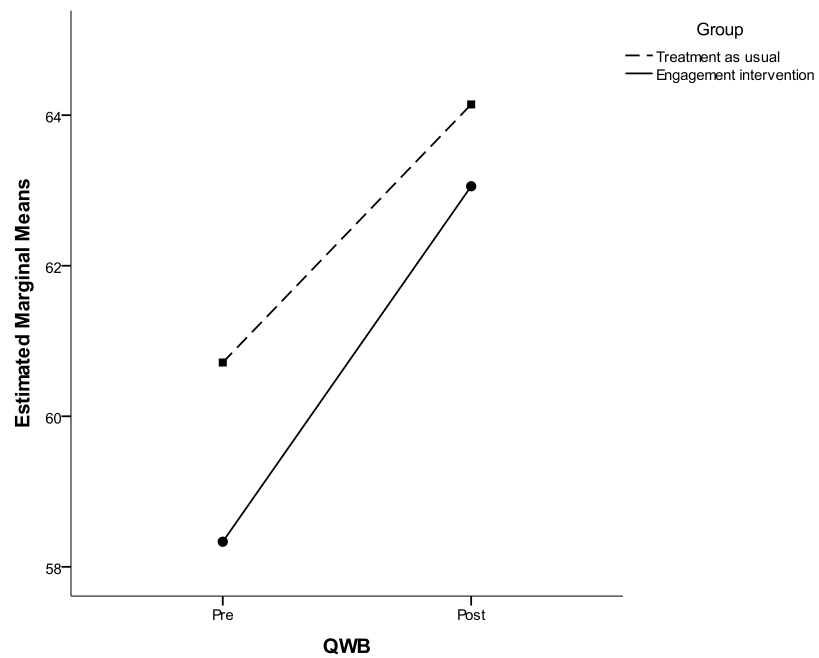


Figure 7. Intention to treat analysis; interaction of engagement intervention and time, for QWB (overall health) scores.

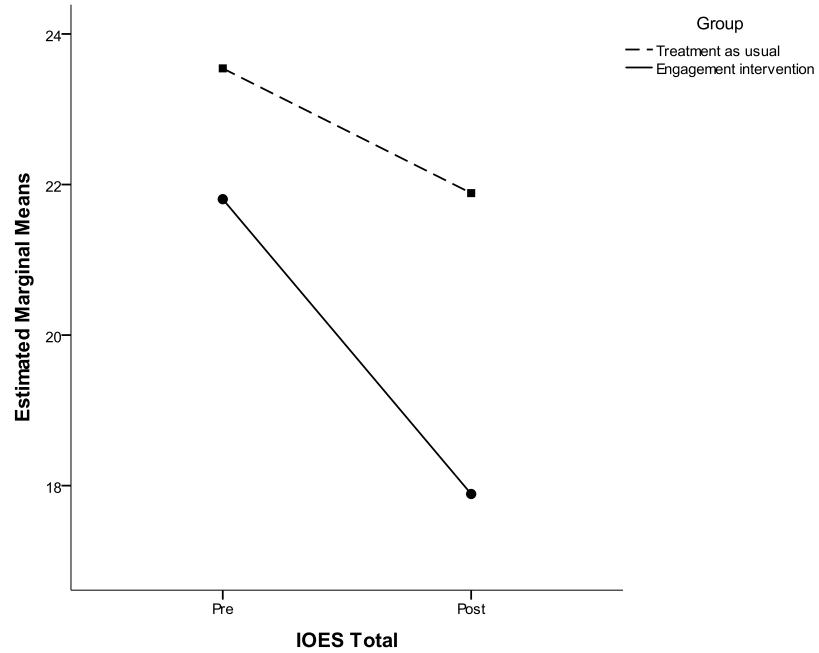


Figure 8. Intention to treat analysis; interaction of engagement intervention and time, for IOES Total (anxiety) scores.

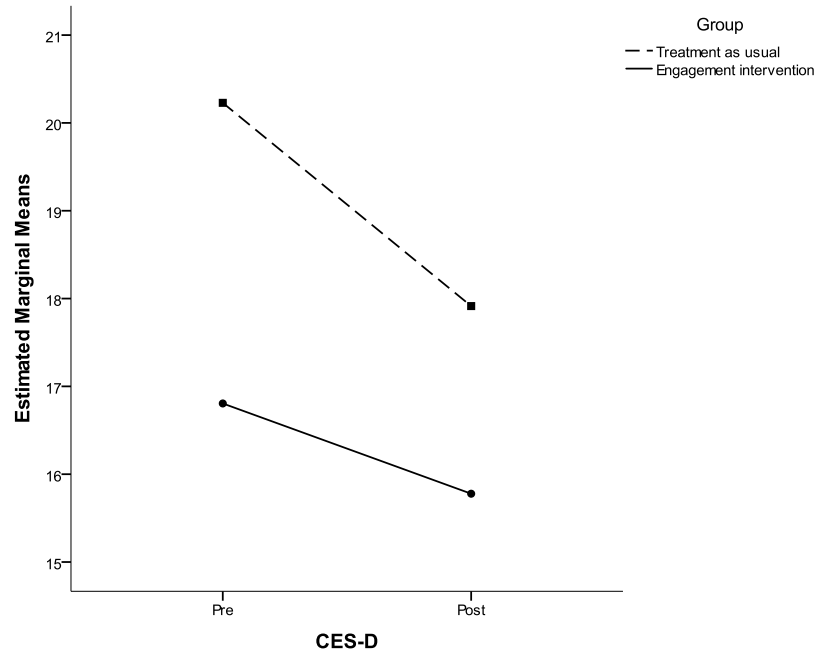


Figure 9. Intention to treat analysis; interaction of engagement intervention and time, for CES-D (depression) scores.

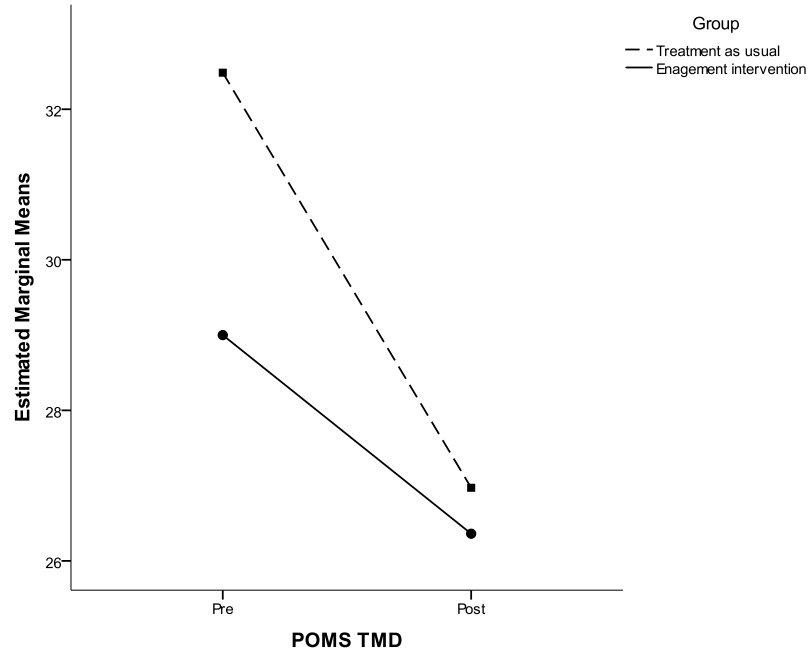


Figure 10. Intention to treat analysis; interaction of engagement intervention and time, for POMS TMD (mood disturbance) scores.

