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LOMA LINDA UNIVERSITY  
School of Science and Technology  
in conjunction with the  
Faculty of Graduate Studies

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An Expanded Behavioral Model for Online Support Services

by

Laura Boxley

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

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September 2011

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

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## ABSTRACT OF THE DISSERTATION

### An Expanded Behavioral Model for Online Support Services

by

Laura Boxley

Doctorate, Graduate Program in Clinical Psychology  
Loma Linda University, September 2011  
Dr. Jason Owen, Chairperson

The rapid expansion of online technologies and health resources has created opportunities to develop broadly available interventions to address the needs of the modern patient. This study proposes a theoretical structure based on Andersen's Individual Determinants of Health Service Utilization Model to describe who is using online support and how it is being used. Also unique to this analysis was the use of objective behavioral data to describe and predict website utilization, and linguistic analysis to evaluate the content of what is shared in online groups. Eighty-four men and women completed baseline evaluations and were randomized into either online support or a waiting-list control condition. The overall theoretical structure did not produce a significant model; however the individual variables education, past online experience, and time spent online were predictive of participation. The somewhat unexpected finding that those with no prior online group experience and those who were high school educated were more likely to participate is discussed. If replicated, these findings may lend support to the idea that online interventions could provide needed support to individuals who do not typically participate in face-to-face interventions, and that the barriers to online group participation are not the same as the barriers for face-to-face group participation.

# **CHAPTER ONE**

## **INTRODUCTION**

Technological advances have changed our everyday lives in innumerable ways, including the ways in which we consume health information. This change has been not only rapid, but exponential; whereas in 2002, 73 million Americans stated that they had looked online for health information, in 2006, 113 million stated that they had sought health information in any one of 17 distinct categories (Fox, 2006). Eight million Americans daily are getting online to access health resources, comparable to the frequency at which they spend doing other activities such as paying bills online or searching for addresses and phone numbers. As the internet becomes increasingly accessible, the pervasive influence of online applications becomes more powerful.

With the evolution of health and consumer behavior research, traditional methods of health education, communication and support are beginning to be viewed as insufficient in addressing the complex behaviors and context of the average American. “Generic messages to ‘stop smoking’, ‘eat 5 a day’ or ‘get a mammogram’ are not adequately customized to the needs of diverse populations to motivate or sustain behavioral changes” (Neuhauser & Kreps, 2008, p. 367). While television, radio and print media have been extensively used to address health issues, research indicates that these forms of media may not be sufficiently compelling mechanisms of intervention (Backer, Rogers, & Sopory, 1992; Serdula et al., 2004). Online education, support and intervention applications provide an opportunity for healthcare providers and academics to articulate their message in a novel, personal, and possibly more effective way.

In a national study of health behavior, The Pew Internet and American Life Project (2009) found that 42% of all adults say they or someone they know has been helped by following medical advice or health information found on the internet, representing a substantial increase from 25% in 2006. Increasingly, patients are looking for personalized information and social resources, with 41% of patients reporting that they have gone online to read about someone else's health or medical issues on online newsgroup, website or blog (Fox, 2009). These individuals are actively seeking out information through technology, with 19% report having signed up to receive updates about health or medical issues, and 13% reporting that they have listened to a podcast about health or medical issues. With the momentum surrounding online health resources, opportunities exist to develop broadly available interventions to address the concerns and needs of the modern patient. Online resources are a new medium evolving with technology, access and social ideals; as such, social scientists are currently faced with a long list of tasks, two of the most fundamental being who is likely to use these resources and how are they currently being used.

Existing studies evaluating the use of online resources have taken a predominantly descriptive approach, identifying characteristics and predictors of online support group use outside of a theoretical model. This study proposes a theoretical structure based on Andersen's Individual Determinants of Health Service Utilization Model (Figure 1), to describe who is using online support and how it is being used. This proposed model, the Expanded Behavioral Model for Online Support Services, will characterize the predisposing, enabling and illness level variables associated with online support group utilization (Figure 2). Also unique to this analysis is the use of objective

behavioral data, such as keystroke level analysis, to describe and predict utilization. In addition to behavioral data, linguistic analysis will be used to probe beyond keystrokes and identify how the content of what is shared in an online group is associated with online resource use.

### **Emergence of Online Health Resources**

The current enthusiasm surrounding online health resources is not unfounded: In a March 2005 PEW study, 12% of the adults surveyed (representative of approximately 17 million people) stated that the internet ‘played a crucial or important role as they helped another person cope with a major illness’ (Fox, 2005). Furthermore, 7 million individuals reported that ‘the internet played a crucial or important role as *they* coped with a major illness. Online health resources come in many permutations; organizations such as the American Cancer Society ([www.cancer.org](http://www.cancer.org)) have provided large, generally educational websites, while The Wellness Community ([www.thewellnesscommunity.org](http://www.thewellnesscommunity.org)) has focused on private, scheduled chat room group support sessions. What these sites do not provide, however, are comprehensive private online group support and psychoeducation services for individuals with confirmed cancer diagnoses. The current randomized clinical study provides these services, while collecting physical and mental health data over the course of the study, along with web access and keystroke data. The development of online resources requires considerable investment. The effectiveness of these resources has the potential to be improved by conducting detailed observations of the needs and behaviors of the target audience. Randomized clinical trials, strategic website design and observational study of online behavior provide novel methods for

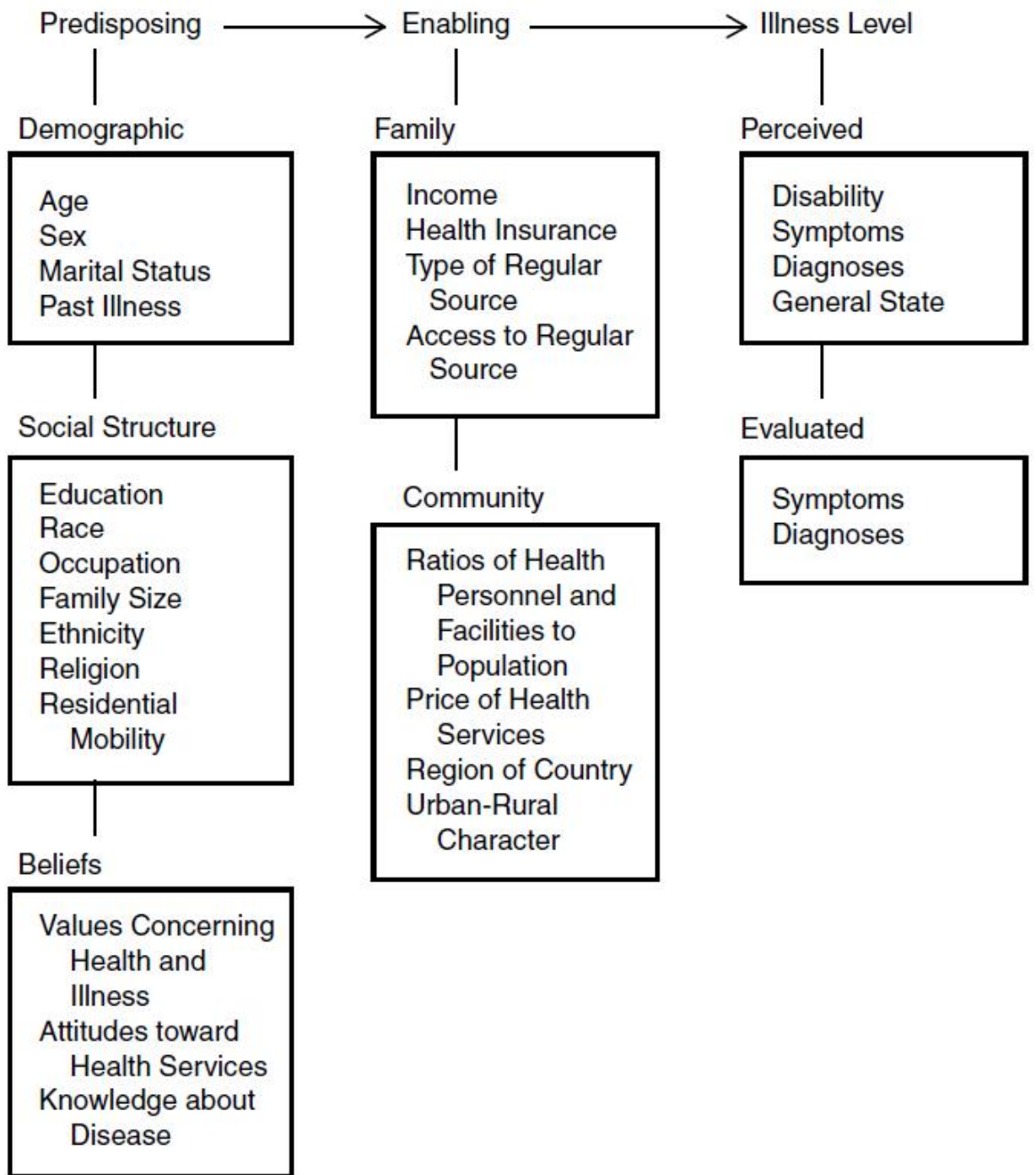


Figure 1: Andersen's Individual Determinants of Health Service Utilization Model

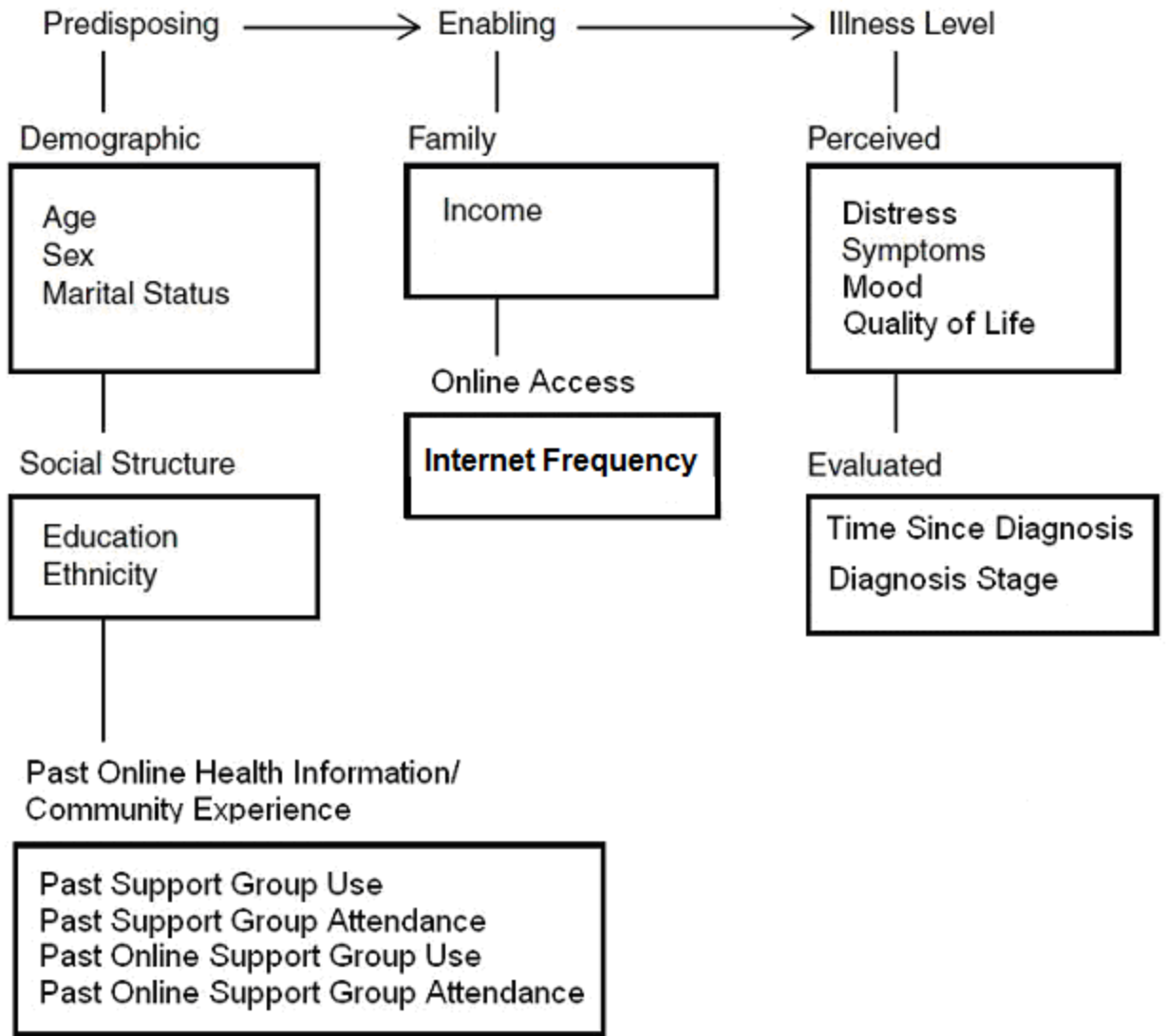


Figure 2: Expanded Behavioral Model for Online Support Services

evaluating the mental health needs of cancer survivors and testing the efficacy of psychosocial interventions.

### The Problem of Cancer

Cancer poses a significant challenge to many Americans, and is one of many patient populations who may benefit from online interventions. The National Cancer

Institute's Surveillance Epidemiology and End Results (SEER) data from 2004 to 2006 suggests that 40.58% of men and women born today will be diagnosed with some form of cancer during their lifetime ([www.seer.cancer.gov](http://www.seer.cancer.gov)). In 2009 alone, SEER data estimates that 1,479,350 Americans will be diagnosed with some form of cancer, and 562,340 will die from cancer. With over 11 million men and women in the United States currently living with a history of cancer (of any type), there is significant need for modern, effective interventions that address issues such as screening practices, diet, exercise, as well as mental health. Research conducted over the past 20 years has demonstrated that online interventions can improve health education and health behavior, reduce cancer risk, improve screening practices and improve patient care (Eysenbach, 2004; Kreps, 2006; Neuhauser & Kreps, 2003; Revere & Dunbar, 2001; Buller et al., 2008).

### **Psychological Repercussions of Cancer**

Cancer not only challenges one's physical health, but also challenges one's mental health. Research suggests that 22-50% of individuals diagnosed with breast cancer meet diagnostic criteria for depression, while 3-19% meet criteria for acute stress disorder (Morris, Greer, White, 1977; Lasry et al., 1987; Cordova et al., 1995; Alter et al., 1996; Green, et al., 1998; Andrykowski, Cordova, Studts & Miller, 1998). Mermelstein and Lesko (1992) report rates of depression 4 times that of the general population and Maraste et al. (1992) describe rates of anxiety as high as 14%. Common anxiety specific problems cited by patients include anxiety about recurrence (Mahno, Cella et al., 1990), sexual dysfunction (Fallowfield & Hall, 1991), death anxiety (Spiegel & Glafkides, 1983), and occupational difficulties (Tross & Holland, 1990).



This distress can not only be acute, it can be chronic: 20-30% of patients may suffer severe distress for two years or more post-surgery (Ganz, Lee et al., 1992; Browne et al., 1990). In a recent National Health Interview Survey of the factors that contribute to serious psychological distress among long term cancer survivors, the likelihood of experiencing distress was associated with younger age (less than 65 years of age), being unmarried or not living with a partner, having less than a high school education, and the presence of comorbid illnesses (Hoffman, et al., 2009). When evaluated for distress in the past 30 days, long term cancer survivors were found to be more likely to have significant psychological distress than the non-cancer comparison group (5.6% versus 3.0%), however at a rate lower than others have estimated. Interestingly, after adjusting for race, relationship status, education, insurance, comorbid illness, smoking, and activities of daily living, cancer survivors are still more likely to experience serious psychological distress when compared to those without cancer. Specifically, 25% cancer survivors with comorbid illness under the age of 45 report serious psychological distress. Of those long term cancer survivors who reported distress, 33% report having seen a mental health professional within the past 12 months, while 18% reported that they could not afford it. Hoffman and colleagues (2009) describe possible contributors to distress among cancer survivors, including delayed health effects, secondary cancers, difficulties in functional adjustment, and neurological complications.

Several factors may tax one's coping skills when they receive a cancer diagnosis. Cancer may disrupt one's social environment by both physically removing them from usual patterns (doctors appointments, reduced mobility, etc) and disrupting interpersonal relationships, as friends and loved ones may feel reticent to engage the patient as they

have in the past (Courens, Stevens, Crebolder & Philipsen, 1996). Indeed, Strang and Qvarner (1990) observed that 85% of cancer patients reported less self-initiated contact with friends and 65% reported that the intensity of their pain caused their isolation. Decreased communication is particularly problematic, given that social support has both a both psychologically and physically protective influence (Berkman, Leo-Summers et al., 1992). Social affiliation not only has positive emotional effects, but may also reduced one's overall mortality risk and is as strongly related to age-adjusted mortality as smoking. (House, Landis et al., 1988).

