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# Exploring Gender Differences in Online Cancer Support Groups

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

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Exploring Gender Differences in Online Cancer Support Groups

by

Natalie Christine Kaiser

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A Dissertation submitted in partial satisfaction of  
the requirements for the degree of  
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 opinion is adequate, in scope and quality, as a thesis for the degree of Doctor of Philosophy.

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# CONTENTS

Approval Page .....	iii
Acknowledgments.....	iv
Table of Contents .....	v
List of Tables .....	ix
List of Figures .....	x
Abstract.....	xi
Chapter	
1. Introduction and Literature Review .....	1
Distress Among Cancer Patients .....	4
Gender Differences in Distress.....	4
Factors that may Contribute to Gender Differences Overall.....	5
Biological Factors .....	5
Socialization Factors and Gender Roles .....	7
Cognitive Personality Factors .....	8
Coping Differences.....	8
Trends in the Course of Gender Differences in Distress.....	9
Gender Differences in Cancer-Related Distress .....	10
Interventions Targeting Cancer-Related Distress.....	12
Effectiveness of Psychosocial Interventions Targeting Cancer-Related Distress.....	12
Differential Effectiveness for Men and Women .....	13
The Internet as a Way of Providing Intervention .....	14
Benefits of Internet as a Modality for Intervention.....	14
Criticisms of the Internet as a Modality for Intervention.....	15
Demographics of Internet Users.....	16
Gender differences in Internet Use .....	17
Factors that may Influence Gender Differences in Online Access/Usage .....	18
Internet as a Modality for Cancer Support Groups .....	19
Benefits found to OCSG Participation .....	20
Material Included in OCSG .....	22

Predictors of Use in Online Psychosocial Interventions.....	22
Gender-Specific Factors in OCSG Participation .....	23
Recruitment Method and Targeted Health Behavior .....	24
Gender Differences in Coping .....	25
Gender Differences in Cancer-Related Needs.....	26
Observed Differences in how Men and Women use OCSG's .....	27
Gender Differences in Cancer Experience .....	27
General Communication Differences Between Men and Women .....	28
Gender Differences in Online Cancer Support Group Communication.....	28
Emotional Expressiveness: Men & Women.....	29
Gender Differences in Outcomes or Efficacy of Online Interventions .....	30
Theoretical Perspectives in the Research .....	30
Theory Behind Gender Differences in Distress.....	30
Theory Describing Internet Use .....	33
Gender and the Model of Internet Use .....	33
Internet Usage by Ethnic Minorities and Women .....	34
Participation in OCSG.....	35
Limitations in the Existing Literature .....	36
Gender Differences in the Distress Literature .....	36
Cancer-related Distress Literature.....	36
OCSG Literature .....	37
Methodology Limitation .....	37
Measurement Limitations.....	38
Sample Composition Limitations .....	38
Facilitation Limitations.....	38
Limitations in Understanding Gender Differences in OCSG Use .....	39
Research Plan .....	39
Aims and Hypotheses .....	40
Summary and Conclusions .....	41
2. Methods.....	43
Participants .....	43
Procedure.....	44
Features of the Online Support Group .....	45
OCSG Intervention.....	45
Theoretical Underpinnings of the Intervention .....	46
Professional Facilitation .....	46
Social Features of the Website.....	47

Framework for Healthspace.net .....	48
Measures .....	49
Self Report Data .....	49
Demographic and Cancer Data .....	49
Timing of Surveys.....	49
Standardized Measures .....	49
Emotional Expression Measure.....	53
Qualitative Evaluation.....	53
Behavior and Linguistic Data .....	53
Data Analysis.....	54
Linguistic Inquiry and Word Count (LIWC) .....	55
How does LIWC Work? .....	55
The LIWC Dictionary .....	56
Psychometric Properties .....	56
Evaluation of Research Hypotheses .....	57
Hypothesis 1 .....	57
Hypothesis 2 .....	57
Hypothesis 3 .....	58
Hypothesis 4 .....	59
Hypothesis 5 .....	60
3. Results .....	61
Participant Demographics.....	61
Total Recruitment Base .....	61
Individuals who were Attempted to be Contacted .....	62
Individuals who were Screened .....	67
Individuals Eligible for Participation .....	67
Participants who Enrolled in the Study .....	68
Participants who Consented Online to Participate in the Group.....	68
Individuals who Participated Online in the Intervention .....	69
Demographics by Recruitment Method Within Web-Use Data .....	70
Hypothesis 1: Gender Differences in Distress at Baseline .....	72
Hypothesis 2: Gender Differences in Decision to Participate in the Group.....	73
Hypothesis 3: Gender Differences in Topic Interest and Website Functions .....	76
Qualitative Data Analysis.....	76