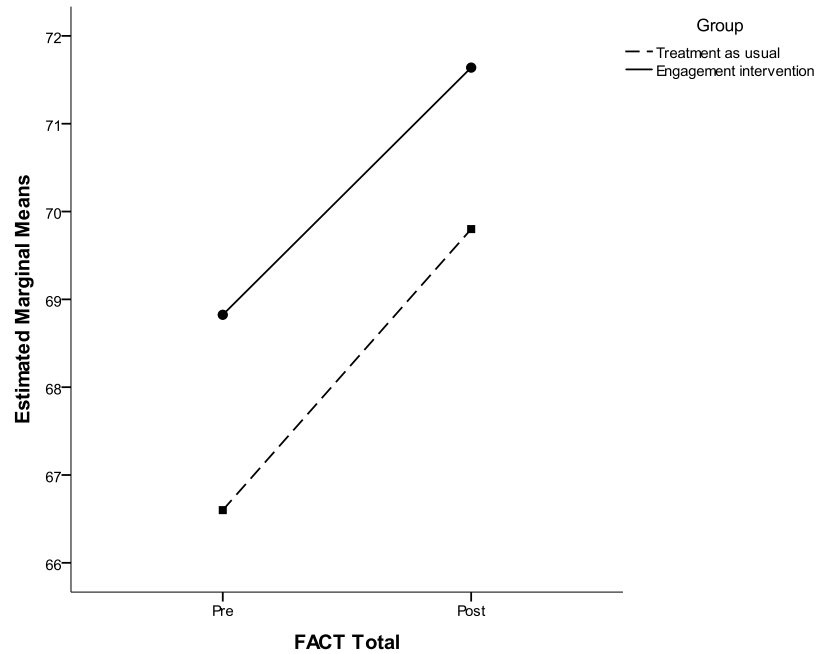
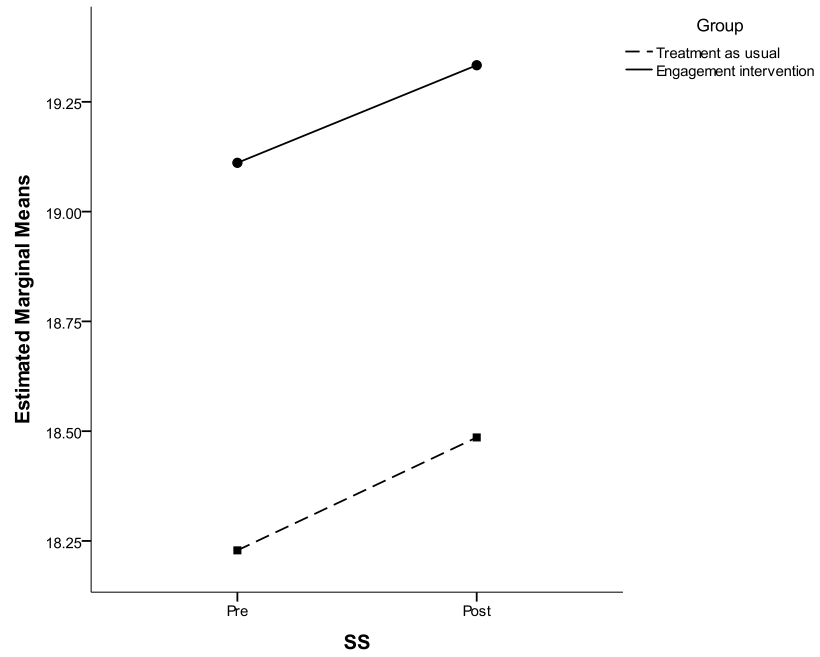


Figure 11. Interaction of engagement intervention and time, for FACT Total (quality of life) scores.



*Figure 12.* Intention to treat analysis; interaction of engagement intervention and time, for SS (social support) scores.

## CHAPTER FOUR

### DISCUSSION

This study is the first to implement an intervention to improve engagement in an OSG for breast cancer survivors. According to Eysenbach (2005) and many others, low engagement is a significant problem faced by online support groups. As predicted, this engagement intervention was successful in improving engagement on the website. Our hypothesis was partially supported as engagement was better in the intervention group on some of our measures of engagement. Even when there were significant differences, effect sizes on most of the remaining measures of engagement favored the intervention group. By incorporating several measures of engagement, this study also helped provide evidence for the validity of some measures of engagement. This will help future studies in OSGs better measure engagement, decreasing some of this (previously discussed) challenge in the study of OSGs.

Engagement in the chat and blog were specifically encouraged in communications to the participants in the EI group. It appears that increased engagement in one of these may promote increased engagement with other parts of the website. Part of the reason for this may be because weekly topics were announced on the website. The topic came with corresponding exercises for participants to blog about and was announced as being a topic for discussion for the weekly chat. In order to prepare themselves, participants could read about the topic in the psycho-educational part of the website. This integration of the psycho-educational material could be one reason for increased engagement in this part of the website. Consequently, because participants were engaging more with these additional parts of the website, they also accumulated more time on the website. On



websites with several interactive features, our findings also lend support to the validity of total website time as a measure of engagement. Favorable effect sizes on most measures of engagement in this study suggest that it is less likely that part of this accumulation of website time is due to erroneous factors, such as participants forgetting to sign off. As it pertains to the other measures of engagement, the study also lends support for obtaining multiple measures of engagement to better determine the validity of any one measure when interpreting results. For example, while we did not find significant differences between TAU and EI on number of blog posts, we did find differences on total word count. Examining them together allowed for stronger conclusions into the overall quality of blog postings by each group, despite not doing more sophisticated text analysis. This increase in quality of posts may promote increased engagement between participants. Partial support of the importance of quality of posts is provided by a study by Lewallen, Owen, Bantum, and Stanton (2014), in which findings suggested that higher word count in posts led to increased responses by other members, thus increasing the interaction among participants.

Another reason why engagement in the blog or chat may increase engagement with other parts of the website may be due to a type of carry over effect, whereby changes in one area may promote desired changes in other areas. As it pertains to study design, carry over effects are generally undesirable in within-subjects designs (Greenwald, 1976). This is because carry over effects limit interpretability of findings when one area was the focus of the intervention. Limiting these carry-over effects in the study design will certainly help to determine the unique effect of any one component of an OSG on improving engagement. However, with the aim being increased OSG use,

carry over effects may ultimately be desirable to help improve participants' engagement with website overall. Health behavior interventions, such as those for smoking cessation, have sought to capitalize on these carry over effects to promote change in different negative health behaviors. Interventions targeting smoking cessation in alcohol dependent individuals have reported mixed findings in the role of carry-over effects on outcomes (Hintz & Mann, 2007; Cooney et al., 2009).

The hypothesis that the increased contact would lead to decreased time to post in the chat, blog, discussion board, and website overall was not supported. However, very small effect sizes were found for time to post in chat and blog, which were the specific activities that we encouraged for participants in the intervention group. The small sample size of our study may have decreased power to detect significant differences. The lack of any significant difference between groups on time to post to website and time to post on discussion board were not surprising given that many participants' first post to the website was on the discussion board. As participants entered the group, they often posted introductions on the discussion board. Because participants were frequently admitted in batches, website activity often spiked when new groups of participants were granted access. As this activity often occurred before participants were randomized to either the TAU or EI group, this provides pre-randomization support for the importance of increased website engagement to encourage engagement from others.

Total engagement may also be related to long term engagement. However, we did not examine this specifically. Future studies can extend this study by examining time to last post after first post. This may speak not only to how effective the engagement intervention was in promoting initial use, but also to how effective that initial activity

was to promoting continued use. Some studies have found early intervention to be successful in promoting initial engagement (Schneider, de Vries, Candel, van de Kar, and van Osch, 2013) and increased engagement overall, like our study found. However, continued study into the factors that promote long term engagement is also needed.