### **Psychosocial Support and Intervention Strategies**

Psychosocial interventions for cancer often include one or more of the following strategies: psychoeducation, cognitive-behavioral techniques, supportive-expressive therapy, and/or pharmacological treatment. These methods may be used individually or in tandem to address symptoms and side effects of treatment (pain, fatigue, nausea and vomiting), psychological comorbidities (depression, anxiety), and end of life issues (advanced directives, existential issues, palliative care). Psychosocial support has widely been associated with improved psychological and behavioral outcomes. In a meta-analysis of 43 randomized controlled trials, Ross, Boesen, Dalton and Johansen (2002) found that 70% of the studies reported significant differences between those who participated in the control group versus those who had participated in the intervention arms of psychosocial studies. Furthermore, 23 of the studies reflected improvements in one or more areas of well-being such as emotional adjustment, pain, anxiety and depression. In an evaluation of possible pathways by which interventions may work,

Graves (2003) found that interventions with social cognitive components such as improving self-efficacy (skills training, goal setting), outcome expectation (cancer survivor testimony, behavior modeling) and self-regulation (relaxation training, self-monitoring) had a greater impact on global affect, depression, social, physical outcomes and quality of life than interventions that did not include social cognitive elements.

Some have suggested (controversially) that psychosocial support is associated not only with improvements in psychological health, but also with improved rates of survival. Spiegel, Bloom and colleagues (1981) found that following supportive group therapy participation, their patients were less anxious, less phobic, less depressed, and decreased their use of denial over time, while patients in the control condition receiving routine care emotionally deteriorated. Additionally, support group members in this study reported experiencing half the pain of the control group. Ten years after the intervention treatment group members lived an average of 18 months longer than the control group participants (Spiegel, Bloom et. al., 1989). Fawzy and colleagues (1993) also contributed evidence to the possible survival benefits of groups support among cancer patients, finding that skin cancer patients who had participated in a 6 week therapy group 5 to 6 years prior had lower mortality than the control group. However, several attempts at replicating these studies have failed (Spiegel et al., 2007; Cunningham et al., 1998; Goodwin et al., 2001). In a review of this controversial literature, Coyne, Stefanek and Palmer (2007) critically reviewed the study design, interpretation, and reporting of these studies and concluded, “no randomized clinical trial designed with survival as a primary endpoint and in which psychotherapy was not confounded with medical care has yielded a positive effect”. Despite the controversy, research continues with new support for the survival benefits of

supportive-expressive group therapy for cancer patients (Spiegel et al., 2007) as well as new criticism and contradictory findings (Kissane, Grabsch & Clarke, 2007). What the authors of both of these studies may agree on is that group therapy provides measurable emotional benefits that are valuable independent of possible survival benefits (Spiegel et al., 2007).

It is important to acknowledge, however, that the benefit of participating in psychosocial interventions may be moderated by the individual's level of distress or resources. For example, Goodwin et al. (2001) found that among women with breast cancer participating in a supportive-expressive support group, those who were more distressed reported benefiting from participation, while those who were less distressed did not. Helgeson and colleagues (2000) similarly found that individuals who initially reported fewer personal resources and less social support benefited more with respect to improved physical functioning than those who began the intervention with adequate support. Furthermore, those with higher levels of support before entering the study actually saw a decrease in physical functioning following participation in the peer discussion group. The relationship between distress and benefit also appears to extend across cancer diagnosis and gender; Helgeson, Lepore, and Eton (2006) found that men with relatively low self-esteem, prostate-specific self-efficacy and more symptoms of depression benefited most from a psychoeducational intervention.

The overall impact of psychosocial intervention on the quality of life a cancer patient, however, seems encouraging. In a meta-analysis of quality of life, treatment modalities and clinical parameters, Rehse and Pukrop (2003) observed an effect size of 0.31, suggesting that psychosocial interventions could make a significant difference in

the quality of life experienced by cancer patients. Specifically, there is significant evidence to suggest that psychosocial interventions can have an impact on improved coping strategies such as pain management (Thomas & Weiss, 2000), nausea reduction (King, 1997) and ameliorating fatigue (Ahlberg, Ekman, Gaston-Johanson, & Mock, 2003; Ream & Richardson, 1999), as well as reducing psychological symptoms such as depression (Fukui et al., 2000; Classen, Butler & Koopman, 2001; Mantovani, Astara & Lampis, 1996) and anxiety (Classen et al., 2001; Fukui, Kugaya et al., 2000). A small group of studies have also suggested that psychosocial interventions can significantly impact the end of life issues that emerge from the diagnosis and treatment of cancer (Cole & Pergament, 1999; Georgesen & Dungan, 1996; Mitchell, Lannin, Mathews, & Swanson, 2002).

### **Group Support for Cancer Survivors**

There are many hypotheses with respect to how and why group therapy (in its many forms) works. Social Comparison Theory hypothesizes that affiliative behaviors increase under conditions of high anxiety (Davison, Pennebaker & Dickerson, 2000). Social-Cognitive Processing Theory (Lepore, 2001) suggests that trauma related distress may remain elevated if the individual fails to engage in suitable discussion of his or her thoughts and feelings regarding the traumatic experience. Lepore's model suggests that patient distress is the result of a failure to assimilate or accommodate challenging events into existing belief systems. Generally, cognitive and emotional processing may be facilitated in a supportive online environment by the expression of both thoughts and feelings regarding a cancer diagnosis (Creamer et al., 1992). Research in emotional

expression and adjustment to cancer suggests that active processing and emotional expression lead to improved long-term psychological adjustment (Stanton et al., 2002). Successful, long term psychological adjustment requires a supportive social environment where one feels they can share their thoughts and feelings, as well as process traumatic events (Lepore, Sliver, Wortman, & Wayment, 1996). Furthermore, patients with fewer social constraints tend to have higher emotional intelligence and less distress (Schmidt & Andrykowski, 2004).

While discussing cancer support group research with the Dalai Lama, prominent psychologist David Spiegel asked him why he felt that women with advanced cancer seemed to do better when they faced each other's death directly in a group (Spiegel & Classen, 2000). The Dalai Lama replied,

“When I am worried, I ask one of my assistants to explain to me what I will be doing for the next two days, and then I feel better, because I know what is ahead of me. That is the way we Buddhists feel about death. We spend much time preparing for it. In that way, it is no longer unfamiliar territory.”

The Dalai Lama's comment illustrates from a novel perspective why information and collaboration provide opportunities for skill building and preparation, each of which are valuable factors contributing to well-being. These factors not only aid in addressing the existential concerns associated with cancer diagnosis, but also help the individual decide how they want to embrace life.

A loss of social support, coupled with the health-related distress can leave patients feeling very alone with their problems. Group therapy provides an opportunity to address how frightened and unprepared many patients are for illness. The interpersonal aspects of group are essential to improved outcomes (Lara et. al, 2004). While complaints may be

negatively punished, group support provides an empathic and experienced audience.

Studies of social support suggest that female cancer survivors confide in friends, relatives and partners and are unlikely to seek out mental health care. Furthermore, women report feeling most understood by women friends rather than by their partners (Faller, Schilling et al., 1995). Providing a virtual environment can connect patients from all walks of life who may have difficulty talking to friends and family, finding local resources, who have mobility or pain issues, or perhaps feel reticent to join face-to-face groups.

Verbal acts of writing and speaking provide opportunities for the individual to process and often reframe traumatic events in a supportive environment. In a study of 13 expressive writing interventions across multiple diagnoses, Smyth (1998) observed that writing about one's thoughts and feelings about stressful or traumatic experiences was associated with positive physical and psychological health. Disclosure and retelling, whether in a face to face group setting, an online discussion board, a public blog, or a personal diary, may garner significant benefits for cancer survivors. While the length and extent of disclosure among these modalities is likely to vary (Owen et al., 2004; Pennebaker et al., 2001), the narratives told in each of these modalities can foster emotional expression, and may be associated with emotion identification and adjustments in world view (Thorton, 2002). Qualitative study of narrative structure suggests that it is not the presence of a well-organized biographical story that is associated with health, but rather that one is actively developing and editing this story and sharing it with others (Ramirez-Esparaza & Pennebaker, 2006).

Whether written or oral, an ideal supportive- expressive group environment is one in which participants are encouraged to confront their problems, strengthen their

relationships, and find enhanced meaning in their lives. In 2001, Classen and colleagues observed that participation in such a group was significantly associated with a decline in both trauma symptoms and mood disturbance (Classen et al., 2001). Similarly, Spiegel, Bloom and Yalom (1981) also observed significantly less mood disturbance on the Profile of Mood States (POMS) scale, fewer maladaptive coping responses, and less phobia among treatment versus control groups.

Intervention groups may also positively influence emotional regulation. In a study of supportive expressive group therapy and changes in coping, Giese-Davis (2002) reported significant reductions in suppression of negative affect and improvements in the restraint of aggressive, inconsiderate, irresponsible and impulsive behaviors. Similarly, Cameron and colleagues (2007) found that breast cancer patients participating in their 12 week intervention reported increased usage of emotion regulation strategies such as alteration of emotional arousal (relaxation techniques), emotional expression, and cognitive reappraisal (increased perceived control, decreased perceived risk of recurrence). The control group receiving standard care, however, did not report these changes. Overall, intervention participants reported more improved emotional wellbeing, cancer worry, anxiety and coping efficacy when compared to standard care controls. Continued benefit was observed at the 6 month assessment mark, when participants reported more relaxation use when compared to baseline and sustained levels of perceived control. In contrast, control participants reported decreases compared to baseline. Sustained differences in perceived risk, worry and efficacy were not evident, however, at 6 month and 12 month follow up.



## **Predictors of Use of Face- to-Face Support Groups**

Broad population characteristics have been identified as being influential with respect to support group utilization. Across diagnoses, Owen found that support group use was predicted by female gender, educational achievement, use of other complementary and alternative medicine, depression, presence of a chronic health condition, and self-report of poor health (2007). While Asian Americans and Latinos were found to be less likely to use a support group, no difference was observed between Whites and African Americans. Likelihood of support group utilization was greatest among those who were diagnosed in middle age (45-64), however support group use was not associated with time since diagnosis, cancer interference, or cancer related pain and discomfort. In a related study evaluating the demographic, psychosocial and attitudinal predictors of help seeking after cancer diagnosis, Steginga and colleagues (2008) found that being younger, female, having higher cancer-specific distress, and positive attitudes toward help seeking was associated with use of psychosocial support services. Furthermore, the intention to pursue psychosocial support from a health professional was associated with positive expectations, greater cancer-specific distress and fewer negative attitudes toward help seeking. Dutta and Feng (2007) also observed that those who perceived themselves as being at greater risk for developing cancer were more likely to use online health communities than individuals who did not feel susceptible. Taken together, these studies describe support group members as relatively younger, Caucasian women with perceived need for care and positive expectations toward participation.

Population level study also provides important insights with regard to the relationship between cancer type and support seeking. In a study of the support group use

of approximately 9,000 Californians across health conditions (California Health Interview Survey), Owen and colleagues (2007) found that 23.7% of cancer patients reported having utilized a support group for health reasons, with 11.2% of these groups being cancer specific. Among those who had participated in cancer specific support groups, participation was relatively high among patients with leukemia or Hodgkins disease (41.3%) or breast cancer (25.9%) when compared to patients with skin cancer (3.0%) or lung cancer (0.3%). The number of sessions attended also varied widely by diagnosis, with leukemia and Hodgkins patients attending most frequently (mean number of sessions= 74.1), followed by breast cancer (mean=12.0) and skin cancer patients (mean= 2.5). The reasons for such broad variance in use is unclear, however possible mediators of participation include disease burden, survival rate and access to support services.

### **Benefits of Support Group Use**

Among those who chose to participate in face-to-face support groups, most appear to garner benefits, as psychosocial interventions for cancer survivors have been shown effective in producing improved outcomes. In a meta-analysis of cognitive behavioral and education intervention strategies Osborn, Demoncada and Feuerstein (2006) found that cognitive behavioral strategies were related to short term benefits in both depression and anxiety, and long term effects in quality of life. Other meta-analyses investigating psychosocial interventions for cancer patients have also found small to moderate effect sizes for reducing stress, (Ledesma & Kumano, 2009) reducing cancer-related fatigue (Kangas, Bovbjerg & Montgomery, 2008), decreasing anxiety symptoms (Luebbert,

Dahme & Hasenbring, 2001) and improving quality of life (Graves, 2003; Rehse & Pukrop, 2003).

The variety of groups available may also be an influential factor in patient outcomes. In a recent meta-analysis, Zimmerman and colleagues evaluated 56 psychosocial cancer intervention studies looking at the overall effectiveness and potential moderators of group support for breast cancer patients (2007). When looking at breast cancer specific groups versus mixed cancer groups, mixed group interventions including cognitive behavioral therapy, relaxation and education, achieved higher effect sizes than the homogenous breast cancer group. Effectiveness also varied by treatment approach; psychoeducation (e.g., Dura & Ibanez, 1991; Helgeson et al., 1999; Edelman et al., 1999) garnered moderate effect sizes overall, with small effect sizes for cognitive behavioral (e.g., Allen et al., 2002; Antoni et al., 2001; Kissane et al., 2003), relaxation (e.g. Burish & Jenkins, 1992); Walker et al., 1999), and supportive therapy approaches (Classen et al., 2001; Giese-Davis et al., 2002; Goodwin et al., 2001). Of note, the timing of the intervention was significant, as patients who were recently diagnosed or recently had surgery found more benefit from cognitive behavioral therapy and education interventions than those who were currently under medical treatment. These results concur with Fawzy et al. (2000) who found that structured interventions that focused on health education, stress management, coping and group support were more beneficial for early stage or recently diagnosed patients. In light of these results, the authors suggest that early stage patients may have a unique need for psychosocial intervention compared to those at later disease stages. The Zimmerman study underscores the efficacy of

education, relaxation and cognitive behavioral strategies in group support, areas that may have significant potential when designing analogous online services.

### **Moving Psychosocial Interventions Online**

The positive effects of cancer support groups have the potential to transfer well to an online environment. Internet support groups for cancer have been shown to increase social support, reduce social isolation, increase personal empowerment, improve self esteem (Im, et al., 2007), as well as reduce depression and cancer related trauma (Houston et al, 2002; Lieberman et al. 2003 ;Winzelberg et al. 2003). Second to only alcoholics, cancer patients are the most likely to seek and offer online support (Davison, Pennebaker & Dickerson, 2000) when compared against 20 disease categories. Furthermore, individuals with breast cancer were found to have formed over 40 times as many online support groups as heart disease patients, a patient group for which psychosocial and behavioral interventions could substantially benefit. Taken together, these findings suggest that online group therapy may be an acceptable option for cancer survivors with benefits similar to those reported in face to face interventions.

### **Patient Attitudes Toward Online Support**

In a study of patient attitudes toward online support (Im et al., 2007) participants reported that they were looking for emotional support, interaction with other survivors and information. Interestingly, “many of the participants were much more satisfied with ICSGs (internet cancer support groups) compared with traditional face to face support groups because they could avoid uncomfortable personal face to face interactions with

strangers, they did not need transportation for ICSGs and they could get more up to date information through ICSGs” (p. 709). Other participants stated that they preferred the online group because they fit more flexibly around their time commitments, stating that they felt isolated by their busy schedules or geographic locations, and that ICSGs, “provided them with a channel to reach out to other patients with cancer in similar situations”. When asked about why she favored online groups, one patient wrote:

“It is nice when you can’t sleep at 2 am and you can get on and talk to others that are in the same boat” and “when I was working it took all of my energy and now that I’m on my fifth line of chemo it has taken all of my energy. But the online support groups are there all the time, so that was helpful.”

Most participants valued being a group member, wanting “meaningful interactions with other because they tended to have difficulties interaction with their family members and friends because of their disease.” They also explained that they didn’t like groups where other participants were unresponsive or where they felt they didn’t get enough attention from moderators. Issues of privacy, anonymity and confidentiality were also concerns for most participants. Studies such as this are the minority and much more research is needed with respect to patient beliefs, especially those of minorities.

### **Use of Online Support Groups in the Population**

Davison, Pennebaker and Dickerson (2000) suggest that “virtual support occurs at higher rates among patients whose conditions, although not necessarily life threatening, are debilitating in ways less responsive to purely medical care.” In this national study, the highest level of support (both online and face to face) was found among alcoholism, AIDS, breast cancer and anorexia populations. The lowest levels of support were found

in hypertension, migraine, ulcer and chronic pain groups. The highest rates of participation were observed among multiple sclerosis, chronic fatigue, breast cancer and anorexia populations. Furthermore, “On-line and face-to-face support patterns were significantly correlated, suggesting that broad tendencies to seek support do vary by diagnostic category” (p. 214).