Hypothesis 4: Gender Differences in Online Postings and Level of Emotional Expression .....	92
Hypothesis 5: Gender Differences in Social Connectedness .....	95
4. Discussion.....	99
Recruitment Base.....	99
Gender Differences in Regards to Recruitment and Group Participation .....	101
Qualitative Findings .....	107
Gender Differences in Emotional Expression and Connectedness to Others .....	109
Limitations and Suggested Areas of Future Research .....	110
References .....	114
Appendix	
Responses to Qualitative Questions.....	134

## TABLES

Table	Page
1. Group differences at each step of the recruitment process .....	66
2. Gender differences in website usage .....	75
3. Percentage within gender for qualitative categories mentioned.....	78-79
4. Gender differences in online postings and emotional expression .....	93
5. Gender differences in social connectedness.....	96

## FIGURES

Figures	Page
1. Integrated model of depression: understanding gender differences .....	32
2. Model predicting Internet Use .....	34
3. Personal pages.....	48
4. Recruitment flow chart broken down by gender .....	63

## ABSTRACT OF THE DISSERTATION

Exploring Gender Differences in Online Cancer Support Groups  
by

Natalie Christine Kaiser

Doctor of Philosophy, Graduate Program in Psychology  
Loma Linda University, September 2011  
Dr. Jason Owen, Chairperson

The internet has been demonstrated to be a promising modality to deliver mental health care services to cancer survivors suffering from multifaceted distress (Winzelberg et al., 2003; Fernsler et al., 1997; Fogel et al., 2003; Gustafson et al., 2001; Hoybue et al., 2005; Houston et al., 2002; Klemm et al., 1998; Lieberman et al., 2003; McTavish et al., 1995; Sharf, 1997; Weinberg, 1996, & Shaw et al., 2006). However, the extant literature in regards to online cancer support groups has been limited to pilot studies and composed of Caucasian women with breast cancer (Klemm et al., 2003), neglected to evaluate qualitative data, and have been limited to unidimensional online interventions without professional facilitation. The current study evaluated gender differences in regards to cancer-related distress, as well as recruitment, desired features, interests, and utilization of a multifaceted (i.e., chat room, discussion board, private webmail, informational coping modules) online cancer support group for a mixed gender and mixed diagnosis group of cancer survivors. Results were mixed in that they both confirmed and disconfirmed hypothesized gender differences; null findings were documented in terms of gender distress, yet recruitment-level analyses indicated that more women expressed interest in and were eligible for participation (based upon reporting of distress). However, roughly equal percentages of men and women enrolled. Despite this fact, women tended to utilize the social features of the site more so than male participants did (based upon time spent online, on the discussion board, personal pages, time spent blogging, and greater number of logins).

Furthermore, females tended to be more socially connected to other participants, while males tended to interact with facilitators through private webmail exchanges. Findings can help to inform intervention development, understand how males and females may uniquely experience cancer, and contribute to the understanding of how the burgeoning literature of tele-health interventions can make mental healthcare more convenient, effective, and widely disseminated.

## Introduction and Literature Review

The American Cancer Society asserted that in the year 2007, there were 11.71 million Americans living with some form of cancer; they also estimated that in 2010, 1.53 million new cases of cancer would be diagnosed in the United States (NCI, 2010). Furthermore, estimates revealed that 64% of those diagnosed with cancer survive five or more years post-diagnosis (Sabatino et al., 2006). Recent efforts have not only focused on trying to extend longevity following a cancer diagnosis, but the oncology community is also beginning to seriously consider *how well* people live, or quality of life (Jacobsen & Jim, 2008). Because this group is a prevalent and growing population within our society, it is important to be able to identify and address their needs. One of the most significant problems facing people with a diagnosis of cancer is multifaceted distress (Hewitt & Rowland, 2002). Previous research indicates that 25-30% of all newly diagnosed and recurrent cancer patients experience significantly elevated levels of emotional distress (Zabora et al, 2001). Furthermore, heightened anxiety and depression are not limited to the active treatment period and may persist for months or even years following treatment (Cordova, Andrykowski, & Kenady, 1995). According to Bardwell et al, (2006), prolonged and untreated depression may be associated with poorer medical adherence, longer hospital stays, increased morbidity, and possibly even increased mortality.