The hypothesis that the intervention would significantly improve psychosocial outcomes over time (as indicated by the Time x Intervention interaction) was not supported. IOES Total and CES-D are instruments that specifically measure anxiety and depression, respectively. Small effect sizes were found for these two measures in the interaction and in between-group comparisons. Anxiety and depression are likely to affect the other measures examined (Distress; quality of life, FACT Total; overall health, QWB; mood disturbance, POMS TMD), and may be one reason why differences between groups and the interaction had negligible effect sizes. The social support measure used in this study is a broad measure of social support. It is the only measure examined where there was no significant change in participants' scores over time. However, there was a small effect in the difference in change scores between EI and TAU groups. This may suggest that participants may have included the website as a source of social support, when completing follow up questionnaires for this measure. Nonetheless, it appears that participants' perceptions of total support were no different after the intervention compared to before, even if some of their definitions of support may have changed or expanded.

Another reason for the lack of significant findings on social support may be because of the different ways in which social support may be beneficial. As previously reviewed (Preece, Nonnecke, & Andrews, 2004; Setoyama, Yamakazi, & Namayama,

2011), some individuals may find that supporting others through sharing their experiences to be helpful for them as well, and may be the ones who are more likely to be 'posters' on a website. However, 'lurkers' also benefit from reading others' posts. If a lurker identifies strongly with another's post, they may also receive the benefits of support given to the poster by others' responses to the post. While the lurker may not necessarily feel connected to other members of the group (Preece, Nonnecke, & Andrews, 2004), they may still receive overall health benefits in knowing that others struggle with the similar issues as well as incorporating suggestions given by others. Likewise, minimally engaged users in the TAU group could still receive psychosocial benefits that the increased engagement of the EI group produced.

As it relates to longitudinal data collection, results of this study anecdotally suggest that more frequent contact encouraging active engagement in an OSG may result in less follow up attrition. A higher percentage of participants in the EI group completed posttest measures compared to participants in the TAU group. The higher frequency of contact received by participants in the EI group may have helped the study remain relevant enough to motivate them to complete follow up questionnaires.

While successful for our primary hypothesis, this study also had several limitations. One of these is the low sample size for each group. Small effects sizes for several analyses beyond those explicitly measuring engagement suggested that low power may be one reason for lack of significant findings on psychosocial measures and time to post data. Future studies should try to increase the number of participants in each group to increase power to detect significant differences.

Furthermore, there were a large number of participants in the EI group who explicitly requested their withdrawal from the study. This is likely due to their being contacted more frequently, thus providing them with additional opportunity to explicitly remove themselves from the study. No participants in the TAU group explicitly withdrew. While this increased frequency of contact may promote increased participant withdrawal, it also provided more information on why participants specifically withdrew. This information is often unavailable when participants drop out. The reason given by all participants who explicitly withdrew is that they did not have the time to engage in the website. This finding is in line with a study by Gorlick, Bantum, and Owen (2014) on minimally engaged participants. Their results indicated that the second most frequently reported reason for low engagement was limited time. This may have been a top reason for low engagement by other members in our study. Paradoxically, this time barrier that OSGs seek to overcome is also a top reason for lack of engagement with an OSG. A participant in the Gorlick, Bantum, and Owen study stated that combined with other ways in which they were dissatisfied with the website, they were ultimately not interested in spending their time on the website. Even if limited time is a potential confounding factor in OSG engagement, if dissatisfaction with the other parts of the OSG (e.g., number of active participants in a group) is reduced, participants may choose to allocate more time towards engaging more with the website.

While other components of our intervention (e.g., both phone and email contact, specific suggestions to engage in blog and chat, tutorial packets to help with navigating the website) likely contributed to increased engagement, it is unclear which of these had the most impact. As mentioned earlier in the discussion of carry over effects, future

studies should isolate each of these components as individual and randomized interventions, to see which of these has the largest effect on engagement. This will help improve efficiency of the engagement by concentrating energy on those components that are likely to help overcome barriers to engagement, such as time.

Another limitation of this intervention is that it is time consuming, and ultimately not cost effective, to implement. While the intervention was largely successful in promoting engagement with the website, this is not likely to be implemented in natural settings as we did. To do this would incur a higher cost to the owner of the website to staff more hours to contact non- and low engaged participants more frequently. This supports another reason for why future studies should isolate the different components of our study and experimentally test them. Having better information on which component is more effective would make contacting participants more efficient and ultimately more cost effective. Identifying those components that are more likely to improve engagement may allow for specific automated reminders, which will likely improve cost-saving benefits of the website.

Finally, the majority of participants in this study were highly educated, middle-aged, married white women with histories of breast cancer and much experience using the Internet. These results may not generalize to others in the less represented demographic groups examined. Further study is required to better elucidate the effects of these demographic variables on engagement in larger and more diverse samples. Another limitation is that the participants in this study were also recruited from a national women's advocacy organization. Thus, the participants in this study may represent a

subset of highly motivated participants, and our results may not generalize to other breast cancer survivors.

These results are promising in that engagement was measured in a variety of ways, within various self-directed, professionally facilitated, and socially interactive domains which may help future studies better target and improve engagement. Overall, this study provided useful information about the importance of varying types and amount of contact to promote engagement with an OSG. Providing specific encouragement to engage in synchronous and asynchronous parts of the website, which would allow participants to share their experiences, provide support, and receive support may have helped improve overall engagement with the website as well. Ultimately, with more active users, the website provided many different ways to encourage interaction among participants and engagement with the website.

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**APPENDIX A**  
**POSTAGE-MAILED PACKET**

**Frequently Asked Questions**

Hello there, [participant]! Thanks again for joining the group, we are really happy to have you here! You should have received a few messages to your email and your message inbox on the website detailing some of the things that you can do on health-space, with two of the main activities that we encourage being to blog and post responses to the weekly guidance exercises and to join the weekly chat. Different things affect members' participation on the website, so we wanted to highlight some of these in case you were already thinking about these, or think about them in the future. You will also find attached pictures of different pages on the website to help you find different links in case you need some help with this:

- How secure is this group?
  - The group is secure. Only registered health-space users and the study investigators have access to the information you might share on the health-space website. Once you complete the study, your information is not shared with any other party. The health-space.net website is offered as part of a research-based study, but we report results of the study in aggregate only and make sure that no one can link you specifically to this study.

However, as with all information exchanged over the Internet, there is a risk that your information could be intercepted by a malicious third party

(i.e., hacker), so we encourage you to be cautious in sharing any information that could be used to steal your identity.

- Do I have to share everything I post with the group?
  - No, you don't have to. You can still blog responses to the guidance exercises and make them private. Any other blogs that you post to the website can be kept private. Although it will be more beneficial than not blogging at all, we still encourage members to respond to each others' posts as this interaction had added benefit. We respect your decision to share as much or as little as you want.
- I get a lot of emails from the group whenever someone post something, is there any way to turn that off?
  - Yes, there is. Each notification email you receive has a link that you can click on to opt out of receiving notification emails from the website. However, because you would not be receiving these notifications, it would be very important to remember to sign in once a day to see what other members have posted and respond.
- I can't attend the chat at the time that it occurs now.
  - Please let your facilitator know as soon as possible if you are unable to make the chat time (Wednesday evenings from 5-6:30 Pacific or 8-9:30 Eastern). We can try to find an extra time to offer another group if enough members are interested in another time. You can post a message to the group soliciting feedback, or create a poll on the website to see if other members are facing this same challenge.

- When I go to the chat room, I can't seem to get in.
  - One thing is to make sure that the browser that you are using (i.e., Internet Explorer 8, Internet Explorer 9, Mozilla Firefox, Apple Safari, etc) has the most recent version of Java. If that doesn't work, send a message through health-space.net to TechSupport, which is listed as one of the members of your group. You can also send an email to [info@health-space.net](mailto:info@health-space.net), or try calling 1-800-395-1595 to let us know what difficulties you're having, and we will try our best to help you resolve them.
- I'm pretty shy, and it takes some time for me to get to know others.
  - It's ok! ☺ One of the great things about being online (and one of our members has mentioned this in the past) is that people only know as much as you want to tell them. Also, because the members in the group are from all around the country, the chances are pretty small that anyone would know who you are. You can increase your anonymity by using a non-personal screen name, and refer to yourself only by that name, and by not uploading any pictures of yourself.
- I'm still not sure if I want to do this. On the one hand I can see how being part of the group can help me, but on the other hand, I'm not sure if I really want to do this.
  - That's ok. One thing that you may find helpful, is to make a list for yourself detailing the reasons in favor of joining and being active in the group and reasons in favor of not joining. Oftentimes, these help people



to clarify what they want to do and help them move forward in one direction or another.