In a population level study of online support group use among those with chronic health problems, Owen et al. (2009) evaluated characteristics associated with both online and face-to-face support group use and perceived benefit. Investigators found that among Californians living with chronic health concerns, 16% had used a face to face group and 1.8% had used an online group. Those who had chosen online interventions were generally had more education, higher income, poorer health status and had used other complementary and alternative therapies (CAM). Furthermore, online support users were more likely to have reported depression, anxiety, stroke, diabetes, cancer and arthritis. Seniors and Latinos, however, were less likely to report having used an online group.

In a 2004 study evaluating breast cancer patient access, availability and perceived interest in online support, Owen et al. found that approximately 70% of patients reported internet access and 45% enrolled in the intervention group. The accessibility of internet access also varied by age, with 90% of women 45 or younger reporting access, compared to 63.3% of women 46-55, 65.6% of women 56-65, and 28.6% of women 66-75. None of the women over the age of 75 reported online access. Of interest, 65.9% of patients surveyed reported that they expected equivalent or better outcomes from online interventions when compared to face to face groups. Owen suggests that as younger women may be especially likely to utilize online resources due to lifestyle constraints,

such as the need to balance work with childcare and/or caring for a dependent elder. Furthermore, individuals with diseases that have a lower mean age of diagnosis may also benefit from online mediated support.

### **Barriers to Online Support Group Participation**

The reasons why patients chose not to participate are difficult to ascertain, making it problematic to discuss why some online therapy resources tend to have lower levels of participation when compared to traditional forms of therapy (Waller & Gilbody, 2009). While studies demonstrate clinical efficacy in providing psychoeducation and social cognitive therapies (Graves, 2003; Zimmerman, 2007), substantial numbers of participants are lost in recruitment with little explanation of attrition. Among those who were recruited, the Waller and Gilbody suggest that dropout rates among computer mediated cognitive behavioral therapy were higher than traditional therapy, with only 56% completing the full intervention in this study. Among these individuals, personal circumstance was a more commonly cited reason for dropping out than technology literacy or social background. In light of their findings, Waller and Gilbody (2009) call for more research attending to barriers of participation and soliciting more feedback from patients who chose to drop out. In an analysis of 16 computer-mediated cognitive behavioral therapy studies, Kaltenthaler and colleagues (2008) found comparable dropout rates when compared with traditional therapy, however take-up rates were much lower among the computer mediated groups. Six of the studies reviewed asked participants about the acceptability of the computer mediated service upon completion, several reporting positive expectations and high satisfaction with their experience.

While active members are readily observed (in convenience samples), it can be more difficult to assess the experience of inactive patients or those that opt out (Owen et al., in press). Estimates of passive participation vary, however Nonneck and Preece (2000) found that 46% of health related online support group members were composed of ‘lurkers.’ When the investigators asked both health support and non-health support group users why they chose to lurk, participants cited: 1) concerns for privacy, 2) they felt no need to post, 3) a need to find out more about the group, 4) respect for other’s time and attention restrictions, 5) no skills to make the software work, and 6) no “click” with the group dynamics (Preece, Nonnecke & Andrews, 2004). Active participants differed from lurkers in that lurkers indicated that they participated online to get information while active participants indicated that they participated, to offer expertise, enjoy oneself, entertain others, build a professional relationship, tell stories, participate in conversation, make friends, get empathic support and be a group member (Preece, Nonnecke & Andrews, 2004; Nonnecke, Andrews & Preece, 2006). Active participants also visited online groups more often to see “how others were doing, to enjoy themselves, as part of their daily routine and because other members expected them to be there. While active participants and lurkers did not differ in information-related interests for online participation, lurkers were generally older and more recently diagnosed. Lurkers significantly differed by reports of less enhanced social well-being, however did not differ on measures of “being better informed, feeling more confident in the relationship with their physician, improved acceptance of the disease, feeling more confident about treatment, enhanced self-esteem and increased optimism and control. Little is known about the potential impact of lurking behavior, however it appears that both active and



passive participation in online groups could provide positive outcomes. That said, passive participants may need some form of support and disclosure if they were not receiving support online, as inhibition has been associated with increased rumination, anxiety, mood disturbances, physiological arousal, and increased rates of illness, seeking care or physical symptoms (Henderson et. al., 2002). Finding ways to maintain contact with individuals who chose not to participate or who participate passively is an important component of patient care that warrants further inquiry. Adjustments in direct contact, dynamic behavioral monitoring, or improved intervention design may provide ways of improving support utilization and satisfaction.

### **The Application of Online Technology to Support Groups and Skills Training**

Online support groups come in many different permutations. Fundamental to these groups, however, is the presence of either synchronous (real time chat rooms) or asynchronous (discussion board or listserv) conversation, whereby members post messages read by other members of the group (Yalom, 1995). Groups can be either public or private, and of limited or undetermined length of time. Internet groups also vary with respect to whether they are purely a peer to peer service, or whether they are professionally moderated. In addition to a site's basic communication functions, developers may include applications such as health related didactics, psychoeducation modules, personal profiles and blogs to provide additional opportunities for social interaction and information utilization (Weis, 2003). The advantages of online resources include the potential for 24 hour accessibility, cost-effectiveness, interactivity, social

networking, multimedia capacities, anonymity and tailoring (Fernsler & Manchester, 1997; Klemm et al, 2003; Madara & White, 1997; Galinsky et al., 1997). These advantages are evidenced by their impact: about 1/3 of online health seekers said that they or someone they knew had significantly benefited from the information and advice they received online (Global Reach, 2004).

### **How Online Support Groups Work**

To participate on an asynchronous discussion board, individuals simply require a web enabled computer. After connecting to the board's website and entering a username and password, they are generally linked to discussion board or a discussion board index. The discussion board itself often has a central window listing member comments, or “posts,” next to their user name. The content of the discussion progresses from top (newest post) to bottom (oldest post), with each post listed on top of the previous. Some discussion boards provide a small window for typing and submitting posts directly on the discussion board page ([forums.networkofstrength.org](http://forums.networkofstrength.org)), while others provide a link to a separate page where one can type and submit their message ([Health-space.net](http://Health-space.net)). Many boards have additional features such as the ability to post pictures, audio, and video. The specific advantage of the discussion board in comparison with face to face groups or synchronous chat is the lack of a required meeting time; discussions progress at their own pace 24 hours a day with group members logging in at their own convenience (Weis, 2003). As a result, minutes or hours can pass between posts, making the pace of conversation variable. The typically slower pace of discussion board conversation,

however, is easier to follow than chat room conversations which can be rapid and require solid typing skills to keep up (White & Dorman, 2001).

Accessing a synchronous web chat is similar and straightforward. To participate in the conversation, all group members must be logged on to the intervention website at a scheduled time (Bender, O'Grady & Jadad, 2008). To view the chat room, participants log in with a specific screen name and password. The screen display for a basic chat room is divided into 3 parts: a window displaying who is logged into the chat room, a central window listing the posts each individual makes during the online conversation, and a window from which the user types and submits their messages (Meier et al., 2006). When a member of the group submits a text comment, the message is added in real time with the newest comments loading from the bottom. To read earlier comments, participants scroll upward. Only the participants who are currently logged on can read and submit comments. It is not uncommon, however, for website administrators to make transcripts of the online discussion available for download to help those who were not able to attend the group's session stay updated on group topics (thewellnesscommunity.org).

### **Models of Online Intervention**

The theoretical frame under which an online group or intervention is developed is largely dependent on the philosophy of the developers. For example, groups like Bosom Buddies ([www.bosombuddies.org](http://www.bosombuddies.org)) are structured based on the Supportive-Expressive Group Therapy Model, providing an asynchronous peer support network for cancer survivors (Carey, 2005). Other sites such as the American Cancer Society's

(www.cancer.org) take a predominantly psychoeducation approach, while Shaw and colleagues (2000) used an existential-phenomenological approach to describe the giving and receiving of support in an online environment. As previously discussed, face to face intervention studies that include elements such as psychoeducation and social cognitive techniques such as improving self-efficacy (skills training, goal setting), outcome expectation (cancer survivor testimony, behavior modeling) and self-regulation (relaxation training, self-monitoring) are more likely to have a significant impact on patient outcomes than standard care (Zimmerman, 2007; Graves, 2003). While these studies lend support to the underlying theoretical frame for these interventions, the field of online support is very young and lacks a definitive online psychosocial intervention model.

### **Outcomes of Online Cancer Support Groups**

While the research supporting face to face cancer support groups is robust (Classen et al., 2001; Spiegel & Bloom, 1983; Cain et al., 1986), the development of online cancer support groups remains in its infancy. In a review of the current research on online cancer support groups, Klemm and colleagues (2003) identified just 10 eligible studies for evaluation. All ten studies were descriptive studies based on convenience samples mainly focusing the content, use and patient reaction to the online resources. Researchers in 9 of the 10 studies reported that cancer support groups were beneficial to those who participated and helped them cope with their cancer, however Klemm identified several weaknesses to the observed studies including small sample size and homogenous samples: 6 of the 10 studies excluded male participants and 6 focused on

Caucasian women with breast cancer. The authors concluded that there was insufficient data to reach a conclusion about the efficacy of online cancer interventions, and recommend larger, experimental designs that address both short and long term benefits, diverse cancer types, mood disturbance and coping. The authors also highlight the need for outcome measures and the inclusion of ethnic and gender diversity.

To date, three randomized trials have evaluated the effects of an online psychosocial intervention on patient-based outcomes in cancer survivors. In one of these few randomized trials, Gustafson and colleagues (2001) implemented the Comprehensive Health Enhancement Support System (CHESS), a pilot study of a computer mediated intervention providing information services, support services and decision services for breast cancer patients. Women participated in the intervention approximately 6 times per week, with Caucasian women averaging 14.6 minutes per session and minority women averaging 7.7 minutes per session. The difference observed between these groups was attributed to the greater use of the discussion group among Caucasian participants (68% versus 38% of total use). Investigators found that breast cancer survivors demonstrated more competence in seeking information, greater comfort participating in care and had greater confidence in their doctors post intervention. Furthermore, 5 months later the experimental group reported sustained the effects of better social support and informational competence than the control group. The authors add that disadvantaged individuals (minority race, lower education, and lack of insurance) showed the most improvement. No main effects, however, were found for quality of life and breast cancer concerns.

Winzelberg's 2003 randomized clinical trial of a 12 week structured support group for breast cancer patients also provides interesting data with respect to patient use and support group efficacy of online interventions. Study participants accessed the website an average of 34 times and posted an average of 36 messages. Participants were also given access to a personal online journal, however this application was not used regularly, with 14 of the 72 total subjects posting an average of one message.

Winzelberg found reductions in depression, cancer-related trauma and perceived distress following participation with moderate effect sizes (0.38-0.54), comparable to values found in face to face support groups (Sheard & Maguire, 1999; Classen et al., 2001). However, website use variables (such as number of postings and logins) were not significantly associated with outcome variables. On average participants logged in and posted messages 3 times per week, although the range for both logging in and posting was broad. In a 9-item follow up questionnaire asking patients about their experience in the group, participants reported that they used the group for: providing and receiving emotional support, forming new friendships, understanding that their problems were not unique, and confronting difficult problems and fears.

Owen et al. (2005) implemented a self-guided internet-based coping skills intervention to assess the potential quality of life benefits associated with online support and psychoeducation. Of those who participated in the 12 week intervention, 82% reported that the intervention was helpful. On average participants logged in for 35.5 sessions, spending about 3.4 total hours on the website. Participants viewed the discussion board an average of 52.2 times, leaving 9.5 posts. Seventy-three uses of the coping exercises were recorded. While no main effects of treatment were observed,

investigators observed that women with poorer perceived health status experienced greater improvement in perceived health over time than the control group. Further, they identified linguistic indicators of positive change such as greater emotional expression, greater cognitive processing and decreased expression of health concerns. Specifically, expression of sadness was associated with improved quality of life, and expression of anxiety and sadness was associated with a reduction in intrusive cancer-related thoughts. Furthermore, more expression of anxiety, sadness and general negative affect was associated with improved emotional well-being. Of interest, frequent discussion of health-related concerns was associated with poorer outcomes on measures of quality of life, health status, intrusive thoughts and symptom prevalence. Additionally, after controlling for disease stage and treatment variables, more frequent discussion of cancer treatment was associated with poorer emotional well-being. Taken together, linguistic variables provide novel information needed to fully articulate both the experience of patients participating in online interventions and the potential outcomes as a result of participation.

### **Online Support Participation: Utilization, Disclosure and**

#### **Outcomes**

The importance of support and disclosure cannot be oversold, as a positive dose-response relationship has been observed between the number of individuals the participant stated they could confide in and cancer survival rates (Maunsell et al, 1995). Unfortunately 20-30% of breast cancer patients report little or no disclosure to particular facets of their social network (Henderson et al. 2002). Furthermore, 7% inhibited their

discussion of their disease to most or all of their social network. The extent to which one disclosed was predicted by youth, greater disease severity, greater optimism and stress-related growth. Online communities may provide important opportunities for patients to discuss cancer-related feelings and concerns with a knowing audience.

Differences in online participation and disclosure among breast cancer and prostate cancer patients also underline the potential gender and disease related variables that influence involvement. Klemm et al. (1999) observed that breast cancer patients were more likely to share experiential information and were more likely to share support orientated content. Prostate cancer patients, however, were more likely to be information seekers. Owen, Klapow, Roth and Tucker (2004) observed many differences between these two groups. In online discussion boards, Breast cancer patients used more words indicative positive feelings, anxiety, social processes and cognitive mechanisms. Participants in prostate cancer discussion boards used more words indicative of cancer information, disease status, health care facilities and personnel, medical tests and procedures, cancer treatment, cancer descriptions, complementary and alternative medicine, and FDA approved medications. No significant differences were observed between breast cancer and prostate cancer patients with respect to use of words indicating optimism, anger, sadness, causation or insight. There were also no outcome differences with respect to treatment, physical symptoms or side effects. Participants who were largely inactive, submitting just one message to the group, averaged fewer words indicative of cognitive processes, insight or cancer related information.

Programs such as the Comprehensive Health Enhancement Support System (CHESS) have looked specifically at online cancer information use among minority and



low income groups assessing online behaviors. When African American participants did use the discussion board function, they still preferred to discuss treatments (66%), followed by daily life (33%), and emotional response (6%). White women, however, spent more time discussing their daily life (52%) than treatments (39%). Although African American women used the discussion board less frequently, their usage of the boards was focused on treatment issues. Furthermore, after three months African American women had largely discarded the discussion board. White women, however, continued to use the discussion board to “chat” about day to day concerns. It appeared that for African American women, day to day issues were secondary to cancer issues. Other explanations for the attenuation of participation include discomfort sharing online, or perhaps African American participants were receiving sufficient social support in their day to day lives. Notably, the two groups did not differ on the extent of self-disclosure, but rather the frequency at which they discussed personal information. After 2 months, CHESS utilization was associated with reports of improved cognition, decreased negative emotion, improved social support, and shorter hospitalizations (Gustafson et. al. 1999).

In a study of older women, those who used CHESS more frequently improved across emotional health, cognitive functioning and active life variables more than those who used CHESS the least (Gustafson, McTavish, & Hawkins, 1998). Additionally, CHESS utilization has been associated with reports of improved cognition, decreased negative emotion, improved social support, and shorter hospitalizations (Gustafson et. al. 1999). Overall, CHESS studies represent some of the more comprehensive online studies available, shining much needed light onto issues of online support and participant utilization. Taken together, these studies underscore the relationship between

psychosocial, gender, disease and patient utilization variables in describing the differential use of online groups.

### **Online Intervention Research and Development**

Online health interventions are still a burgeoning field, growing quickly like many other fields such as online banking, commerce and entertainment (Fox, 2006). As such, increasing comprehensive and sophisticated methods of observation, measurement and programming are needed to adequately address patient needs in these rapidly evolving environments. Current research has provided valuable information about current trends as well as opportunities for expand existing services, however the online environment is increasingly dynamic. For example, while internet users have been traditionally White and middle to upper class, previously underrepresented groups such as the elderly and minorities are going online at ever increasing rates (Fox, 2006). Also, there are a tremendous number of existing websites on the internet, either thriving or forgotten in a game of social and informational Darwinism. With over two hundred million hits to a typical browser search for ‘cancer,’ successful and impactful online resources must be very well designed and easily accessed to reach their target audience.

When designing online resources, developers face a dynamic market in which online health consumers are increasingly proficient and confident in their ability to find answers to their pressing questions (Fox, 2006). They also use their resources in a complimentary way, combining multiple modes of media, communication and interpersonal contacts to learn more about their disease and to obtain the resources they need to cope (Dutta-Bergman, 2004). These findings underscore the importance of

understanding one's target audience and designing online resources that cater to these preferences and usage patterns. Recommendations offered to improve health communication interventions include: "(1) construct better models that reflect a deeper understanding of dynamic social processes and take into account the great diversity of subcultures; (2) design communication that is more contextual and tailored; (3) create communication that has the reach of mass media and the impact of interpersonal media; and improve the interactivity of communication through the use of multiple and new media" (Neuhauser & Kreps, 2008, p.367).