Gender differences in depression have been widely documented in the general population (Nolen-Hoeksema, 2006); women have been found to be twice as likely as men to develop a diagnosable depressive disorder (Kessler, McGonagle, Swartz, Blazer, & Nelson, 1993). Such findings have spurred investigations examining the possible contributing factors such as biological factors (i.e. Bierut et al., 1999), socialization factors (i.e. Nolen-Hoeksema, 2004), increased stressors and stress reactivity (i.e. Maciejewski, Prigerson, & Mazure, 2001), cognitive-

personality factors (Beck, Rush, Shaw, & Emry, 1979), and coping styles (Rosenfeld, 1999), among others. Similarly, gender differences in distress among the community of cancer patients have been a topic of interest in the literature. However, there seem to be contradictory results. While some studies have found there to be no gender differences in terms of cancer-related distress (Beresford et al., 2006; Zabora et al., 2001; Carlson et al., 2004; & Matthews, 2003), other studies have found that females tend to display more anxiety and depressive symptoms (Mystakidou et al., 2005; Deimling et al., 2006). Interestingly, no studies have reported men with higher levels of psychological distress when compared to women.

Thus, the study of gender differences in cancer-related distress is critical. Understanding gender differences in cancer-related distress may shed light on the epidemiology of distress in general. Moreover, it is well understood that men and women experience cancer differently (Harrison, Maguire, & Pitceathly, 1995), have differing needs surrounding a cancer diagnosis (Sanson-Fisher et al., 2000; Thorne & Hallberg, 2004), and may use different coping methods (Seale, 2002). Such differences are crucial to consider in specifically targeting men versus women in psychosocial interventions. There are gaps in the literature regarding the benefits of psychosocial interventions for patients with certain demographic, disease, and treatment characteristics. Hence, little is understood about different strategies to appeal to men and women in terms of recruitment, intervention style, facilitation, and outcomes of interventions (Gotay, 1991). To date, most studies examining cancer-related distress interventions have been limited to women (Jacobsen et al., 2006).

While the need for cancer-related interventions targeting distress is apparent, there is under-recognition of the need for psychosocial care by primary oncology teams, and even when recognized, there are several barriers to care that exist (Fallowfield, Ratcliffe, Jenkins, & Saul, 2001). For example, barriers include a lack of professionals available in the community to

provide care to patients, a lack of financial resources to provide such care, geographic and scheduling barriers, and childcare issues, just to mention a few (IOM, 2007). Hence, the internet has been recognized as a promising venue to offer psychosocial services, because it has the potential to overcome the usual barriers encountered with face-to-face interventions (Jacobsen & Jim, 2008). The number of people participating in computer-mediated social support groups is thought to be in the millions (Horrigan, 2001) and continues to rise steadily in the past few years (Fox et al., 2003). The benefits of such online cancer interventions have been recognized, including increased social support, increased personal, empowerment and self-esteem, reduced negative moods and cancer-related trauma (Winzelberg et al., 2003; Fernsler et al., 1997; Fogel et al., 2003; Gustafson et al., 2001; Hoybue et al., 2005; Houston et al., 2002; Klemm et al., 1998; Lieberman et al., 2003; McTavish et al., 1995; Sharf, 1997; Weinberg, 1996, & Shaw et al., 2006). However, research has been limited to pilot studies utilizing homogenous cancer types that are typically gender-specific (i.e. breast and prostate cancer), providing little insight into the gender differences that may play into recruitment strategy, facilitation techniques, topics explored, and even outcomes of online cancer support groups.

Thus, in order to further the effort to understand the dynamics of cancer-related distress, the current study sought to explore gender differences in cancer-related distress and how such differences might impact utilization, interest, and outcomes of internet based support groups. An overview of the gender differences in distress among the general population as well as cancer patients is provided, in addition to an illustration of the intervention literature targeting men and women (i.e. namely online interventions). From such knowledge, improved methods of targeting and meeting the unique needs of men and women through more efficient and convenient mediums will potentially lead to increased participation and better outcomes,



thereby decreasing the elevated distress rates observed among this population and improving quality of life.

### **Distress among Cancer Patients**

A diagnosis of cancer can be the source of a great amount of psychological distress. Distress rates vary in the literature, yet a study of five comprehensive cancer centers found the prevalence to be around 43%, as measured by the Distress Thermometer (Jacobsen et al., 2005), specific sources of cancer-related distress remain unclear. Research by Kaiser, Hartoonian, & Owen (2009) indicates that the prevalence of clinically significant distress may be somewhat lower (5.7%), but individuals diagnosed with cancer are significantly more distressed than both the “healthy” population, and those diagnosed with some other chronic disease (other than cancer), after controlling for between-group differences. With survival rates of cancer currently averaging about 66% (ACS, 2008), there is new focus on improving quality of life among this growing and prevalent population. Conversely, over half a million cancer patients in the U.S. are expected to die in 2008 (that is averaging about 1,500 per day). Hence, the population of cancer patients represents a broad spectrum of individuals with unique demographic features, needs, resources, and coping methods. Further examination of the nuances underlying sources of distress as well as intervention methods is thus warranted to help better understand and serve this critical population.