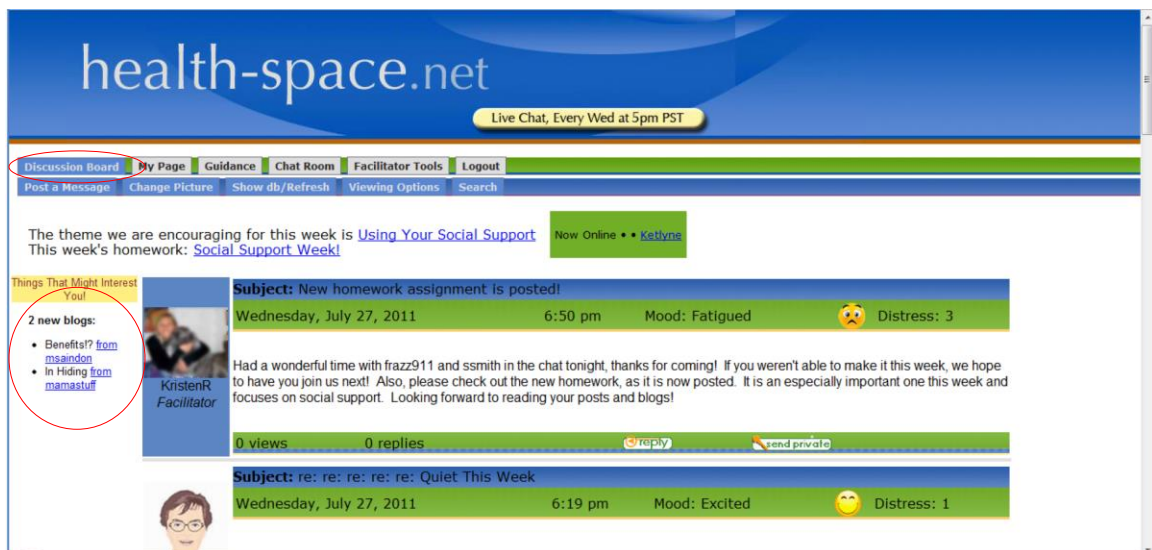
- I'm really excited to get started, how can I help myself stay on track?
  - One great way to stay motivated to do pretty much anything we do on the website is if you have any people that you know personally that you trust and feel are generally supportive of you, you can try to involve them. Having someone who cares check in, support, and motivate us in reaching our goals, is a great way to help us stay interested in achieving that goal.

You can also try planning in times in your schedule to read the guidance exercises and blog your responses. Having that set time can help to structure your time so that you know that it's coming up, rather than try to do these activities when you find the time. With the chat, part of its appeal is that you can log in from anywhere, however, similar to in-person group meetings, you have to make the time commitment to be there every week. Sometimes this may mean temporarily re-arranging your schedule, if you can, for the twelve weeks of the study. Simply being aware of how to arrange your time is another way to help yourself stay active in the group.

creenshots

The **DISCUSSION BOARD** is the first page that you see when you log in. It is also your home screen. In this guide, red circles and arrows will point out where these tabs would appear on your screen.


You can see how many new messages you have in your inbox, and how many new blogs have been posted, with direct links to read them.



## Discussion board → Viewing Options (2<sup>nd</sup> row of tabs)

The first row of tabs are your main tabs, and are always visible no matter what page you are viewing. The selections for the second row may change depending on which of the 1<sup>st</sup> row tabs that you select.

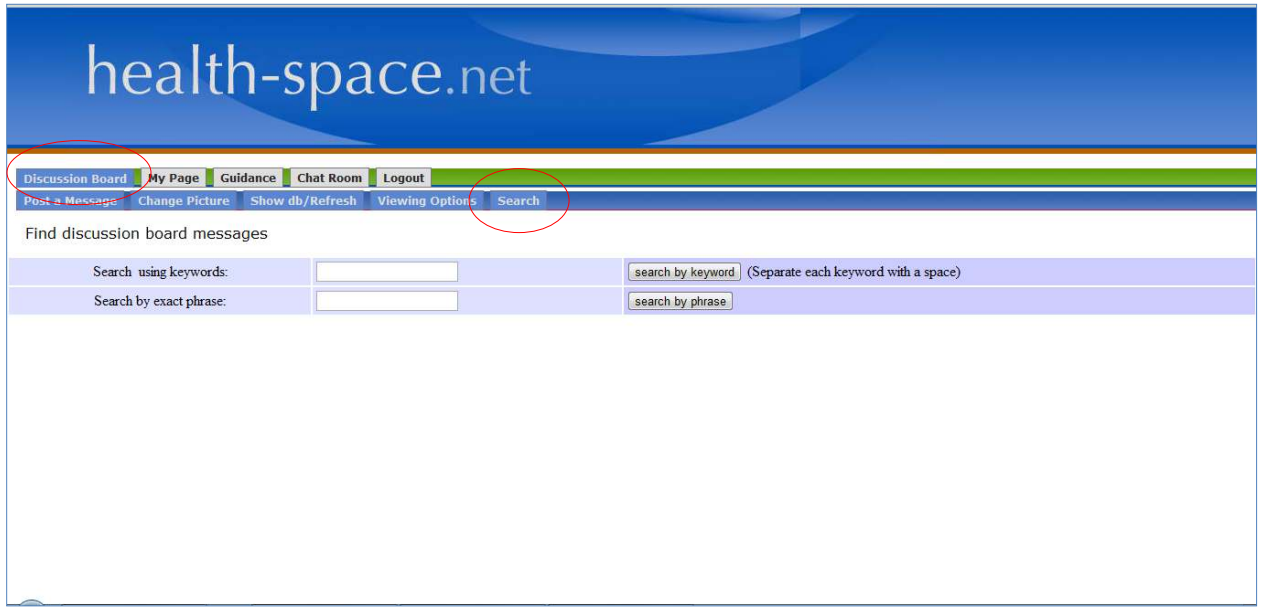
You can have the discussion board display postings as far back as is available, including those from before you joined the group.



The screenshot shows the health-space.net website interface. At the top, the logo "health-space.net" is displayed in white on a blue background. Below the logo, a yellow button indicates "Live Chat, Every Wed at 5pm PST". A navigation bar contains several tabs: "Discussion Board", "My Page", "Guidance", "Chat Room", "Facilitator Tools", and "Logout". Below this bar, a secondary row of tabs includes "Post a Message", "Change Picture", "Show db/Refresh", "Viewing Options", and "Search". The "Viewing Options" tab is circled in red. Below the navigation, there are links for "Past 24 hrs", "Past Week", "Past 2 Weeks", "Past Month", and "All", with "Past Week" also circled in red. A "Now Online" indicator shows "Katelyna". The main content area displays a list of posts. The first post has the subject "New homework assignment is posted!" and is dated Wednesday, July 27, 2011, at 6:50 pm. The mood is "Fatigued" and the distress level is 3. The post content reads: "Had a wonderful time with frazz911 and ssmith in the chat tonight, thanks for coming! If you weren't able to make it this week, we hope to have you join us next! Also, please check out the new homework, as it is now posted. It is an especially important one this week and focuses on social support. Looking forward to reading your posts and blogs!". The post shows 0 views and 0 replies, with buttons for "reply" and "send private". The second post has the subject "re: re: re: re: re: Quiet This Week" and is dated Wednesday, July 27, 2011, at 6:19 pm. The mood is "Excited" and the distress level is 1. The post content begins with "Thank you all for your thoughts & support. Will fill you in on the wedding late this weekend".