A knowledge base of the behavioral correlates of online use and participation in health resources is needed for the growth and development of online support services. Specifically, there is a need to quantify variables such as time spent on discussion boards, number of posted messages, time spent participating in online interventions and didactics, and number of logins to help describe user behavior and correlates of benefit. Studies of this kind, however, are rare and require considerable investment in website design and programming to achieve. These types of research designs are necessary, however, as they contribute uniquely to the description of online health behavior and provide an additional tool with which to evaluate online psychosocial resources. Combining the use of automated online keystroke analysis with psychological assessment measures may provide clearer picture of how online health consumers utilize online resources and what variables are associated with improved psychological health and coping.

Generally, there is some evidence to suggest that greater utilization of web site resources such as length of online support use and number of posts may be related to outcomes such as wellbeing (Rodgers & Chen, 2005; Owen et al., 2005). Additionally,

study specific observations suggest that behavioral observation of the website usage by participants can shed light on outcomes. For example, Shaw and colleagues (2007) evaluated the relationship between automatically collected behavioral use data such as web pages visited, time spent on each page, and discussion board participation and reported health information competence. Investigators found that combined use of the discussion board and automated feedback components of the website was associated with amplified learning effects, above that of the automated feedback service independently. The information available on behavioral data and keystroke analysis of online support websites is bleak, underscoring the necessity of applying technical computer skills to psychosocial research. The utilization of web resources and its potential relationship to health outcomes necessitates a theoretical frame under which to fully articulate mechanisms of change. Andersen's (2005) model of health care utilization provides a potential structure under which to begin describing personal, social and technological characteristics that lead to use of online support.

### **Andersen Model of Individual Determinants of Health Service**

#### **Utilization**

Prior to Andersen's model, health care had been largely described in terms of supply and demand (Andersen & Bartkus, 1973). Andersen proposed a framework for predicting health services utilization which takes into account individual and societal determinants in an effort to explain key patterns of health care utilization (Andersen & Newman, 2005). Andersen initially developed his model in the 1960's using national survey data to describe the use of health care among families, to aid in the development

of policy, and to measure and promote equitable access to health care (Andersen, 1995). The strength of this model was its attempt to integrate “the how’s and why’s” of utilization. In subsequent years, Andersen moved away from describing healthcare use in terms of the family unit and toward describing individual healthcare use, finding it more efficient to describe familial influence than attempt to describe families as a homogenous unit (Anderson, 2008). The model has seen other changes over time, including the inclusion of healthcare system variables in the 1970’s to recognize the importance of health policy and the organization of the health care system. The 1980’s and 1990’s saw the addition of personal health practices such as diet and exercise, as well as perceived and evaluated health status. In its most recent phases, Andersen’s model saw the inclusion of aggregate measures rather than traditional, singular variables. Across each phase of the model, however, the fundamental 3 domain structure was present: 1) the predisposition of the individual to use services (i.e., predisposing characteristics), 2) their ability to secure services (i.e., enabling factors), and 3) need/illness level (Andersen & Newman, 2005).

Predisposing characteristics refer broadly to things that may predispose a person to need and use health services. Andersen defines these characteristics as including demographic factors (age and gender), social structure (education, occupation, ethnicity, health of environment, etc), and health beliefs (attitudes, values, and knowledge that might influence perceptions of need and use of health services). While these variables, like age for instance, are directly associated with health they are not a reason for health service utilization. Enabling characteristics include the means available for individuals to access care. Enabling variables may include income, health insurance or, in the case of

online supportive care, online access. These variables are associated with health services utilization in that it is a gateway needed to obtain access. Illness level characteristics include variables such as probability of occurrence, objective illness criteria, and perceived illness. Illness factors are often the primary issues thought of when discussing need for health services.

Direct applications and revisions of the Andersen model have been proposed to address the specific concerns of a variety of patient populations such as the use of condition specific health services among the homeless (Behavioral Model for Vulnerable Populations; Gelberg, Andersen & Leake, 2000;), medical visits among children (Haggerty, Roghmann & Pless, 1992), and doctor's visits and hospital stays among the elderly (Ory & Bond, 1989). The Andersen model has also been used specifically to predict utilization of face-to-face support groups. A study of Latinas with breast cancer reported that none of the predisposing factors used in the model predicted support group use. Among enabling factors, familial encouragement was the online significant contributor to support group use, while among need/illness factors spiritual well-being was associated with support group use. Two other studies have used the Andersen model with cancer populations, the first assessing predictors of colorectal cancer screening among Japanese Americans, and the second describing PTSD incidence (Andrykowski & Cordova, 1998) as opposed to predicting health care utilization.

Andersen encourages the integration of relevant variables that may not be explicitly named under existing domains in the facilitation of new and innovative study (Andersen, 1995). While several studies have looked at predictors of online support group use, there does not appear to be any inclusive models describing online support

group utilization, for cancer or other health conditions. Given this need, an Expanded Behavioral Model for Online Support Services is proposed using Andersen's Individual Determinants of Health Service Utilization as its foundation (Andersen & Newman, 2005). The use of the Andersen model is relevant in that it creates a fundamental theoretical structure attempting to describe (as broadly as anyone has tried) the potential barriers and facilitators of online participation. Furthermore, most online support studies of participation have been more descriptive than theoretical, therefore factors identified as potentially affecting online support need to be assessed using a theoretically based, multivariate frame to identify variable contribution. To investigate online support utilization, relevant internet-related variables were added to the enabling, predisposing and illness factors in accordance with Andersen's descriptive criteria. These additions were made in an effort to articulate the unique variables associated with novel application of a new media. New added domains include Past Online Health Information/Community Experience (past face to face and online support use) and Online Access (time spent online, connection type). Other model domains were utilized as fully as possible given the constellation of variables available.

### **Current Study**

As part of a larger clinical trial providing online group therapy and support centered around a comprehensive, our research team developed secure website ([www.health-space.net](http://www.health-space.net)) offering the following services to cancer survivors: synchronous (chat) and asynchronous (discussion board) communication, personal email accounts, a 12 week multimedia intervention, and personal pages where participants posted blogs and

pictures, as well as read the website news stream written by website moderators. The goal of the trial was to develop a comprehensive online resource for cancer patients of mixed diagnoses and gender, focusing on emotional expression, cognitive behavioral skills training, and psychoeducation.

### **Specific Aims, Hypothesis and Analysis**

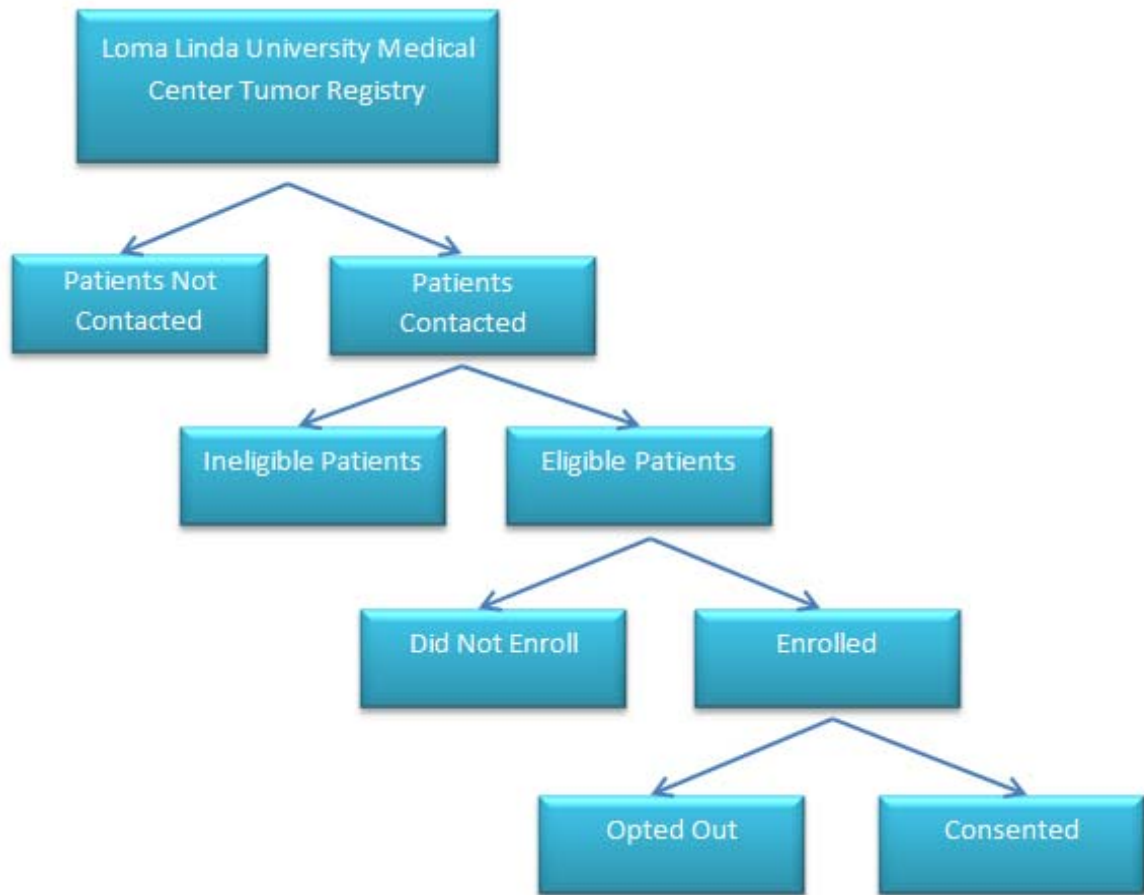
Aim 1: To describe the demographic characteristics of those people who participated in the intervention.

Hypothesis 1: Among Loma Linda University Cancer Registry patients who meet criteria for initial recruitment contact, enrolled participants are more likely to be female, younger, and a breast cancer diagnosis relative to those who do not enroll.

Aim 2: To identify predisposing, enabling, and illness level factors associated with basic online support use for cancer survivors using a modified Individual Determinants of Health Service Utilization Model (Expanded Behavioral Model for Online Support Services Model)

Hypothesis 2: Online support services use will be a function of the predisposing, enabling and illness characteristics of the individual. Each of these categories will make an independent contribution to the overall model and the understanding of online support group use. Online support group use is defined by the dichotomous variable of any discussion board posts (participation = 1) and no discussion board posts (participation = 0).





*Figure 3: Recruitment Evaluation*

Hypothesis 3: The contribution of online access and Online/Supportive Health Community Beliefs will be the strongest predictors of active online support group participation.

Aim 3: To evaluate the utility of the model for predicting behavioral engagement with the online intervention.

Hypothesis 4: Each factor (predisposing, enabling and illness variables) will contribute significantly to a model predicting behavioral use of the online intervention using word count (the dependent variable).

Aim 4: To explore linguistic correlates of behavioral engagement with the online intervention

Hypothesis 5: More time spent on the website and more logins will be associated with the use of emotion focused words (number of affect words, percentage of affect words, number of positive emotion incidences, percent positive emotion, number of negative emotion incidences, and percent negative emotion).

## **CHAPTER TWO**

### **METHOD**

#### **Participants**

Participants were recruited from the Loma Linda University Medical Center Tumor Registry. Each potentially eligible participant was sent a letter (Appendix A) informing them about the website, emphasizing the unique opportunity to anonymously access a variety of services including discussion boards, a live chat room, coping tips and personalize homepages under the supervision of a clinical health psychologist and doctoral students. Participants also received a newsletter (Appendix B) addressing frequently asked questions, enrollment details, and common barriers to participation. The goal of the newsletter is to familiarize potential participants with online interventions and the support they provide.

#### **Procedure**

Interested participants were screened by phone or through the study website. Eligible participants were required to be 18 years of age or older, speak English, have independent internet access, and be experiencing significant levels of distress as indicated by a score of 4 or greater on the Distress Thermometer. Once the participant completed a baseline survey administered through the study website, they were randomized to the treatment or wait-list cohort. Participants then received a phone call from one of the facilitators or research assistants thanking them for their participation and fielding any additional questions regarding recruitment and participation. Participants were assigned online accounts where they designated their login information, password, and complete

intake and consent information. Wait-listed individuals were provided with monthly newsletters and updates until the date of their assignment to the treatment condition. Open enrollment will be used, with participants being added to the group in accordance with attrition. Ideal group size was 10-15 members.

Participants were encouraged to spend time developing their personal page and blog, reading weekly intervention materials and posting on the discussion board and in the chat room. For each completed questionnaire at baseline, 3 months, 6 months, 9 months and 1 year, participants were paid \$10 in the form of a gift card. For the purposes of this study, the baseline assessment data was used to predict utilization. A combination of doctoral students and psychologists served as the online facilitators, guiding discussion and encouraging participation. The didactic portion of the online intervention was designed as a 12 week long, multimedia virtual slide show adapting and extrapolating on themes from existing face-to-face group therapy curriculum (Watts & Edgar, 2004; Allison et al., 2004; Vilela et al., 2006).

The 12 week multimedia intervention was an adaptation of Nucare, a face to face psychoeducation program designed to teach coping skills to cancer survivors and their families (Edgar et al., 1992; Watts & Edgar, 2004). The program emphasizes personal control enhancement as well as emotional and instrumental coping responses, incorporating feedback, collaboration, and creating learning experiences. Intervention techniques included structured problem solving exercises, relaxation techniques, cognitive coping skills, goal setting, communication skills building, social support and lifestyle factors. Nucare has been demonstrated to improve quality of life and reduce

symptoms of depression in both breast cancer and colorectal cancer patients (Rosberger et al., 2002; Edgar et al., 1992).

Elements of the NuCare program were augmented with media such as video instruction of coping basics, steaming relaxation audio files, automated quiz feedback, and opportunities to post comments at the completion of intervention topics (Appendix A). Many of the intervention workbook exercises were also incorporated, providing opportunities for participants to practice skills such as distortion identification and effective communication style directly on the web site. All visual and web design aspects of the intervention are original.

Also included on the site was an opportunity for participants to create a personal page to display pictures and write autobiographical information to share with the group. Group members were informed about how to protect their personal information and are encouraged to post whatever information they feel comfortable sharing. Additionally, on their personal page group members could post blogs about whatever issues or topics they would like to write about. Blog posts could be public, where other members of the group can read them and post comments, or private, serving instead as a personal journal. Finally, the personal page hosted email where group members can exchange emails without having to disclose their personal email address.

### **Facilitation and Discussion Board Activity**

Each group was facilitated by a minimum of two facilitators, including doctoral level Loma Linda students and a licensed clinical psychologist. Facilitators were provided with their own website accounts with analogous email, blog and posting

functions. The role of the facilitator was to monitor discussion board posts, emphasizing the skills outlined in the coping skills modules as well as open expression of the feelings and concerns of the group members. Facilitators could also post blogs or discussion board comments to inspire conversation about relevant topics or direct attention to important group events. Group members had the opportunity to contact facilitators live in the chat room at least once a week once a week.

### **Assessments**

All variables used in analysis were collected from the tumor registry and the baseline assessment, both databases being frozen in May of 2010. Select demographic and disease related variables made available by the tumor registry included patient gender, age, ethnicity, tumor site, date of diagnosis, and cancer stage. These basic variables were used to assess Aim 1 and the evaluation of the relationship between predisposing factors and interest in online support, specifically looking at how gender, age and tumor site related to participation.

#### ***Predisposing Variables: Demographics, Social Structure and Past***

##### ***Online Experience***

Age, gender, and marital status obtained from the tumor registry comprised the *Demographics* subcategory of the predisposing group. Education and ethnicity variables obtained through the baseline survey comprised the subcategory of *Social Structure* as a component of the predisposing group. The baseline online survey data regarding previous use of face to face or online support groups, as well as the frequency at which each form

of support was comprised the subcategory of *Past Online Health Information/Community Experience*.

### ***Enabling Variables: Family and Online Access***

Income, obtained from the tumor registry comprised the subcategory of *Family*. Internet frequency will comprise the Online Access subcategory.

### ***Illness Level Variables: Perceived and Evaluated***

#### **Health-Related Quality of Life**

Health-related quality of life was ascertained using the Functional Assessment of Cancer Therapy (FACT). Using a 5-point Likert scale, the FACT-G is a 33-item questionnaire assessing overall quality of life as well as individual domains including social well-being, physical well-being, emotional well-being and functional well-being (Cella et al., 1993). The test-retest correlation coefficient for the FACT-B total score is 0.92, demonstrating sufficient stability in quality of life assessment over short periods of time (3 to 7 days). Subcategory test-retest correlation coefficients are as follows: physical well-being, .88; functional well-being, .84; social well-being, .82; emotional well-being, .82; relationship with doctor, .83; and total score, .92. In a sensitivity test of 104 breast, lung and colon cancer patients receiving chemotherapy, multivariate analysis of variance confirmed a significant overall effect ( $P = .002$ ), indicating that the FACT-G can clearly distinguish the three groups.