## Discussion Board → Search

The search is performed on anything ever posted on discussion board, not just how far back your view goes.



The screenshot shows the health-space.net website interface. At the top, the logo "health-space.net" is displayed in white on a blue background. Below the logo is a navigation bar with several tabs: "Discussion Board", "My Page", "Guidance", "Chat Room", and "Logout". The "Discussion Board" tab is highlighted in green. Below the navigation bar is a secondary menu with links: "Post a Message", "Change Picture", "Show db/Refresh", "Viewing Options", and "Search". The "Search" link is circled in red. Below the navigation bar, the text "Find discussion board messages" is displayed. There are two search input fields. The first is labeled "Search using keywords:" and has a text input field followed by a "search by keyword" button. A note next to the button says "(Separate each keyword with a space)". The second is labeled "Search by exact phrase:" and has a text input field followed by a "search by phrase" button.

## My Page

Here is where you can edit your profile. You can say as much or as little as you like.

health-space.net

Discussion Board | **My Page** | Guidance | Chat Room | Logout

Edit Profile | My Home | My Group | My Page | My Mailbox

**My Account**

**Photos**

see my page as others see it

Edit Profile

**Mailbox**

Inbox | Write Mail

From	Date	Subject
kristen	7/26	Want a real connection? Come to the chat tomorrow evening!
jackieg	7/19	re: re: re: re: re: re: Welcome JackieG!
kristen	7/19	The Place To Be is the LIVE CHAT tomorrow (Wed) at 5 PM (PST)!
katsew	7/18	re: Hi Katsew!
jackieg	7/15	re: re: re: re: re: Welcome JackieG!
kristen	7/13	Addendum for Chat Reminder!
jackieg	7/12	re: re: re: Welcome JackieG!
kristen	7/12	Live Chat Tomorrow at 5 PM PST!
jackieg	7/11	re: Welcome JackieG!
debinn	7/6	re: re: re:
debinn	7/5	re:
kristen	7/5	Please Join Us in the Live Chat Tomorrow at 5 PM (PST)!
relray	7/1	Which Module to Read
		Reminder for Live Chat tomorrow

News | Blog | Polls

**There is a NEW message on the Coping and Mindfulness discussion board.**  
 posted by KristenR on Friday July 29 at 3:39 pm  
 Read more about it in the [Guidance area!](#)

**Friends**

- friendship needs nurturing
- friendship needs nurturing
- acquaintance

## My Page → My Page

Here is one place where you can upload your blog. You can also easily find any posts that you have made to the discussion board.

Ketlyne

Ketlyne's Blog



**My Interests:** I enjoy singing, dancing, and reading (and have recently figured out a way to do more of that, yay!), and pretty much anything that gets me up and moving. I enjoy running anywhere outside of a gym because I like the changing scenery. I also spending time with my family and friends and try to make the most of the times that I spend with them. I have my quirks and one of the things that I love so much about them is that they let me be myself. I love, love, love the ocean...A LOT; there is just something about the sounds of the waves and the smell of the sea that takes me to another place :-)

**My cancer story:** I used to be a nursing assistant and have

running anywhere outside of a gym because I like the changing scenery. I also spending time with my family and friends and try to make the most of the times that I spend with them. I have my quirks and one of the things that I love so much about them is that they let me be myself. I love, love, love the ocean...A LOT; there is just something about the sounds of the waves and the smell of the sea that takes me to another place :-)

**My cancer story:** I used to be a nursing assistant and have worked with patients with many different diagnoses, including cancer patients receiving treatment. My experiences there are what led me to become a clinical psychology student to help patients who are dealing with some pretty serious illnesses, and I have since gained one year of experience providing therapy. I have also been involved on the recruitment end of Health-Space and am now excited to be working a little more actively with the website to provide therapy along with the rest of the team. I look forward to doing my part in helping you to cope with your diagnosis and learn something about myself in the process.

## My Page → Edit Profile

These are prompts to help you describe yourself and your story, there are more prompts available than are displayed here. You can also choose to make your responses to certain prompts private, so that other group members cannot see them when they visit your profile.


health-space.net

Discussion Board My Page Guidance Chat Room Logout

Edit Profile My Blog My Group My Page My Mailbox

Share stuff about YOU with your group members - or check "private" to keep this information private!

**My Photo**

 Replace this photo with --->  No file chosen  want this photo to be your discussion board avatar?

**Cancer Type**

My understanding of my cancer is:   Keep this private

**When Diagnosed?**

**When Diagnosed?**

I was diagnosed:   Keep this private

**My Age**

I am:   Keep this private

**Where I'm From**

I'm from:   Keep this private

**My Family situation**

What you should know about my home or family life:   Keep this private



**My Interests**

Here are the things that interest me most in life:

I enjoy singing, dancing, and reading (and have recently figured out a way to do more of that, yay!), and pretty much anything that gets me up and moving. I enjoy running anywhere outside of a gym because I like the changing scenery. I also spending time with my family and friends and try to make the most of the times that I spend with them. I have my quirks and one of the things that I love so much about them

Keep this private

---

**My Story**

What you might like to know about my life and/or my cancer:

I used to be a nursing assistant and have worked with patients with many different diagnoses, including cancer patients receiving treatment. My experiences there are whar led me to become a clinical psychology student to help patients who are dealing with some pretty serious illnesses, and I have since gained one year of experience providing therapy. I have also been involved on the recruitment end of Health-Space and am now excited to be working a little more actively with the website to provide therapy along with the rest of the team. I look forward to doing my part in helping you to cope with your diagnosis and learn something about myself in the process.

Keep this private

Add this photo --->  No file chosen

**Add Another Photo**

Add this photo --->  No file chosen

**Add Another Photo**

Add this photo --->  No file chosen

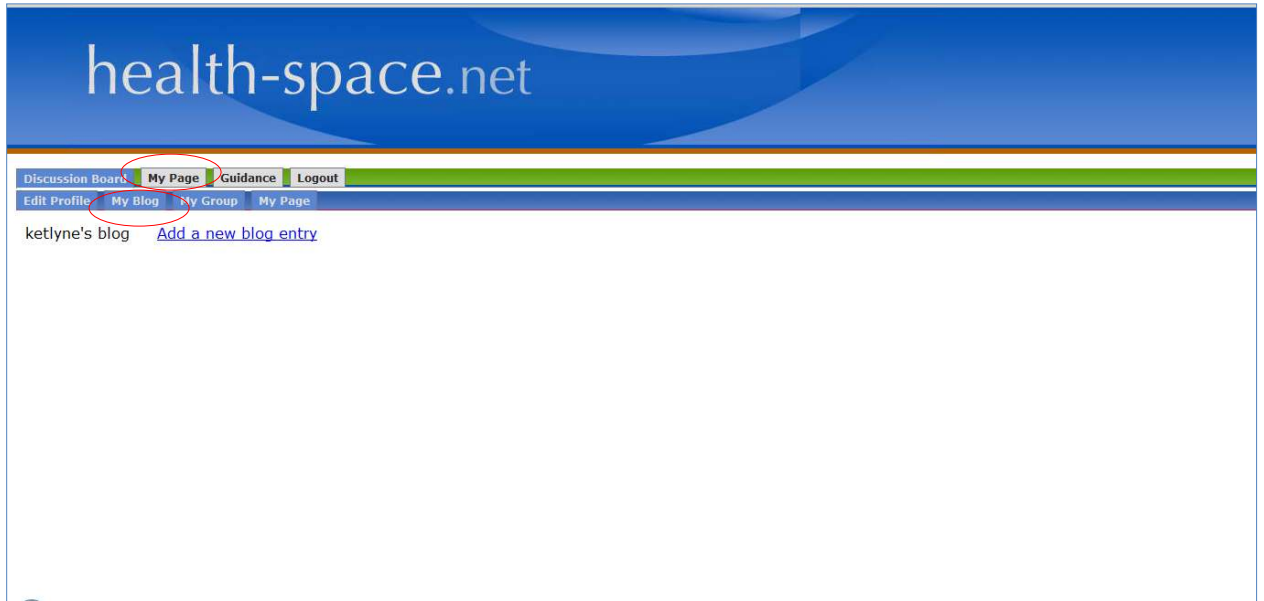
**Add Another Photo**

Add this photo --->  No file chosen

You can add more photos to your photo album, if you like. Just submit these 5 photos and then click "edit profile" again on the next page. Your new photos will show up, and you can add 5 more repeat. Submit and repeat to add as many photos as you like!

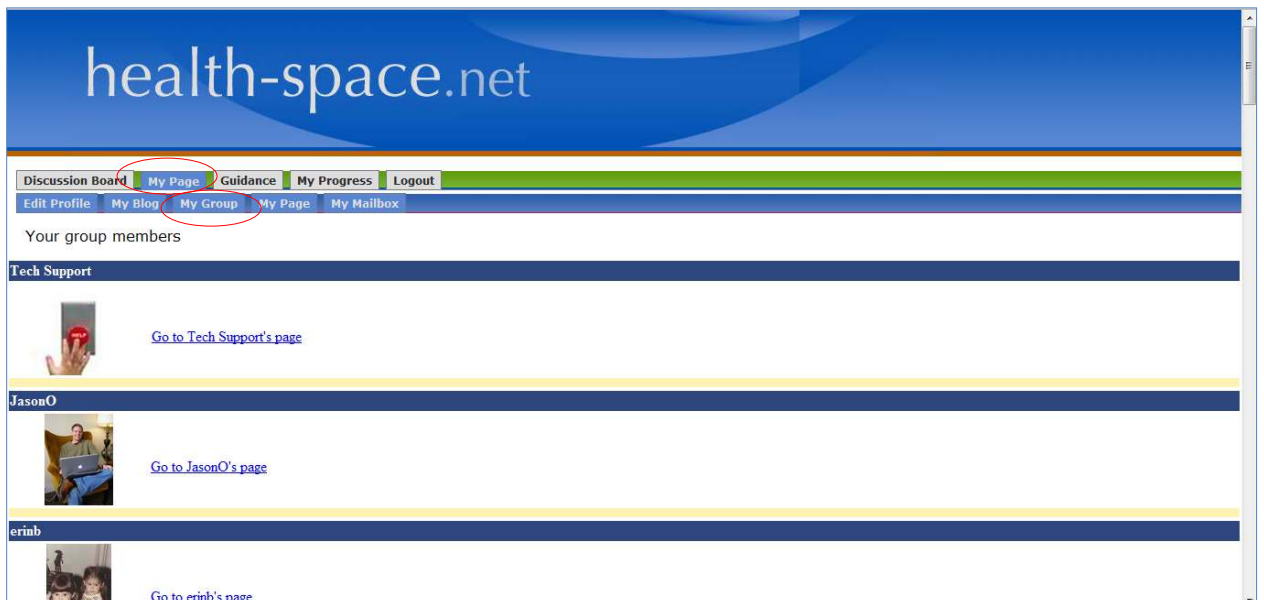
## My Page → My Blog

Another way to access your blog and upload new blogs.

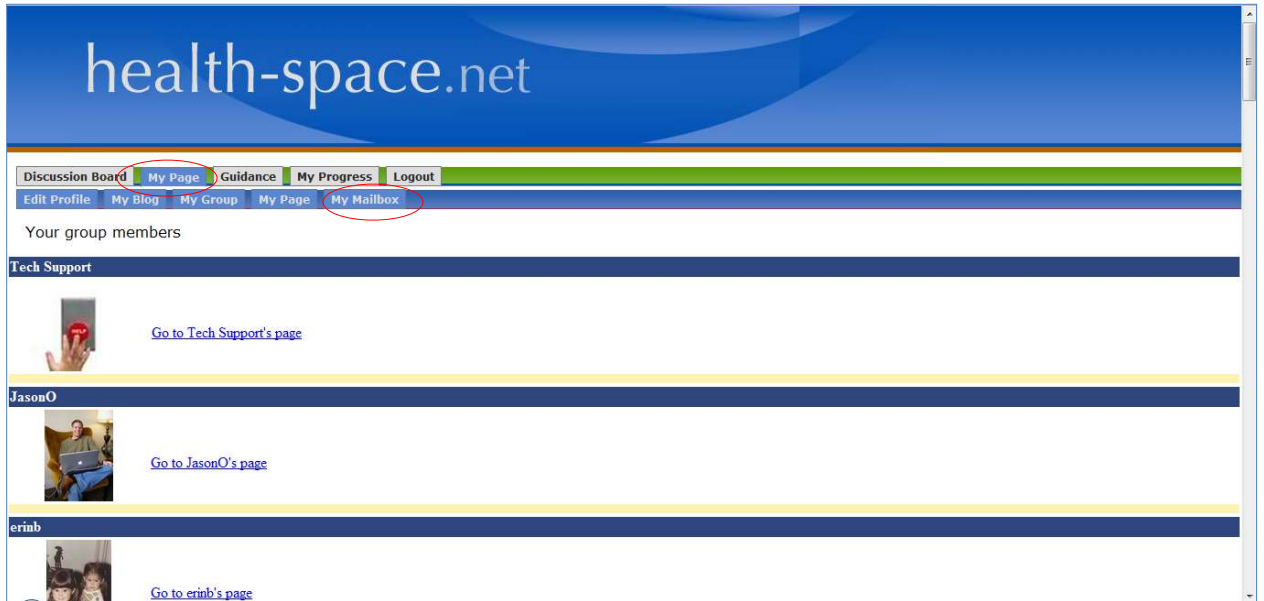


## My Page → My Group

To see who is currently in the group, and read their profile to get to know them.



## My Page → My Mailbox




health-space.net

Discussion Board **My Page** Guidance My Progress Logout


Edit Profile My Blog My Group My Page **My Mailbox**

Your group members


Tech Support

 [Go to Tech Support's page](#)

JasonO

 [Go to JasonO's page](#)

erinb

 [Go to erinb's page](#)