## **Physical Well-Being**

The Memorial Symptom Assessment Scale (MSAS) was used to determine physical well-being. The MSAS is a 32-item measure investigating the prevalence, frequency, severity, and distress related to symptoms often described by cancer patients (Portenoy, 1994). Symptom distress is rated on a Likert-type scale from 0 (not at all) to 4 (very much) indicating how distressing the participant has found each identified symptom over the past week. Validated for use with cancer survivors, the MSAS has demonstrated sufficient reliability (0.84-0.88), as well as good content and construct validity. Total symptom distress was calculated by summing the total distress value accumulated across all items.

## **Depression**

The Center for Epidemiologic Studies Depression Scale or CES-D was designed as a measure to assess depression among the general population (Radloff, 1977), however has also shown to be a valid measure for use with cancer patients (Hann et al., 1999; Schroevers et al., 2000). Primarily measuring affective and somatic aspects of depressed mood, the CES-D consists of 20 items on a four point scale based on frequency of occurrence. Possible scores range from 0 to 60, with higher scores indicating the greater severity the patient's symptoms. At a cut off score of 17, Katz et al. (2004) found a 100% sensitivity, 84.7% specificity and a positive predictive value of 63.2%.

## **Distress**

Psychological distress was also assessed using the Impact of Events scale (IOES).



The IOES is a 22-item Likert-type scale, comprising three subscales corresponding to the Diagnostic and Statistical Manual of Mental Disorders-Fourth Edition specified PTSD symptoms: avoidance (IOES-avoidance; mean of eight items measuring the extent to which the respondent avoids situations that remind him or her of the stressful or traumatic event), intrusion (IOES-intrusion; mean of eight items assessing the extent to which one experiences intrusive thoughts), and hyperarousal (IES-arousal; mean of six items measuring anger, irritability, heightened startle response, and hypervigilance). A total IOES score (IOES-total) is composed of the sum of the three subscales. The instrument has good internal consistency (Cronbach's  $\alpha = 0.79-0.92$ ) and has been shown to be sensitive to the effects of psychosocial intervention (30).

### **Mood**

Mood was assessed using The Brief Profile of Mood States (POMS-B). POMS-B is a 30-item shortened version of the original 65-item measure, composed of six subscales: tension-anxiety (assessed as both subjective state and somatic experience of anxiety); depression-dejection (taps feelings of inadequacy, isolation, guilt, futility, sadness); anger-hostility (examines overt hostility and irritability); fatigue-inertia (assesses feelings of weariness); and confusion-bewilderment (assesses efficiency and clarity of thinking) (McNair, Loo, & Droppleman, 2003). The respondent rates each adjective based on how they have felt in the past week on a 5-point Likert-type scale ranging from "Not at all" to "Extremely". It is also possible to calculate a total score of mood disturbance, known as the POMS total, by summing the scores of the 5 subscales for the negative mood states and subtracting from it the score for the positive subscale

## **Evaluated Illness**

Evaluated illness level was assessed using diagnosis stage and time since diagnosis data obtained from the tumor registry.

### ***Behavioral Variables***

Online participant behavior was also managed, collected and stored using Structured Query Language (SQL) and Practical Extraction and Report Language (PERL). Behavioral variables of interest included keystroke data associated with website utilization, number of logins, total mouse clicks, total words typed, overall time spent accessing the website, time spent viewing the discussion board and intervention, application utilization (blogs and surveys), and participant interaction. Unique “sessions” were created whenever a user logs in to the secure website. Session data was used to track keystrokes for each page of the study website, so that the number of clicks and total time spent can be stored separately for each component of the online intervention (e.g. discussion board, personal pages, coping modules, etc.).

## **Computerized Text Analysis (CTA)**

Linguistic Inquiry and Word Count (LIWC) was used to characterize the emotional, cognitive, and structural components present in online therapy transcripts. LIWC 2007 relies on established dictionaries to target and quantify words associated with specific linguistic domains. Approximately 80 output variables were collected per subject with respect to 4 general descriptor categories (total word count, words per sentence, percentage of words captured by the dictionary, and percent of words longer than six

letters), 22 standard linguistic dimensions (e.g., percentage of words in the text that are pronouns, articles, auxiliary verbs, etc.), 32 word categories tapping psychological constructs (e.g., affect, cognition, biological processes), 7 personal concern categories (e.g., work, home, leisure activities), 3 paralinguistic dimensions (assents, fillers, nonfluencies), and 12 punctuation categories (periods, commas, etc). The complete LIWC dictionary is composed of nearly 4500 words or word stems defined in one or more hierarchical subcategories. LIWC calculates the percentage of target words described by each of the nearly 80 outcome variables. Computed from a random sample of 2800 proprietary text files, the average Cronbach's alpha for the internal reliability of the specific words within each LIWC category was 0.83 (range: 0.14 - 0.98). The validity of LIWC domains was assessed by comparing the correlations between LIWC output and judges' ratings. The average agreement between LIWC and judges' ratings was .45, suggesting substantial agreement, with a range of .07 to .87 across LIWC categories. Pearson correlations were used to identify linguistic markers of benefit-finding.

### **Planned Statistical Analyses**

Aim 1: To evaluate the relationship between predisposing demographic factors and interest in online support.

Hypothesis 1: Among Loma Linda University Cancer Registry patients who meet criteria for initial recruitment contact, enrolled participants are more likely to be female, younger, or have a breast cancer diagnosis relative to those who do not enroll.

Proposed Analysis: Basic descriptive analysis (where appropriate: frequency, distribution, range, means, standard deviation) at progressive stages illustrating who comprises the cancer registry as a whole, who was eligible for the study, who consented to participation and received materials, and who completed T1 assessment in terms of the available tumor registry variables. In order to determine whether there are significant differences between those who enrolled and those who did not based on age, disease and gender, independent samples t-tests for continuous variables (age) and chi square analyses for categorical variables (gender and diagnosis) was conducted. Cancer was categorically defined as 1= breast cancer, 0= other.

Aim 2: To identify predisposing, enabling, and illness level factors associated with basic online support use for cancer survivors using a modified Individual Determinants of Health Service Utilization Model (Expanded Behavioral Model for Online Support Services Model)

Hypothesis 2: Online support services use will be a function on the predisposing, enabling and illness characteristics of the individual. Each of these categories will make an independent contribution to the overall model and the understanding of online support group use in terms of the dichotomous variable of any discussion board posts (participation = 1) and no discussion board posts (participation = 0).

Hypothesis 3: The contribution of online frequency will be the greatest predictor of active online support group participation.

Proposed Analysis for Hypothesis 2 and 3: Descriptive analysis was conducted for all variables, and multicollinearity was evaluated by looking at the Pearson correlations between variables to avoid model instability or distortion. Logistic regression models were then used to compute adjusted odds ratios (with 95% confidence intervals) identifying the predisposing, enabling, and illness predictors (independent variables) of online support participation among cancer survivors. Not using or using the online discussion board was the dependent variable, with a binary response of either yes (1) or no (0). Gender was defined coded as female (1) and male (0). Ethnicity was defined as Caucasian (1) versus “other” (0), which included all other ethnicities. Education was defined sorted into categories of high school education (1) and college educated (0). Marital status was coded married (1), and not married, divorced, and widowed (0). Income was defined as those making less than the median income of \$50,000 (0), versus those who made more than the median income (1). Internet frequency was defined as how many times per week the individual was getting online.

In accordance with Andersen’s original order of analysis, predisposing variables (demographic, social structure and online health) will be entered into the model on the first step. Next, enabling factors (family and online access) were entered, followed by illness variables (perceived health and evaluated physical health). Adjusted odds-ratios represent the unique, additional explanation provided by an individual

predictor. A p-value less than 0.05 will be considered statistically significant. The change in the  $-2 \log$  likelihood associated with each of the variable blocks entered indicate the relative contributions of the variables and how well the model fits the data when variables were added to the analysis. The multivariate Wald Chi Square test will be used to evaluate the statistical significance of the set of coefficients in the model. Odds ratios and associated confidence intervals will be used to evaluate whether predisposing, enabling and illness level factors are associated with online utilization.

Aim 3: To explore the utility of the model for predicting behavioral utilization of the online support group.

Hypothesis 4: Each factor (predisposing, enabling and illness variables) will contribute significantly to model predicting behavioral use of the online intervention using word count (the dependent variable).

Proposed analysis: Regression will be used to predict the continuous dependent variable words typed in terms of Andersen's 3 tiered, stepwise model, first entering the following independent variables: predisposing variables (demographic, social structure, supportive health care beliefs) followed by enabling factors (family, online access) and illness variables (perceived illness and evaluated physical health) .

Aim 4: To describe the linguistic characteristics of active participants.

Hypothesis 5: More time spend on the website and more logins will be associated with the use of emotion focused words (number of positive emotion incidences,

percent positive emotion, number of negative emotion incidences, percent negative emotion).

Proposed analysis: Pearson correlation coefficients will be calculated between the following LIWC variables: number of affect words, number of positive emotion words, number of negative emotion words, percentage of affect words, percentage of positive emotion words, and percentage of negative emotion words .

## CHAPTER THREE

### RESULTS

#### **AIM I: Characteristics of Participants**

To address the first aim to evaluate the demographic factors of prospective participants, basic descriptive analyses were run to characterize who comprised the cancer registry as a whole, who was recruited for the study, who enrolled in the study, and who consented and participated in the study.

#### *LLU Cancer Registry*

From the Loma Linda University Medical Center Tumor registry, 2160 patients were identified as possible contacts for recruitment. Individuals identified from the 2007-2008 registry included California residents over the age of 18 with any type of cancer. In 2008-2009, recruitment was expanded to include cancer survivors also living outside of California (n = 2160). Across all survivors, gender was available for most recruits (n= 2158), with 61.4% male (n= 1327) and 38.0% female (n=821). Gender information was missing for 0.6% of cases (n=12). The majority of registry patients were White (70.3%, n=1518), followed by Hispanics (15.6%, n=336), Blacks (4.4%, n=96), Asians (2.2%, n=47), and “Other” ethnicities (2.5%, n= 55). Ethnicity data was not available for 5.0% of the registry (n=108). Prostate cancer was the most common diagnosis cited (37.6%, n=813), followed by “Other” (23.9, n=516), female reproductive cancer (10.8%, n=234), breast cancer (9.1%, n=197), blood/lymph/lul/kidney cancer (5.9%, n=128), lung cancer (4.8%, n=104), colorectal cancer (4.1%, n=89), skin cancer (2.7, n=59) and those



identified as having multiple cancers (0.9%, n=20). Age data was available for 1955 registry patients, with the mean age being 61.78 years of age (sd = 13.297).

### ***Recruitment, Eligibility and Enrollment***

Of those identified in the registry, researchers attempted to contact 1318 people. Of the 1318 potential participants that the investigators attempted to contact, 52% (n=688) were reached successfully by phone. Of those who were contacted, 40% (n=274) were successfully screened. Participant eligibility was then determined based on whether or not the patient met all of the following criteria: being 18 years of age or older, speaking English, having independent internet access, and experiencing significant levels of distress as indicated by a score of 4 or greater on the Distress Thermometer. Seventy-eight percent (n=133) of the 171 eligible participants eventually enrolled into the study. Reasons for eligible individuals declining participation included not being interested, feeling that they were too busy, feeling too sick, not wanting to talk about their illness, belonging to another support group, feeling uncomfortable with their computer skills, and preferring face-to-face interactions. Of the individuals who did choose to participate, 55.6% were male (n=74) and 41.4% were female (n=55). Gender data was not available for 3% (n=4) of these participants. With respect to ethnicity, the majority of participants were White (68.4%, n=91) followed by Hispanics (6.0%, n=8), Blacks (3.0%, n=4) and “other” (2.3%, n=3). Ethnicity was unknown for 1.5% (n=2) participants. Data was missing for 18.8% (n=25) of participants. The average age of enrolled participants was 58.94 ( $\sigma = 11.75$ ). Among enrolled participants, prostate cancer was the most common (33.1%, n=44), followed by breast cancer (7.5%, n=10), colorectal cancer (6.0%, n=8),

lung cancer (3.8%, n=5), female reproductive cancer (8.3%, n=11), genitourinary cancer (4.5%, n=6), skin cancer (2.3%, n=3), “other” cancers (28.6%, n=38), multiple cancers (1.5%, n=2). Data was missing for 4.5% of these participants (n=6). Of these enrolled participants, 13.6% of those who were eligible (n=36) chose not to enroll in the study.

To determine whether there were significant differences between those who had enrolled and those who did not, independent samples t tests and chi square analyses were performed. Those who successfully enrolled did not differ significantly by age ( $t(1, 161) = -0.46, p = 0.65$ ), gender ( $\chi^2(1) = 0.01, p = 0.92$ ), or ethnicity ( $\chi^2(1) = 2.99, p = 0.559$ ) from those who did not enroll. With respect to cancer type, when patients with breast cancer were compared with all other forms of cancer, those with breast cancer were more likely to enroll in the study than those with other diagnoses ( $\chi^2(1) = 5.88, p = 0.03$ ). In light of these results, mixed support was found for hypothesis one that enrolled participants would be more likely to be female, younger, or have a breast cancer diagnosis relative to those who do not enroll. Enrolled participants were in fact more likely to have breast cancer, however they did not differ by age or gender.

### ***Consented Individuals Who Chose to Participate***

Of the 133 total participants who chose to enroll in the study, 69.2% (n=92) had completed consents. Of those who provided consent, 91.3% went on to actually participate in the intervention (n=84). In this group, 54.8% (n=46) were male and 45.2% (n=38) were female. In terms of ethnicity, Whites were most common (77.4%, n=65), followed by Blacks (6%, n=5), Asians (4.8%, n=4), Hispanics (2.4%, n=2), and “other” (6%, n=5). Ethnicity data was not available for 3 individuals. The average age of

participants was 57.46 ( $\sigma = 13.73$ ). Prostate cancer was the most common diagnosis (32.1%, n=27), followed by “other” cancers (29.7%, n=25), breast cancer (10.7%, n=9), female reproductive cancer (7.1%, n=6), multiple cancers (7.1%, n=6), skin cancer (4.8%, n=4), blood/lymph/lul/kidney cancer (3.6%, n=3), colorectal cancer (3.6%, n=3), lung cancer (1.2%, n=1). With respect to cancer stage, 13.1% (n=11) had cancer in situ, 20.2% (n=17) had stage I cancer, 13.1% (n=11) had stage II cancer, 9.5% (n=8) had stage III cancer, 7.1% (n=6) had stage IV cancer, and 36.9% (n=31) were unsure of the staging of their cancer. The average time since diagnosis was 65.8 months (sd = 68.1). With respect to participant distress, the average distress thermometer score was 4.75 (sd = 2.8). With respect to education, 25% of consented participants had the equivalent of a high school education or less (n=21), 48.8% were college educated (n=41), 26.2% had a graduate education (n=22). Married individuals accounted for 69% (n=58) of participants, while 31% (n=26) were unmarried (divorced, widowed and unmarried). With respect to employment, 52.4% (n=44) were currently employed, 22.6% (n=19) were unemployed, 25% (n=21) were retired. With respect to salary, 31% (n=26) of participants earned more than \$50,000 per year and 32.1% (n=27) earned less than \$50,000 per year. Salary data was not available for 36.9% (n=31) of participants.



Figure 4: Completed Recruitment Evaluation

**AIM II: To identify the predisposing, enabling, and illness level  
factors associated with basic online support use**

Hypothesis two postulates that the use of online support, as defined by any discussion board participation, would be significantly associated with these factors. Logistic regression analysis was planned using word count as the dependent variable, with a binary response of either any participation (1) or no participation (0). Of the 84 individuals who enrolled and consented to participation, 31 individuals (36.5%) contributed linguistically to the intervention and 53 individuals (62.4%) did not. The mean number of words written was 957.17 (sd = 2664.9; range = 0 – 19235). Logistic regression models were utilized to identify the predisposing, enabling, and illness predictors of online support participation among cancer survivors.