health-space.net

Discussion Board My Page Guidance **Chat Room** Logout

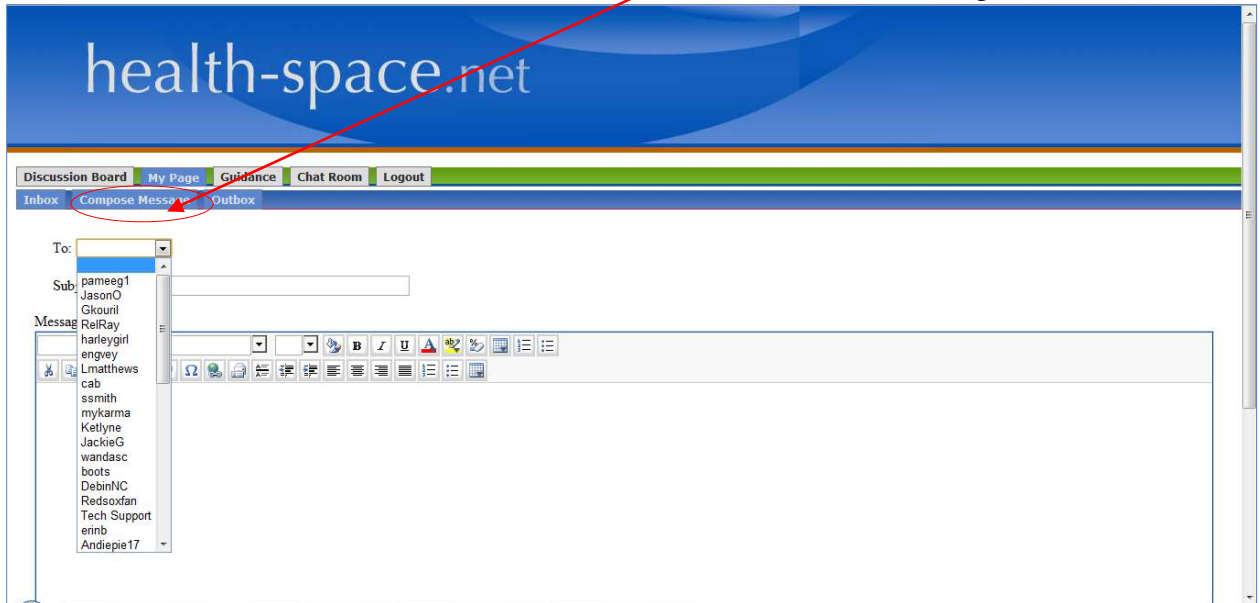
Inbox Compose Message Outbox

 **Mailbox**

Replied	New	From	Subject	Date	Time
		kristen 	<a href="#">Want a real connection? Come to the chat tomorrow evening!</a>	July 26, 2011	10:24 am
		jackieg 	<a href="#">re: re: re: re: re: re: Welcome JackieG!</a>	July 19, 2011	10:11 pm
		kristen 	<a href="#">The Place To Be is the LIVE CHAT tomorrow (Wed) at 5 PM (PST)!</a>	July 19, 2011	4:35 pm
		katsew 	<a href="#">re: Hi Katsew!</a>	July 18, 2011	9:07 am
		jackieg 	<a href="#">re: re: re: re: Welcome JackieG!</a>	July 15, 2011	5:24 am
		kristen 	<a href="#">Addendum for Chat Reminder!</a>	July 13, 2011	12:56 pm
		jackieg 	<a href="#">re: re: re: Welcome JackieG!</a>	July 12, 2011	11:27 pm
		kristen 	<a href="#">Live Chat Tomorrow at 5 PM PST!</a>	July 12, 2011	9:50 pm
		jackieg 	<a href="#">re: Welcome JackieG!</a>	July 11, 2011	9:50 pm

My Page → My Mailbox → Compose Message

drop-down menu to choose from list of recipients for the message




## Guidance Exercises

These are weekly activities that discuss a variety of topics ranging from thinking patterns to personal relationships. We ask members to read through these exercises and blog responses to each week's topic. You can see the full list of topics, as they would appear on your computer screen, below.

health-space.net

Discussion Board My Page **Guidance** Chat Room Logout

Current Topic All Coping Tools My Bookmarks



# Nucare Workbook

Introduction	week 1: Mindfulness and Coping	week 2: Social Support
--------------	--------------------------------------	------------------------------

Introduction	Mindfulness and Coping	week 2: Social Support
week 3: Self and Body Image	week 4: Healthy Lifestyle	week 5: Self efficacy
week 6: Relationships	week 7: Ways of Thinking	week 8: Self Talk
week 9: Relaxation and Imagery	week 10: Disclosing Thoughts and Feelings	week 11: Goal Setting
	week 12: Benefit Finding	

www.health-space.net/cgi-bin/db.pl?action=guidance&action2=show&action3=nucare\_1&sessid=937501712&subjectid=99979&location=nucare\_index

## Chat Room

Note: You will need the need most recent version of Java for the browser that you are using in order to access the chat room

Enjoy the conversation, ketlyne!

Action Options Mobile Help

You have joined room: KitchenTable12  
Welcome!

ketlyne 1

## APPENDIX B

### MESSAGE #2

#### Message #2 (sent from school email account)

Subject line: Checking in about health-space.net

Hi there [participant],

My name is \_\_\_ and I am a research assistant on health-space.net. [Ten – Fourteen] days have passed since you've been in the group and I just wanted to check in and see how things have been going for you. I noticed that you [add as many that apply; note: choose the second one only if none of the rest apply], thanks so much for doing that!

- have not been back to the website
- have spent more time on the website since joining the group
- have created a profile
- joined last week's chat
- posted a response to the guidance exercise
- posted to the discussion board

[However, I/I also] noticed that you haven't [name activity they haven't done, i.e., joined the weekly chat, responded to the guidance exercise, both]. Your responses in the preliminary questions indicated that you were [Stage description for chatting, follow the rest of the decision tree].

Your responses also indicated that you were [stage description for blogging, follow the rest of the decision tree].

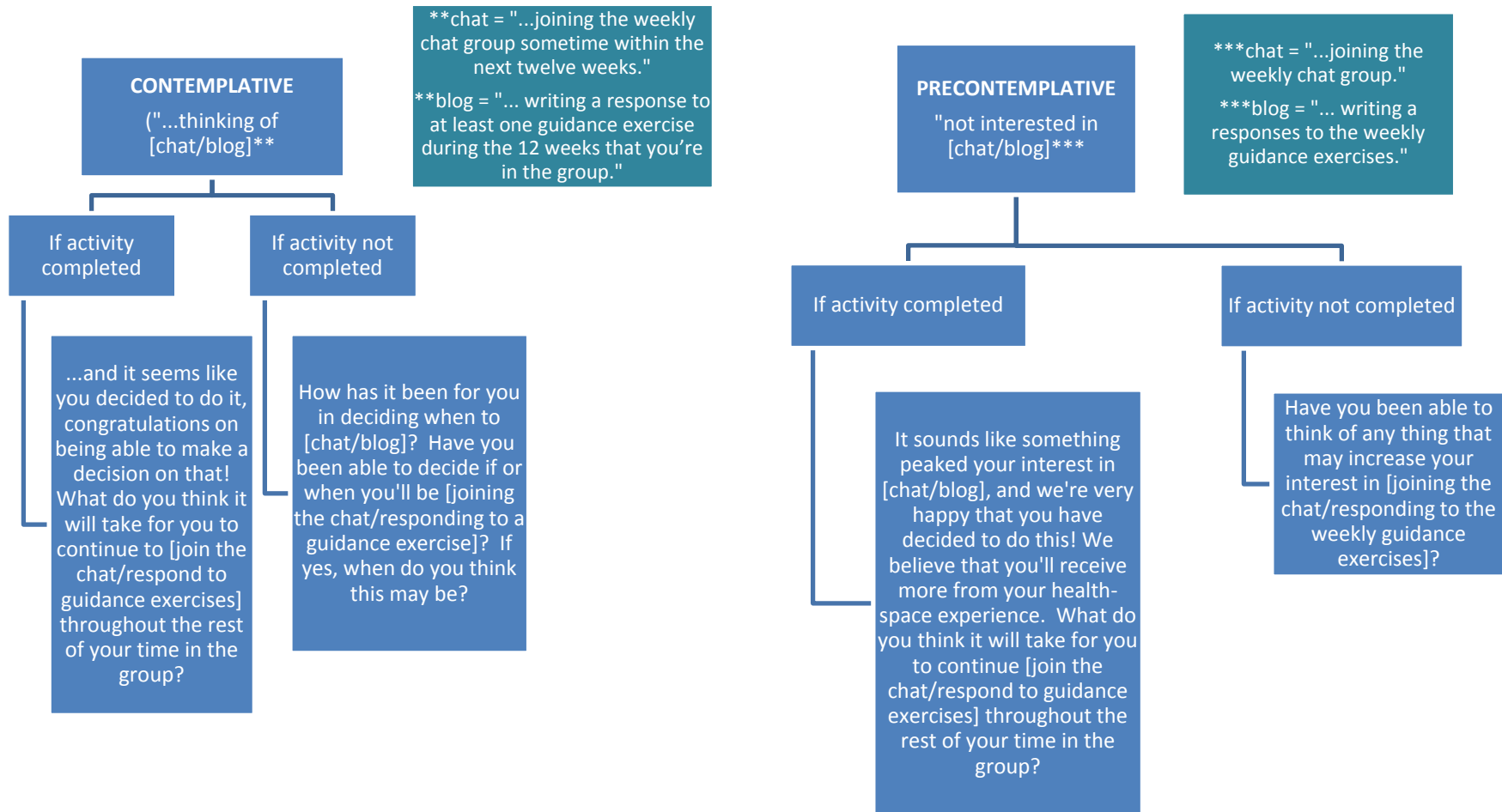
Is there anything that we, at health-space.net, can do to help? Would you let us know if there is? I hope to see you online soon!

Have a great day,

[Research assistant]







~These are the general templates for tailoring the second message. Please make changes as necessary to allow for better flow of the message.

## APPENDIX C

### MESSAGE #3

#### Message #3 (generic; sent from school email account)

Subject: Checking in about health-space.net

Hi [participant]! I noticed that it has been some time since you've [been on the website/done any of the activities on the website] so I just wanted to check in with you to see how you are doing. As you may remember from other messages, we encourage members to write responses to the weekly guidance exercises, respond to other members' posts, and join the weekly chat group (Wednesdays at 5 pm PST or 8:00 pm EST). I respect your decision not to do these activities, but we feel that you'll get the most from the group by doing at least one of them. Is there anything that you feel that I or any of the other facilitators can do to help to make this better experience for you? If so, can you please let us know? We will definitely try our best to help.

I look forward to hearing back from you!

-[Research assistant]

---

Template for doing only one activity:

Hi [participant]! I noticed that it has been some time since you've posted a blog on the website so I just wanted to check in with you to see how that is going for you. As you may remember from other messages, we encourage members to write responses to the

weekly guidance exercises, respond to other members' posts, and join the weekly chat group (Wednesdays at 5 pm PST or 8:00 pm EST). I did notice that you have been [joining the chat group/posting blogs], which is a great way to help you get alot from the group. We feel that you can gain even more from the group by [joining the weekly chat/blogging on the weekly topics]. Is there anything that you feel that I or any of the other facilitators can do to help to make this better experience for you? If so, can you please let us know? We will definitely try our best to help.

I look forward to hearing back from you!

-[Research assistant]

## APPENDIX D

### MESSAGE #4

#### Message #4 (sent from school email account)

Subject line: Following up about health-space.net

Hi there [participant],

[Amount] weeks have passed since you've been in the group and I just wanted to check in and see how things have been going for you. I noticed that you have [list activities participant has done], and I wanted to thank you so much for doing that!

Your responses to the preliminary questions that you answered when you signed up to join the group indicated that you were [delinquent activity stage description]. However, I noticed that you haven't [done specific activity] in quite some time, so I wanted to check in about that. Has anything changed since you joined the group that has affected your [being able to respond to the exercises/join the weekly chat]? We understand that you may have many things that need your attention. Adding [responding to the guidance exercise/joining the chat] does increase that list. One thing that may help you make a decision about [writing a response to the weekly exercise/joining the weekly chat] is to find reasons in favor of [writing responses to the weekly exercises/joining the chat] and reasons against doing this. This chart may help you with that. Also, it may be helpful to think of any benefits you received from [joining the chats that you have joined/writing the guidance exercise blogs that you posted], and (if any) reflect on whether you'd like to continue receiving these benefits for yourself.

Reasons to [join weekly chat/post responses to guidance exercises]	Reasons not to [join weekly chat/post responses to guidance exercises]

If there anything that we, at health-space.net, can do to help, would you please let us know? I hope to see you back on the website soon!

Have a great day,

-[Research assistant]

## APPENDIX E

### PHONE CALL POINTS OF FOCUS

#### Phone Call Points to Focus On

- Before the call, find out what participant has done on the website
- If no answer, leave the following message:
  - **“Hello, my name is \_\_\_\_\_, and this message is for [participant’s real name]. I’m calling from health-space.net and I was calling to follow up with you about your experience with the website. I would really appreciate it if you would return this call so we can speak some more, it won’t take much time. You can call me back 1-800-395-1595. I’ll be here \_\_\_\_\_, so you can try to call back during that time if you can. I’m looking forward to speaking with you!”**
- During the call
  - Introduce yourself and your purpose
    - **“Hello [Mr/Ms Real Name]. My name is \_\_\_\_\_ and I’m one of the members on the health-space.net team. We like to check in with people to see how their experience of the website has been, and this call won’t take very long. So how has it been going for you?”**
  - Discuss web activity
    - **IMPORTANT: If they are doing more one activity but not the other (i.e., chatting but not blogging), do not focus too much on what they’re not doing. Bring it up and move on.**

- If no activity
  - “I noticed that you haven’t done anything on the website yet, so I wanted to check in with you to see if you were having any trouble using the website, or if anything else was affecting your usage of the website.
  - Weave in participant’s responses to preliminary questions screening motivation to engage in the chat and in the guidance exercises.
- If some activity
  - “I noticed that you [list activities already completed], thanks so much for doing that!”
  - If any of these activities correspond to (or is more activity than participant initially indicated they’d be doing) participant’s initial responses to the chat/guidance screener questions, point this out to participant and praise for following through with that.
- Using the decision tree from Tailored Message # 2 template will be helpful for this.
- If person says that they are no longer interested in blogging/chatting, reassure them that they won’t receive any more calls from us, but ask them if they would still be willing to remain the study to complete the different questionnaires.



- Suggestions for tailoring interventions from DiClemente and Velasquez in chapter, “Motivational Interviewing and the Stages of Change,” in *Motivational Interviewing* (by Rollnick and Miller):
  - **Try to pick up on 1 or 2 themes of what they’ve found on the website and try to go with those for the conversation**
  - **Possible technique: Extreme reflection, i.e., “Yeah this is not for you.”**
  - In conversations with the **Precontemplator**, there are four different types that you should pay attention to:
    - Reluctant - *passively reluctant to change to desired behavior, in this case joining chat and/or blogging*
      - allow them to verbalize their reluctance
      - use reflective listening
      - provide feedback about benefits of the website/chatting/blogging
    - Rebellious - *often have a lot of knowledge about the “problem behavior”, in this case not joining the chat or blogging; they like making their own decisions, don’t like being told what to do*
      - provide menu of options (i.e., responding to others’ posts, posting to discussion board posts, reading guidance exercise, writing in response to guidance exercise, getting over s good)
      - encourage to think about choices available, like small incremental changes

- Resigned precontemplator - *have given up on the possibility of change and seem overwhelmed by the problem*
  - help them build their confidence by assisting them in making the decision, to begin with a small change and affirming success they have
  - instilling hope and exploring barriers to change are the best ways to help these people
- Rationalizing precontemplator - *often appears to have all the answers (in favor of not changing behavior); feel like you're in a debate with them*
  - empathy and reflective listening work for these types
  - start with a decisional balance exercise, but start with the pros for not changing then try to get them to do the cons
  - double sided reflections
- **Contemplator:**
  - **Highlight perceived benefits of website and what part of website they can use while recognizing freedom of choice.**
  - find out how long they've been thinking about joining the website
  - help them think through the benefits of joining and any risks that it may pose for them

- try to instill hope that they can receive some benefit from the website
  - important that they receive accurate information about the website and the importance of that on them
  - make info personally relevant by using info shared by participant to make the behavior change appealing to them
- **Preparation/Action:**
- assess commitment to change behavior by seeing what kind of plan they have to make the behavior change successful
  - reflective listening
  - if any plan, see if realistic and if they have a contingency plan in place to serve as back up in case initial plans failed
  - using motivational interviewing to help participant creatively work out a plan
  - gently use suggest strategies that have worked with other clients; gently warn against warn against strategies that seem ineffective or inappropriate
  - careful listening and affirming that they are doing the right thing
  - affirmation for what they have accomplished and assurance that they can continue to make the desired changes.
  - Overall help build up self-efficacy for chatting/blogging