***Predisposing Factors***

Univariate regression analysis of predisposing factors revealed no significant predictive relationship between age, (OR=1.00; 95% confidence interval [CI]=.97–1.03; p=1.00), gender (OR=1.22; 95% confidence interval [CI]=.50–2.98; p=.66), marital status (OR=.91; 95% confidence interval [CI]=.35 –2.36; p=.84), education (OR=.31; 95% confidence interval [CI]= .10–1.04; p=.06), ethnicity (OR=1.25; 95% confidence interval [CI]= .42–3.76; p=.69), past support group use (OR=1.70; 95% confidence interval [CI]=.58–5.00; p=.33), frequency of support group use (OR=1.05; 95% confidence interval [CI]= .92–1.20; p=.44), past online support group use (OR=2.30; 95% confidence interval [CI]=.64–8.30; p=.20), and frequency of past online support group

Table 1

*Predisposing Variables Predicting Any Linguistic Participation*

|                         | <i>Step 1</i>             |            | <i>Step 2</i>              |             | <i>Step 3</i>               |               |
|-------------------------|---------------------------|------------|----------------------------|-------------|-----------------------------|---------------|
|                         | OR                        | 95% CI     | OR                         | 95% CI      | OR                          | 95% CI        |
| <b>Demographics</b>     |                           |            |                            |             |                             |               |
| Age                     | 1.01                      | (.97-1.04) | 1.00                       | (.97-1.04)  | 1.01                        | (.97-1.05)    |
| Gender                  |                           |            |                            |             |                             |               |
| Female                  | 1.00                      | Reference  | 1.00                       | Reference   | 1.00                        | Reference     |
| Male                    | 1.16                      | (.45-3.02) | 1.07                       | (.40-2.89)  | .91                         | (.30-2.71)    |
| Marital Status          |                           |            |                            |             |                             |               |
| Married                 | 1.00                      | Reference  | 1.00                       | Reference   | 1.00                        | Reference     |
| Unmarried               | .98                       | (.36-2.70) | .94                        | (.33-2.68)  | .96                         | (.31-2.99)    |
| <b>Social Structure</b> |                           |            |                            |             |                             |               |
| Education               |                           |            |                            |             |                             |               |
| High School             |                           |            | 1.0                        | Reference   | 1.00                        | Reference     |
| Any College             |                           |            | .26                        | (.07-1.00)* | .22                         | (.05-.96)*    |
| Ethnicity               |                           |            |                            |             |                             |               |
| White                   |                           |            | 1.0                        | Reference   | 1.00                        | Reference     |
| Other                   |                           |            | .96                        | (.29-3.14)  | .77                         | (.21-2.82)    |
| <b>Online Health</b>    |                           |            |                            |             |                             |               |
| Past SG                 |                           |            |                            |             |                             |               |
| Any Use                 |                           |            |                            |             | 1.0                         | Reference     |
| No Prior Use            |                           |            |                            |             | .65                         | (.13-3.24)    |
| SG Frequency            |                           |            |                            |             | 1.05                        | (.88-1.25)    |
| Past OSG                |                           |            |                            |             |                             |               |
| Any Prior               |                           |            |                            |             | 1.0                         | Reference     |
| Use                     |                           |            |                            |             |                             |               |
| No Prior Use            |                           |            |                            |             | 16.83                       | (.99-286.82)* |
| OSG                     |                           |            |                            |             | .77                         | (.52-1.15)    |
| Frequency               |                           |            |                            |             |                             |               |
| Model                   | $(\chi^2 (3)=.17, p=.92)$ |            | $(\chi^2 (5)=4.78, p=.44)$ |             | $(\chi^2 (9)=11.25, p=.26)$ |               |

*Model Summary.* **Step 1:** -2 Log Likelihood = 105.67, Cox and Snell  $R^2 = .002$ , Nagelkerke  $R^2 = .003$ ; **Step 2:** -2 Log Likelihood = 101.07, Cox and Snell  $R^2 = .06$ , Nagelkerke  $R^2 = .08$ ; **Step 3:** -2 Log Likelihood = 94.60, Cox and Snell  $R^2 = .13$ , Nagelkerke  $R^2 = .18$ . Note. \* $p < .05$

use (OR=.97; 95% confidence interval [CI]=.86 – 1.03;  $p=.56$ ) and discussion board participation.

Multivariate hierarchical analysis, however, found significant relationships between both education and past online support group use and discussion board participation; having a college education was associated with a decreased likelihood of discussion board participation and having no prior online support group experience increased the likelihood of discussion board participation.

### *Enabling Factors*

Univariate regression analysis of enabling factors revealed no significant predictive relationship between income (OR=.60; 95% confidence interval [CI] = .18-2.02; p=.41), internet frequency (OR=1.27; 95% confidence interval [CI] = .98-1.65; p=.06), and discussion board participation. Multivariate analysis found no relationship between income and discussion board participation, however greater frequency of internet use was significantly associated with greater discussion board participation.

Table 2

#### *Enabling Variables Predicting Any Linguistic Participation*

|                    | <i>OR</i> | <i>95% CI</i> |
|--------------------|-----------|---------------|
| Income             |           |               |
| >\$50,000          | 1.00      | Reference     |
| <\$50,000          | .52       | (.15-1.87)    |
| Internet Frequency | 1.57      | (1.00-2.46)*  |

*Model Summary:* ( $\chi^2$  (2)=6.16, p =.05; -2 Log Likelihood = 57.00; Cox and Snell  $R^2$  = .11; Nagelkerke  $R^2$  =.16. Note. \*p<.05

### *Illness Factors*

Univariate regression analysis of illness factors revealed no significant predictive relationships between FACT (OR=.99; 95% confidence interval [CI] = .97-1.02; p=.68), IOES (OR=1.00; 95% confidence interval [CI] =.97-1.03; p=.96), MSAS (OR=1.19; 95% confidence interval [CI] =.96-1.48; p=.12), POMS (OR=1.02; 95% confidence interval [CI] =.99-1.04p p=.16), CESD (OR=.1.05; 95% confidence interval [CI] =.98-1.12; p=.18), or time since diagnosis (OR=.99; 95% confidence interval [CI] =.98-1.00; p=.99), and discussion board participation. With respect to multivariate analysis, in the absence of Evaluated Illness variables trauma became a significant predictor (OR=.87; 95%

Table 3

#### *Illness Variables Predicting Any Linguistic Participation*

|                          | <i>Step 1</i>                |               | <i>Step 2</i>                |               |
|--------------------------|------------------------------|---------------|------------------------------|---------------|
|                          | <b>OR</b>                    | <b>95% CI</b> | <b>OR</b>                    | <b>95% CI</b> |
| <b>Perceived Illness</b> |                              |               |                              |               |
| FACT                     | 1.00                         | (.91-1.10)    | 1.05                         | (.92-1.19)    |
| IOES                     | .87                          | (.76-.99)*    | .88                          | (.76-1.02)    |
| MSAS                     | 1.23                         | (.87-1.72)    | 1.22                         | (.79-1.88)    |
| POMS                     | 1.00                         | (.90-1.10)    | .98                          | (.85-1.13)    |
| CESD                     | 1.49                         | (.99-2.22)    | 1.58                         | (.95-2.62)    |
| <b>Evaluated Illness</b> |                              |               |                              |               |
| Time Since Dx            |                              |               | .97                          | (.88-1.08)    |
| Stage                    |                              |               |                              |               |
| Unsure                   |                              |               | 1.00                         | Reference     |
| In Situ                  |                              |               | .37                          | (.01-19.18)   |
| Stage 1 or 2             |                              |               | 5.75                         | (.30-112.22)  |
| Stage 3 or 4             |                              |               | 1.82                         | (.02-169-83)  |
| Model                    | $(\chi^2 (5)=10.29, p =.07)$ |               | $(\chi^2 (9)=15.28, p =.08)$ |               |

*Model Summary.* **Step 1:** -2 Log Likelihood = 26.81, Cox and Snell  $R^2 = .32$ , Nagelkerke  $R^2 = .42$ ; **Step 2:** -2 Log Likelihood = 21.82, Cox and Snell  $R^2 = .43$ , Nagelkerke  $R^2 = .58$ ; Note. \*p<.05



confidence interval [CI] = .98-1.00,  $p=.05$ ) and depression approached significance (OR=1.49; 95% confidence interval [CI] = .99-2.22,  $p=.06$ ). The entire model, however was not significant ( $p=0.07$ ).

### **AIM III: To Identify Predisposing, Enabling, and Illness Level**

#### **Factors Associated with the Quantity Online Support Use**

Multiple regression analysis was performed using total word count as the continuous, dependent variable.

#### ***Predisposing Factors***

Univariate regression analysis of predisposing factors revealed no significant predictive relationship between age ( $\beta = -.01, p = .93$ ), gender ( $\beta = .20, p = .07$ ), marital status ( $\beta = -.09, p = .41$ ), education ( $\beta = -.19, p = .09$ ), ethnicity ( $\beta = .07, p = .52$ ), past support group use ( $\beta = -.03, p = .79$ ), frequency of support group use ( $\beta = -.05, p = .69$ ), past online support group use ( $\beta = .02, p = .89$ ), and frequency of past online support group use ( $\beta = -.03, p = .77$ ) and word count.

Multivariate hierarchical analysis similarly did not find a significant relationship between predisposing variables and word count (Step 1:  $R^2=.05$ , adjusted  $R^2=.02$ ,  $F(3,76) = 1.42, p=.24$ ; Step 2:  $R^2=.08$ , adjusted  $R^2=.02$ ,  $F(5,74) = 1.36, p=.25$ ); Step 3:  $R^2=.10$ , adjusted  $R^2=.02$ ,  $F(9,70) = .82, p=.60$ ).

Table 4

*Predisposing Variables Predicting Word Count*

|                                 | <i>Step 1</i> |        |         | <i>Step 2</i> |        |         | <i>Step 3</i> |         |         |
|---------------------------------|---------------|--------|---------|---------------|--------|---------|---------------|---------|---------|
|                                 | B             | SE     | $\beta$ | B             | SE     | $\beta$ | B             | SE      | $\beta$ |
| <b>Demographics</b>             |               |        |         |               |        |         |               |         |         |
| Age                             | 14.94         | 23.71  | .08     | 11.60         | 23.76  | .06     | 11.46         | 24.76   | .06     |
| Gender<br>(any prior=1)         | 1178.80       | 634.86 | .22     | 1135.10       | 638.07 | .21     | -1202.5       | 653.55  | .22     |
| Marital Status<br>(any prior=1) | -528.91       | 677.47 | -.09    | -528.90       | 678.12 | -.09    | 518.02        | 708.77  | -.09    |
| <b>Social Structure</b>         |               |        |         |               |        |         |               |         |         |
| Education<br>(high school=1)    |               |        |         | -1051.67      | 725.42 | -.16    | -1190.96      | 785.08  | -.18    |
| Ethnicity<br>(white=1)          |               |        |         | 448.10        | 762.84 | .07     | 316.71        | 796.57  | .05     |
| <b>Online Health</b>            |               |        |         |               |        |         |               |         |         |
| Past SG<br>(any prior=1)        |               |        |         |               |        |         | -155.13       | 1033.47 | -.02    |
| SG freq                         |               |        |         |               |        |         | -76.89        | 115.77  | -.10    |
| Past OSG<br>(any prior=1)       |               |        |         |               |        |         | 81.36         | 1142.13 | .01     |
| OSG freq                        |               |        |         |               |        |         | -12.59        | 62.17   | -.03    |

Note. \*  $p < .05$

***Enabling Factors***

Univariate regression analysis of enabling factors revealed no significant predictive relationship between income ( $\beta = -.09, p = .52$ ), internet frequency ( $\beta = -.01, p = .92$ ), and discussion board participation. Multivariate hierarchical analysis similarly did not find a significant relationship between enabling variables and word count ( $R^2 = .05$ , adjusted  $R^2 = .02, F(3,76) = 1.42, p = .24$ ).

Table 5

*Enabling Variables Predicting Word Count*

|                    | <i>B</i> | <i>SE</i> | <i>β</i> |
|--------------------|----------|-----------|----------|
| Income             | -246.28  | 357.26    | -.10     |
| Internet Frequency | 60.91    | 88.79     | .10      |

*Model Summary.*  $R^2=.02$  , adjusted  $R^2=-.02$ ,  $F(2,50) = .44$ ,  $p=.65$

***Illness Factors***

Univariate regression analysis of illness factors revealed no significant predictive relationships between FACT ( $\beta = .04$ ,  $p= .78$ ), IOES ( $\beta = .03$ ,  $p= .82$ ), MSAS ( $\beta = .21$ ,  $p= .27$ ), POMS ( $\beta = .01$ ,  $p= .92$ ), CESD ( $\beta = -.05$ ,  $p= .69$ ), time since diagnosis ( $\beta = -.00$ ,  $p= .97$ ), stage ( $\beta = -.04$ ,  $p= .71$ ), and word count. To assess multivariate categorical relationships, cancer stage was dummy coded into 4 groups: insitu, Stage 1 or Stage 2, Stage 3 or Stage 4, and “not sure.” In this analysis, “not sure” was coded as the reference group. No significant relationships were observed between illness factors and word count (Step 1:  $R^2=.29$  , adjusted  $R^2=-.14$ ,  $F(5,21) = .38.$ ,  $p=.86$  ; Step 2:  $R^2=.24$ , adjusted  $R^2=.16$ ,  $F(9,17) = .60$ ,  $p=.78$ ).

Table 6

*Illness Variables Predicting Word Count*

|                          | <i>Step 1</i> |        |         | <i>Step 2</i> |         |         |
|--------------------------|---------------|--------|---------|---------------|---------|---------|
|                          | B             | SE     | $\beta$ | B             | SE      | $\beta$ |
| <b>Perceived Illness</b> |               |        |         |               |         |         |
| FACT                     | -41.07        | 89.27  | -.15    | -10.09        | 104.48  | -.04    |
| IOES                     | -14.33        | 99.23  | -.04    | -8.36         | 115.62  | -.03    |
| MSAS                     | 212.14        | 294.41 | .21     | 151.78        | 311.99  | .15     |
| POMS                     | 70.85         | 89.19  | .23     | 89.63         | 98.49   | .29     |
| CESD                     | -213.74       | 295.36 | -.27    | -311.35       | 323.28  | -.39    |
| <b>Evaluated Illness</b> |               |        |         |               |         |         |
| Time Since Dx            |               |        |         | -2.39         | 28.41   | -.02    |
| Insitu                   |               |        |         | 440.76        | 2881.92 | .05     |
| Stage 1-2                |               |        |         | 3753.47       | 2414.28 | .46     |
| Stage 3-4                |               |        |         | 3679.07       | 3596.95 | .29     |

**AIM IV: To Describe the Linguistic Characteristics of Active  
Participants**

Of those individuals who participated in the study, the mean number of seconds spent on the site was 11965.23, or roughly 199 minutes. The amount of time spent on the website, however, varied significantly (range= 296-146606 seconds, sd=21324.13). On average, participants initiated 23.24 sessions (range=1-384, sd=51.87) and performed 163.19 mouse clicks (range = 6-2120, sd= 351.05). On average, participants wrote 957 total words (range= 0-19,235, sd=2664.9). During these sessions (Table 7), participants produced an average of over 40 instances of emotional expression, with about 70% of these instances representing positive emotion. On average, positive emotional expression represented 1.44% of total written participation, while negative expression represented 0.47%.

Table 7

*Linguistic Characteristics of Participants*

|               | <i>N</i> | <i>Minimum</i> | <i>Maximum</i> | <i>Mean</i> | <i>Std. Deviation</i> |
|---------------|----------|----------------|----------------|-------------|-----------------------|
| # Affect      | 84       | 0              | 927            | 43.89       | 128.99                |
| # Pos Emotion | 84       | 0              | 604            | 30.50       | 90.16                 |
| # Neg Emotion | 84       | 0              | 322            | 13.33       | 41.14                 |
| % Affect      | 84       | 0              | 25             | 1.91        | 3.54                  |
| % Pos Emotion | 84       | 0              | 25             | 1.44        | 3.22                  |
| % Neg Emotion | 84       | 0              | 3              | .47         | .81                   |

Investigators hypothesized that more time spent on the website and more logins would be associated with the use of emotion-focused words (number of positive emotion incidences, percent positive emotion, number of negative emotion incidences, percent negative emotion).

Table 8

*Correlations Between Behavioral and Linguistic Variables*

|                  | <i>Time on DB</i> | <i>Time on Website</i> | <i>Number of Logins</i> | <i>Number of Clicks</i> |
|------------------|-------------------|------------------------|-------------------------|-------------------------|
| Time on DB       | 1                 |                        |                         |                         |
| Time on Website  | 0.53**            | 1                      |                         |                         |
| Number of Logins | 0.69**            | 0.85**                 | 1                       |                         |
| Number of Clicks | 0.57**            | 0.97**                 | 0.93**                  | 1                       |
| Num_Affect       | 0.37**            | 0.87**                 | 0.69**                  | 0.83**                  |
| Num_Posem        | 0.50**            | 0.81**                 | 0.61**                  | 0.74**                  |
| Num_Negemo       | 0.48*             | 0.83**                 | 0.58**                  | 0.78**                  |
| Percent Affect   | 0.17              | 0.32**                 | 0.31**                  | 0.31**                  |
| Percent_Posemo   | 0.13              | 0.24*                  | 0.24*                   | 0.23*                   |
| Percent_Negemo   | 0.23*             | 0.45**                 | 0.38**                  | 0.44**                  |

\*Correlation is significant at the 0.05 level

\*\*Correlation is significant at the 0.01 level

As observed in Table 8, the number of positive emotion incidences observed linguistically was significantly associated with the amount of time spent on the discussion board, the amount of time spent on the website as a whole, and the number of logins and clicks performed. This relationship was also seen among variables describing number of negative emotion incidences and the percent of negative emotional expression relative to total linguistic sample. One notable exception was the lack of significant correlation between the percent of negative affect relative to total linguistic sample and total discussion board time.

## **CHAPTER FOUR**

### **DISCUSSION**

In this study, the Expanded Behavioral Model for Online Support Services did not produce a significant hierarchical model. Each aim of the study did, however provide useful information with respect to the characterization of tumor registry patients and those who would go on to participate in the online intervention. On average, those who comprised the registry were often male, Caucasian, diagnosed with prostate cancer, and 62 years of age. Those who went on to participate in the study had very similar demographics, and likely reflected the prominent prostate cancer treatment program at Loma Linda University Medical Center. Recruitment efforts provided additional information about those who chose to enroll, revealing that those who expressed initial interest in participating were (on average) highly educated and also married. As predicted, when grouped by diagnosis, breast cancer patients were more likely than those with other diagnoses to enroll in the study.

When the Expanded Behavioral Model for Online Support Services was used to predict participation, the subgroupings based on Anderson's model did not result in significant models; however, the individual variables education, past online experience, and time spent online were predictive of participation. The somewhat unexpected finding that those with no prior online group experience were more likely to participate may be related to the recruitment process, as individuals were drawn from the Loma Linda Tumor Registry rather than the typical convenience sample of interested individuals utilized by many psychosocial interventions for cancer survivors; the substantial recruitment effort appears to have resulted in the inclusion of individuals who would not

have normally sought out online support. These individuals also appear to differ by education, suggesting that online discussion board participation was an important draw for those with a high school education. This result would be a departure from the findings of other face-to-face studies that describe cancer support group users as typically more educated and having had prior experience with alternative treatments (Owen, 2005). If replicated, these findings may lend support to the idea that online interventions could provide needed support to individuals who do not typically participate in face-to-face interventions, and that the barriers to online group participation are not the same as the barriers for face-to-face group participation. For these individuals, their frequent online sessions could be a helpful, enabling variable that makes online intervention participation an attractive option. As such, this new modality for intervention may enable health care professionals to reach populations that have previously gone without services.

The benefit of reassessing the model using total word count was that it underlined the difference between the threshold of participation and the quantity of participation. Unlike the first model, word count was not predicted by any of the variables including education, past online experience or time spent online. These results suggest that there is a substantial difference between the factors that are associated with initial participation on the discussion board and sustained, active participation on the discussion board. It is unclear at this time what descriptive variables might predict the quantity of online linguistic participation, however it is clear that minding the variance in online resource utilization is an important task. One possible factor in the retention of active participants may include the individual's sense that the group is relatable, responsive and empathetic (Yalom & Leszcz, 2005). There are no current studies, however, addressing how



participants evaluate the temperament of online groups and their feelings of connection to the group. Future studies assessing how individual participants feel about the quality of their discussion board participation may prove useful in the design and implementation of online interventions. Further research using objective behavioral data is also a needed step in the evaluation of online interventions, as this type of analysis is relatively new and provides unique insight into the utility of online groups. The effectiveness of this resource for individuals with chronic diseases such as cancer may be improved with detailed observation and targeted optimization.

The evaluation of behavioral and linguistic variables in this study provided interesting information about the quality and quantity of intervention participation. Analysis of participant activity on the website revealed that, on average, participants spent more than 3 hours across 23 sessions accessing online resources. Additionally, time spent on the website, time spent on the discussion board, number of sessions, number of clicks and were significantly correlated with both positive and negative emotional expression. Of particular interest, it seems that the more time an individual spent on the discussion board the better their chances of expressing negative affect. One might speculate that this finding suggests that the more time and more familiarity one has with the discussion, the more likely they would be to have a frank discussion about their experience. Another potential explanation might be that individuals who are in greater need of social resources with which to cope with their experiences are spending more time on the discussion board to meet those needs. This hypothesis would be consistent with current research suggesting that individuals with limited resources or who are

experiencing significant distress are more likely to benefit from psychosocial interventions (Goodwin et al., 2001; Helgeson et al., 2000).

One limitation of this study is that the number of active participants on the discussion board was relatively modest, and that these individuals were mostly Caucasian. These factors may limit the generalizability of these results. Another potential limitation is that there was a very broad range in the quantity of online intervention utilization and discussion board participation. The reasons for this broad range are unclear, and it is possible that individuals who do not participate directly on the discussion board are receiving helpful information and support by reading about the experiences of others. Although outside of the scope of this study, descriptive evaluation of the characteristics of “lurkers” (individuals who read didactic materials and observe the discussion board but do not contribute linguistically to the website) could provide additional information about these types of online participants (Preece, Nonnecke & Andrews, 2004; Nonnecke, Andrews & Preece, 2006). Also of interest, participants in this study were of mixed cancer diagnoses, and while this is not necessarily a limitation it may alter the generalizability of these results as many groups are diagnosis specific.

The clinical implications of this study point toward the importance of both recruitment strategy and intervention method when addressing the needs of a patient population. In a study addressing these concerns, Fayter and colleagues (2006) found that a complex combination of patient factors, health care profession factors and practical organizational factors may have an impact on an individual’s choice to participate in a intervention. As was true for the current study, it seems that having a relationship with the requesting physician, and perhaps by extension to the medical institution, is important

to cancer patient recruitment and participation (Cox and McGarry, 2003) and may be a useful draw with which to reach patients who may not typically populate online support groups.

Identifying interventions that have the potential to meet underrepresented populations is a perennial challenge for psychosocial interventions. The possibility that targeted tumor registry recruitment for an online intervention could result in improved access to vulnerable populations is exciting. Whereas some variables have commonly been found to be barriers to face-to-face group participation (Owen, 2007), these same variables may not be as limiting among a subset of individuals for whom internet use is frequent and embedded in their day-to-day activities. Individuals with existing familiarity with online resources who haven't yet participated in online interventions may be especially open to the potential benefits of this type of intervention. Having a well-formed, professionally mediated website with which to initially engage these individuals could prove useful, and could encourage future interest in online resources for mental and physical health care.

Taken together, the results of this study provide one small, additional piece to the growing literature investigating the utility of online interventions and the improvement of existing resources for patients with chronic diseases such as cancer. While the nature of these resources is ever evolving, and largely still in its formative stages, mental health providers and physicians are likely to see a steady increase in the amount of time patients are spending online, and a corresponding increase in the demand for online health solutions. In their most recent report, the Pew Research Center's Internet and American Life Project found that of the 74% of all adults who use the internet, 80% have looked

online for health information (Fox, 2011). With 62% of all adults now using social networking sites with asynchronous modalities similar to discussion boards, one might expect that online psychosocial interventions will represent an increasingly comfortable medium for patients to find support and information. As our lives increasingly inhabit the virtual world, mental health care will need to evolve in kind to provide patients with options that fit their lifestyle and address their concerns.

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## APPENDIX A

### WEEKLY INTERVENTION TOPICS

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| <i>Week</i> | <i>Topic</i>  |
|-------------|---|
| 1           | <i>Introduction:</i> Participants are asked to review the goals of the intervention, group participation guidelines and tips for communicating in an online environment.  |
| 1           | <i>Coping and Mindfulness:</i> Participants are asked to review what it means to cope with cancer, to view a video about types of coping, to learn about mindfulness, and to post comments about their thoughts regarding the topics discussed.   |
| 2           | <i>Social Support:</i> Intervention describes social support and its benefits, as well as invites the participant to recall and list various sources of support in their lives.   |
| 3           | <i>Self and Body Image:</i> Participants review how their views of themselves may have changed since their cancer diagnosis, as well as the changes that have occurred over the course of treatment. Common conflicts are discussed as well as strategies for coping. At the end of the module, participants are invited to post comments about the module. |
| 4           | <i>Healthy Lifestyle:</i> Intervention describes the components of a healthy lifestyle and participants are invited to participate in a customized physical activity quiz. Participants are also provided with online resources for nutritional recommendations.  |
| 5           | <i>Self Efficacy:</i> Intervention defines self efficacy and provides suggestions for improving one's sense of self.  |
| 6           | <i>Relationships:</i> Participants are invited to reflect on how their relationships may have changed since their diagnosis and treatment. Intervention focuses on communications skills building with friends, family and health care providers.   |
| 7           | <i>Ways of Thinking:</i> Intervention addresses basic concepts of cognitive behavioral theory. Participants are also provided with exercises to further articulate cognitive theory. The goals of this section are to help the participant learn to distinguish thoughts, feelings and facts, as well as identify cognitive distortions.                    |
| 8           | <i>Self Talk:</i> Intervention discusses thought modification and offers suggestions and opportunities to identify personal examples.   |
| 9           | <i>Relaxation and Imagery:</i> Participants review the benefits of relaxation, the influence of relaxation on the body, and simple strategies for relaxation the participant can do on their own. Participants can also download streaming relaxation audio files.  |
| 10          | <i>Discussing Thoughts and Feelings:</i> Intervention review the importance of connecting with others, tools for successful communication and suggestions for dealing with anger. Participants are asked to identify personal examples of   |

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conflict and how it could be handled differently.

- 11 *Goal Setting*: The advantages of goal setting are reviewed, and participants are instructed how to form clear, achievable goals
  - 12 *Benefit Finding*: Intervention defines benefit finding and discusses types of benefit finding. Examples of how other patients have found growth from trauma is also demonstrated. Closing statements and a reiteration of intervention goals are stated. Participants are invited to discuss their experiences on the discussion board.
-

## APPENDIX B.1

### SAMPLE DISCUSSION BOARD PAGE

# health-space.net

Live Chat Hosted by Erin and Jason, Wed 8pm PDT in the Chat Room

---

Discussion Board | My Page | Guidance | Chat Room | Facilitator Tools | Logout

---

Post a Message | Change Picture | Show db/Refresh | Viewing Options | Search

---


Past 24 hrs | East Week | Past 2 Weeks | Past Month | All | New Online • Laurab

---

Things That Might Interest You!

**11 new blogs:**

- can't figure out the profile
- OK! figured out the Profile
- "Down the Hill"
- I want my bread toasted and not toasted
- What a difference a year makes.
- new at this
- happy thursday!
- interesting question . . .
- Tuesday
- Friday?
- TATTOO!?



**Facilitator**

**Subject:** Good news  
 Friday, September 11, 2009 10:41 pm Mood: Dope! 😄 Distress: 4

I am living all of this good news! Thank you all for allowing us to be a part of it, and most of all, for inspiring one another. It sounds like you and your wife have weathered a lot together, yet you maintain this wonderful and positive outlook on life. To what do you attribute that? I have no doubt that your positive outlook, albeit not always easy to maintain, has really helped strengthen you through the difficult times! Cheer's everyone, and enjoy the weekend!

...more...  
 1 view 0 replies [reply](#) [send private](#) [read more](#)

**Subject:** re: re: checking in  
 Friday, September 11, 2009 8:39 pm Mood: pensive 😞 Distress: 5

...Or for a lifetime! Year for and and all the others who have good news to share. You give us hope and encouragement. We celebrate you!

0 views 0 replies [reply](#) [send private](#)

**Subject:** re: re: checking in  
 Friday, September 11, 2009 10:41 am Mood: happy 😊 Distress: 0

So glad that we both get to celebrate good news this month. It always such a relief to hear all is well for another month or year. :)

1 view [reply](#) [send private](#)

# APPENDIX B.2

## SAMPLE PERSONAL PAGE

health-space.net

Live Chat, Hosted by Erin and Jason, Wed 8pm PDT in the Chat Room

Discussion Board | My Page | Guidance | Chat Room | Logout  
Edit Profile | My Blog | 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       |
|-------|------|---------------|
| Jason | 8/2  | great db post |

**News** | **Blog** | **Polls**

**Triggers and Anniversaries....**  
August 25, 2009

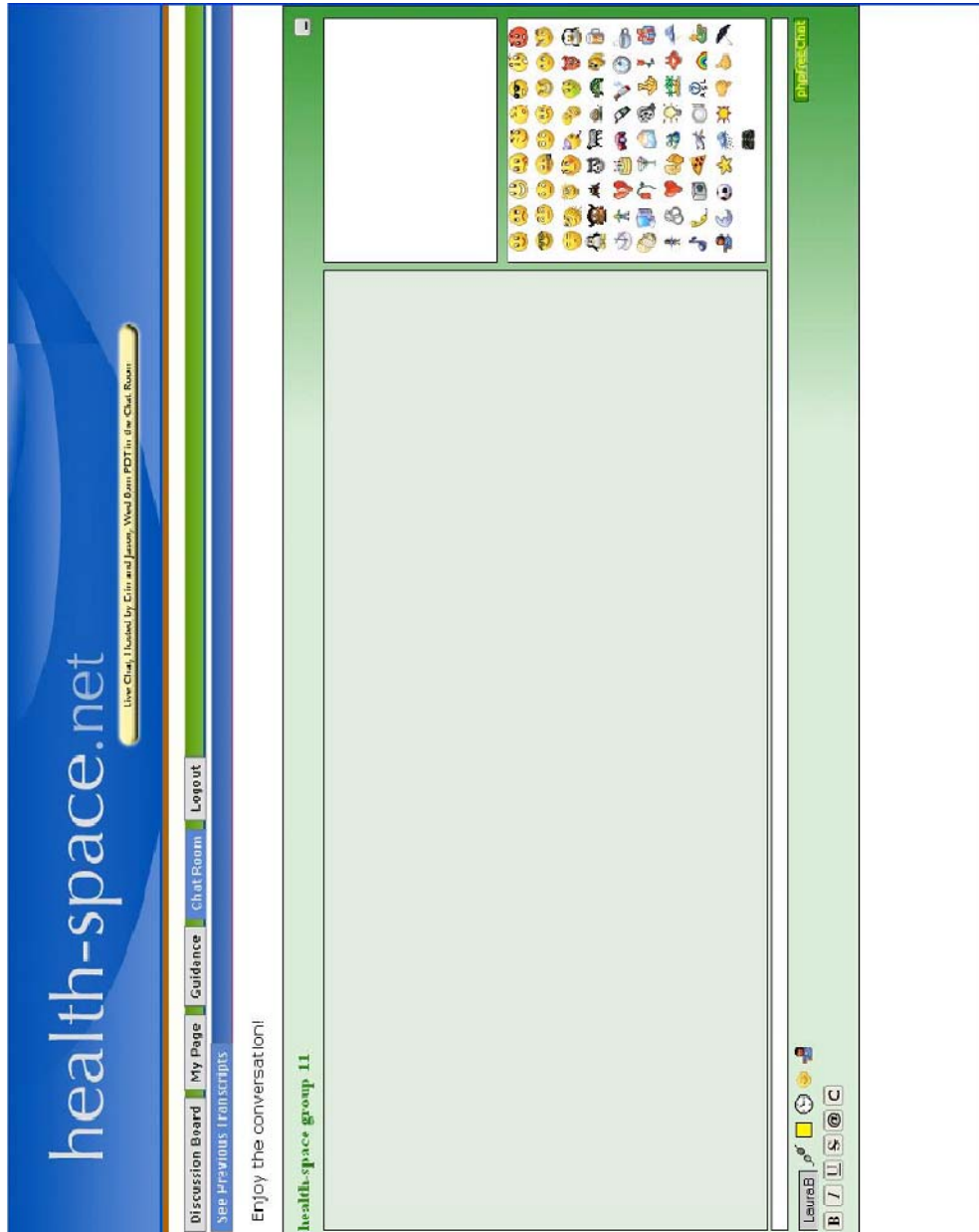
While the word 'cancer' itself can be anxiety provoking, cancer diagnosis and treatment can make associated people, places and objects suddenly aversive. For example, while you may have passed the street your doctor's office is on many times, you may find yourself taking a different route to avoid the anxiety associated. Perhaps a song you barely knew is now an acute reminder (or 'trigger') of the day you heard it on your way to surgery. It is not uncommon for anxieties associated with traumatic events to expand to include previously neutral stimuli. Not unlike survivors of natural disasters or military service, trauma can be triggered by everyday events and encumber your day to day functioning. Anniversaries of diagnosis and treatment can also be very difficult, rendering certain times of the year daunting.

While avoiding your triggers may be a good way to control your anxiety, it may also cause you to isolate yourself or to avoid activities you used to enjoy. It is also fairly difficult to avoid triggers like an anniversary, as they last 24 hours and keep coming back every year. If you find that your triggers are becoming problematic, consider talking to your doctor and/or a psychologist about what you can do to minimize the impact. You may also want to talk to other patients about what their triggers are and how they may have overcome them. For example, I have worked with patients who used 'habituation' to reduce their anxiety. This strategy involves progressive, gradual exposure to the anxiety provoking stimulus until it no longer elicits such a powerful response. Strategies such as these can be used by mental health care providers to help you cope.

cont....

# APPENDIX B.3

## SAMPLE CHAT ROOM



APPENDIX B.4

SAMPLE INTERVENTION PAGE 1



# Nucare Workbook

|                                   |                                      |                              |
|-----------------------------------|--------------------------------------|------------------------------|
| Introduction                      | week 1:<br>Mindfulness<br>and Coping | week 2:<br>Social<br>Support |
| week 3:<br>Self and Body<br>Image | week 4:<br>Healthy<br>Lifestyle      | week 5:<br>Self efficacy     |



## APPENDIX B.5

### SAMPLE INTERVENTION PAGE 2

The screenshot displays the health-space.net website. At the top, the logo "health-space.net" is visible, along with a notification for a live chat session. Below the logo is a navigation menu with options: Discussion Board, My Page, Guidance, Chat Room, and Logout. A secondary menu includes Current Topic, All Coping Tools, and My Bookmarks. The main content area features a video player with a filmstrip border. The filmstrip is labeled "FUJI RVP" and "RVP-501" at the top, and "→ 2A", "3", and "→ 3A" at the bottom. The video player shows a blue screen with the "health-space.net" logo and a play button. To the right of the video player, the text "How do you cope?" is displayed, followed by three bullet points:

- People use a variety of coping methods
- There are no right or wrong ways to deal with cancer, but some coping methods may be more effective.
- General Theoretical Models: behavioral, cognitive, and emotion focused.



## APPENDIX B.6

### SAMPLE INTERVENTION PAGE 3

health-space.net

Live Chat, Hosted by Erin and Jason, Wed 8pm PDT in the Chat Room

Discussion Board My Page Guidance Chat Room Logout

Current Topic All Coping Tools My Bookmarks



Self-efficacy is the belief that we are capable of performing a certain behavior. We can look at self-efficacy in many contexts. While we might feel capable about our performance in certain aspects of our lives, we may feel less capable in other aspects. Try and think about the areas in which you don't feel capable of performing or accomplishing your goals.

With a diagnosis of cancer, one may experience a diminished sense of self-efficacy, which can be frustrating and call for major adjustments in expectations and self-image. Self-efficacy is considered a key psychological resource in adapting to chronic physical illness. Quality of life may be influenced by one's perception of control over situations related to diagnosis and treatment. People who are confident in their abilities actively engage in health-enhancing behaviors. Furthermore, patients who have had increased confidence in self-care strategies (self-efficacy) were associated with having more positive adjustment.

**Here are some tips for improving self-efficacy:**

**Get to know yourself.** Having an understanding of what we are good at and what we need to improve on is the first step to increasing self-efficacy. We first need to identify those aspects of life in which we wish to perform better. Take an inventory of what you are doing well and what you'd like to do better!

APPENDIX C.1

SAMPLE RECRUITMENT FLIER



**health space.net**  
supporting growth together

**Dear Colleague,**

We are excited to offer your cancer patients and survivors a **FREE, CONFIDENTIAL, SUPPORTIVE online community for those who are suffering from mild to moderate distress. Please consider referring your patients who may be eligible for this clinical trial. Your patients may enroll or learn more about this innovative community by visiting [www.health-space.net](http://www.health-space.net).**

**ELIGIBILITY CRITERIA?**

|     |   |     |   |     |  |
|-----|---|-----|---|-----|--|
| 01. | <b>Adult cancer patients and survivors</b><br>Anyone 18 or older with a history of cancer regardless of cancer type or time since diagnosis | 02. | <b>Experiencing distress</b><br>Must have a distress thermometer score of 4 or higher. "On a scale of 0 to 10, what number best describes how much distress you have been experiencing in the past week including today?" (0 = None, 10 = Extreme Distress) | 03. | <b>Internet access in English</b><br>Must have regular access to the internet and be able to read and write in English |
|-----|---|-----|---|-----|--|

**WHAT IS WWW. HEALTH-SPACE.NET?**

A randomized clinical trial funded by the National Cancer Institute (1R03CA137391, PI: Jason Owen, Ph.D.)

A free, Internet-based psychosocial intervention that is confidential, monitored by a team of clinical psychologists, and provides empirically-supported coping-skills training

Participants are asked to complete a survey every 3 months for up to a year and are reimbursed with a gift card for each survey completed

IRB-approved through Loma Linda University (IRB#57065)

**INFORMATION**

Contact ■ E-mail: [info@health-space.net](mailto:info@health-space.net) ■ Phone: 1-800-395-1525 ■ Website: [www.health-space.net](http://www.health-space.net)

## APPENDIX C.2

### SAMPLE RECRUITMENT LETTER

Dear :

We would like to invite you to become a *free member* of an innovative, online-networking group for *cancer patients and survivors*. Support groups, coping tips, discussion boards, a live chat room, and personalized home pages are just some of the features that our networking website has to offer you. Not only can you *communicate* anonymously with others who have been diagnosed with cancer, but also you can *interact* with our *trained group facilitators*, a clinical health psychologist and doctoral students.

The groups are *completely confidential* and limited to those who have received some part of their cancer care or consultation at Loma Linda University. Only registered study participants have access to the secure, *easy-to-use website*. We are able to offer these groups as part of a research study being conducted by Dr. Jason Owen, PhD, M.P.H, who is affiliated with the Behavioral Oncology Research Lab in the Loma Linda University Department of Psychology. Our goal is to learn how we can best help individuals improve their *quality of life* and receive *support* after a cancer diagnosis.

If you *choose to participate*, you will need to be able to regularly access the *internet* and be able to read and write in English. In order to participate, we will ask you to answer a few screening questions and complete baseline and follow-up surveys, all conducted on the study website. You will also be randomized to either receive immediate access to the *online networking group* or to a wait-list. If you are assigned to the wait-list, you will be able to join the online networking group in 3 months.

*Your decision* whether or not to participate in this study will have no impact on your medical care or your relationship with your doctor. All information will be kept strictly confidential and is protected by law. We have enclosed an *information sheet* that fully describes the study and your involvement, should you choose to participate. We hope that the participation and feedback we obtain from your experience will help us to better address and serve the *needs* of those living with cancer and to develop better supportive care services for individuals like you. It is also our hope that you will be able to *benefit* from the interaction, support, and feedback from other individuals with cancer as well as the group facilitators.

**\*There are 2 EASY ways to SIGN-UP for PARTICIPATION:**

**1) You can directly access our website and input your username and password to get started!**

Website: [www.health-space.net](http://www.health-space.net)  
Username (case-sensitive): public health institute  
Password (case-sensitive): iqegGARS

**2) You can wait to receive a call regarding your participation from our project coordinator, Ms. Laura Testerman, who will be contacting you within the week. If you wish to participate, she will register you into the group at the time of the call.**

**\*If you DO NOT wish to be contacted by phone and thus NOT participate:**

**1) You can email us at [info@health-space.net](mailto:info@health-space.net)**

-Include your first and last name and your request to be withdrawn  
-Include the subject heading "Withdraw"

**2) You can call us toll-free at 1-800-395-1525**

-If leaving a message, please include your first and last name and your request to be withdrawn from the "online study"

Your assistance in this effort is very much *appreciated* as the validity of this type of study depends on being able to gain the participation of as many patients as possible. If you have any questions regarding the study, you can view our *website*: [www.health-space.net](http://www.health-space.net), *email* us at [info@health-space.net](mailto:info@health-space.net), or *call* us toll-free at 1-800-395-1525.

Sincerely,

Jason E. Owen, Ph.D., M.P.H.  
Assistant Professor of Psychology  
Loma Linda University

Your name and contact information were obtained from the Loma Linda University Medical Center Tumor Registry, which is part of a larger registry maintained by the State of California. The registry was created by the California Legislature in response to public concern that not enough was being done to find the causes and cures of cancer. Every cancer diagnosed in California is required by law to be reported to the California Department of Health Services, which is responsible for the registry. Information on individuals with cancer can only be released for research purposes to qualified

researchers who have obtained approval for the study from a federally approved Committee for the Protection of Human Subjects, and have agreed to maintain the confidentiality of the information they collect.

## APPENDIX C.3

### SAMPLE MAILING FLIER

# THE HEALTH-SPACE READER

Health-Space.net Online Cancer Support Group      December 5, 2008      Volume 1, Issue 2

## Meet the Facilitators

Thank you for being a part of our online support group! We are actively assigning each of you to the appropriate group. We appreciate your patience and we look forward to interacting with each of you. Our Mission: We want to help you connect to others with cancer to learn more about how to best help improve their quality of life after a cancer diagnosis.

**Jason E. Owen, Ph.D., M.P.H. Facilitator.** Dr. Owen is a licensed clinical psychologist with expertise in health psychology and oncology. He has completed predoctoral and post-doctoral fellowships in cancer prevention and control at the University of Alabama at Birmingham and the UCLA Jonnson Comprehensive Cancer Center. Dr. Owen is currently an assistant professor of psychology at Loma Linda University. **Laura R. Boxley, M.A. Facilitator.** Laura is a doctoral candidate at Loma Linda University. She is currently conducting individual and group therapy for veterans diagnosed with Post-traumatic stress disorder at Jerry L. Pettis Memorial VA Medical Center in Loma Linda. Laura has conducted research under Dr. Owen for the past 4 years in psycho-oncology, with a focus in clinical applications of online technologies and linguistic indicators of coping. With a specialization in health psychology, she hopes to continue her postdoctoral work in a hospital setting. Laura loves to go to concerts and spend time with her fiancé.

**Natalie C. Kaiser, M.A. Facilitator.** Natalie is a doctoral candidate at Loma Linda University. She is currently working in the Department of Neurology at UCLA doing psychological testing for neurodegenerative diseases and also working as a therapist at the University of Redlands. She has conducted research under Dr. Owen for the past 3 years in psycho-oncology, focusing in cancer-related distress. In her free time, she loves to take her 2 year old pug, Sophie, to the beach as well as cooking and spending time with family and friends.

**In this issue:**

Meet the Facilitators 1

The face behind the voice: Meet Laura Testerman 1

Related articles of interest 2

**Special points of interest:**

- Get to know a bit more about the people who will be leading your group.
- Read this month's featured article to learn about how support groups are extending the lives of cancer patients

## Meet the Person behind the Phone: Laura Testerman

You have all received a phone call from Laura Testerman. Chances are, her friendly voice was on the other side of the line when you were first invited to join health-space. Her energetic and empathetic style has helped the behavioral oncology lab get in touch with cancer patients all over the country over the past few years. She's in her 3rd year of the Ph.D. program at Loma Linda University, and finds herself drawn to the human psyche and family systems. In her free time, Laura says she loves to laugh, play tennis, watch TV, and ponder the meaning of life..



# THE HEALTH-SPACE READER

Health-Space.net Cancer Support Group Newsletter

September 15, 2008

Volume 1,

## Frequently Asked Questions About Health-Space.net

We know that there are several questions you may have about the online cancer networking group, health-space.net. We hope that the following information will provide you with what you may want to know.

However, if you have any further questions, please feel free to contact us at anytime! Call toll free at 1-800-395-1525 or email us at [info@health-space.net](mailto:info@health-space.net)

**1. What is health-space.net?** Health-space.net is an online networking group for anyone who has been diagnosed with some form of cancer. The groups are free of charge, completely confidential, and limited to those who have received some part of their cancer care or consultation at Loma Linda University Medical Center.

**2. What will this information be used for?**

We are able to offer these groups as part of a research study that aims to discover how to best help individuals improve their quality of life after a cancer diagnosis. You are in no way obligated to participate, but we feel that this is a great opportunity to connect with others who can understand and support you in your quest to fight cancer, free of charge!

**3. What do I need to do in order to participate?**

It's easy—all you need is a computer with internet access. We ask that you sign into the group at least once a week to participate and receive updates, but you can sign on as much as you want! Group participation is convenient— you can sign on in the privacy of your own home, anytime you want, and navigate the group at any pace that is comfortable or convenient for you!

**4. Do I need to be a computer whiz in order to participate?** Don't worry if you are not completely computer savvy, we have a technical support staff and user friendly tutorials to help you get online hassle free.

**5. What does the online group include?**

The online group offers discussion boards, useful didactic material, friend-to-friend messages, blogs, and photo

postings to share with others. Your participation is also completely anonymous if you wish it to be so.

**6. Who runs the group?** The group is facilitated by a licensed psychologist as well as doctoral students in clinical psychology, whom are supervised by licensed psychologists. However, the facilitators are there as much or as little as you want them to be. The group is individually catered to each individual so that you can get the most out of what you are looking for in your health-space.net experience.

**7. How long does the group last?** Each group lasts for 12 weeks each. If you would like to continue for longer, you are free to do so.

**8. How is my information kept private?**

Only registered health-space users can access the website. The site is secure, and we ask that you keep your login username and password to yourself in order to protect the privacy of other members.

**9. How do I enroll?** You will either receive a phone call from Laura Testerman, our patient contact liaison within the next week, or you can sign up now! You can enroll online directly by visiting us at [health-space.net](http://health-space.net) and entering your username and password included in your letter. Once we have made contact, you will be randomized into either a wait-list group or be eligible to start participating online today! Wait-listed individuals will be kept informed of progress and news via an online or mail-out health-space.net newsletter just like this one.

We look forward to hearing from you soon! Please come and check out all health-space.net has to offer!

**In this issue:**

|  |   |
|--|---|
| FAQ's about Health-space.net           | 1 |
| Barriers and Benefits to Participation | 2 |

**Special points of interest:**

+Get to know a bit more about the group— what it is for and how it is run.

+Discover the benefits of participating in the online support group.

+Learn about the common barriers that we all experience getting started.





Contact us anytime!  
Call toll free at 1-800-395-1525 or  
email us at [info@health-space.net](mailto:info@health-space.net)

Visit us on the web:  
[www.health-space.net](http://www.health-space.net)

What to look forward to in upcoming editions:

- Updates on user reviews
- Useful information about how to cope with cancer

## Barriers and Benefits to Participation



Internet Cancer Support Groups (ICSG's) have become increasingly popular in recent years. The internet is now providing cancer patients and their family members with a destination for information, community, and emotional and psychological support. ICSG's have demonstrated several advantages to the more traditional forms of cancer support groups. Namely, the modality of internet can be delivered both synchronously (i.e. live chat) and asynchronously (i.e. email messages and discussion boards). Secondly, there is increased accessibility to individuals who are geographically distant or who cannot attend groups due to declining health. Furthermore, the support group is available to the individual at any time of day.

whether it be in the middle of the night or early in the morning. Finally, other forms of cancer support groups may be more costly, but ICSG's have zero cost!

Research conducted on ICSG's have found equal to superior outcomes with their participants when compared to other types of support. Participants of ICSG's have reported lower levels of depression and anxiety, and increased degrees of self-esteem and feelings of support. Furthermore, participating in the ICSG is an opportunity to connect with others undergoing a similar experience, interact with mental health professionals, and receive useful guidance for attaining effective coping skills.

There have also been several supposed barriers to participating in ICSG's. We will try to dispel some of the myths regarding the barriers as well as address some of the realities. For example: 1. "Online support groups are only attended by rich, white, older men." NOT TRUE! With lowering prices of internet accessibility and improved, faster internet service, people of all ethnicities, incomes, and gender are connecting online. 2. "I don't have enough time to participate." ICSG's can be accessed anytime— it can be flexible to any schedule and you choose when and how much time you spend online. 3. "I don't really have anything to talk about. I am

dealing with my diagnosis just fine."

Participating in an online group can be informative, regardless of your degree of distress. These groups create opportunities to be able to help connect with others who are having a more difficult time coping. 4. "I am not good at using my computer or the internet." Health-space is meant to be a simple and user-friendly site to navigate and interact with. We provide simple tutorials and offer technological support to those experiencing difficulties. We also try to ease into the group by spending the first couple of weeks getting acquainted with the site and trying out navigating the site. 5. "I'm not going to really gain any meaningful interactions from communicating online." People have found that the bonds that they have formed online have been every bit as meaningful as face to face; people are often willing to share more of themselves when not face to face, which can facilitate deeper connections. What do you have to lose? Just try it!

If there are any other barriers that you can foresee to participation, please contact us and we can discuss any possible solutions!

We look forward to seeing you online and having you experience for yourself the benefits of [health-space.net](http://health-space.net).

WE ALWAYS APPRECIATE ANY FEEDBACK.