### **Gender Differences in Distress**

Gender differences in the general population have been widely documented (Nolen-Hoeksema, 2006). Unfortunately, gender differences in distress are poorly understood and little has been done to examine how and why such differences exists. More specifically, understanding this phenomenon may help to target men and women differently for improved

participation and outcomes of much needed psychosocial interventions. Although findings are mixed, the consensus is that women in the general population are twice as likely as men to develop a diagnosable depressive disorder (Kessler, McGonagle, Swartz, Blazer, & Nelson, 1993). Women's high rates of depression exact tremendous costs in quality of life and productivity, for women, themselves and their families. Reasons underlying lower reported distress among men include stigma, measurement methods, social, biological, and individual factors. Moreover, understanding the gender difference in depression will help shed light on the underlying causes of depression in general (Nolen-Hoeksema, 2001).

**Factors that may contribute to gender differences in distress overall.** Numerous factors thought to contribute to the gender difference in distress have been examined. Some of the factors provide a succinct explanation for the differences, such as supposed biases in measures of distress, which are thought to contain language more specific to females. Thus, women may falsely appear to be more distressed (Nolen-Hoeksema, 1987); while other factors are more complex and far reaching, such as gonadal hormone hypotheses and socialization factors. Nonetheless, an integrated model of these factors likely best explains sources of distress among men and women.

**Biological factors.** Women are more prone to react to stressors with a depressive outcome because of both biological and socialization related differences between men and women. Primarily, there are alleged genetic explanations offered for such differences. Twin studies indicate that genetics play a heavier role in depressive disorders than previously thought (Bierut et al., 1999; Jacobson & Rowe, 1999; Silberg et al., 1999), although these findings have been inconclusive and mixed.

Gonadal hormones have also been implicated in contributing to differences in distress (Steiner, 1992; Soares & Zitek, 2008). Women are thought to experience depression during

periods when hormone levels change substantially, such as during the premenstrual phase, postpartum period, or the start of menopause. Hormones and neurotransmitters share common pathways and receptor sites in areas of the brain linked to mood, particularly through the hypothalamic-pituitary-gonadal axis (Soares & Zitek, 2008).

Finally, more frequent stressors and greater stress reactivity may operate cumulatively to increase rates of depression in women, attributed to over activity of the hypothalamic-pituitary axis (HPA axis). Ovarian hormones modulate the regulation of the HPA axis and can be deregulated even more during times of stress and extreme hormonal change (Young & Korszun, 1999). Moreover, women have been found to have elevated HPA axis activity because of more adverse life events which predispose them. Researchers have also linked a specific gene to depression in women, but not in men (CREB-1). An alteration in this gene is thought to lead to specific subtypes of depression in women because it reduces one's resilience to environmental stress (Zubenko et al., 2002a, 2002b).

Furthermore, early exposure to adverse childhood events may begin a reciprocal relationship between stress and stress reactivity that perpetuates and kindles women's vulnerability to depression over time (Nolen-Hoeksema, 1994). Females are also thought to experience more adverse life events (Bebbington, Tennant, & Hurry, 1991), such as physical and sexual abuse (Koss, Bailey, Yuan, Herrera, & Lichter, 2003). In like manner, women are more likely to experience chronic stress such as poverty (Belle & Doucet, 2003), which may in turn increase exposure to crime, violence, illness and death of offspring, physical and sexual assault. Furthermore, discrimination experienced as the stereotyped "weaker and more inferior sex" likely results in chronic stress (Landrine, Klonoff, Gibbs, Maning, & Lund, 1995).

While findings remain mixed concerning gender differences in exposure to stressful life events, it has been found that women are about three times more likely than men to experience

stress in the wake of a stressful life event. Such findings may be further explained by the biological process aforementioned. Finally, women seem to have greater rates of first-onset depression than do men, but once they are depressed, women and men seem to have episodes of similar duration and are equally likely to have recurrent depressive episodes (Kovacs, Obrosky, & Sherrill, 2003).

**Socialization factors and gender roles.** There is an observed discrepancy between women's social roles and status relative to men's roles and sociocultural status. Traditional social practices that foster stereotypes of gender roles in terms of masculinity and femininity are thought to render women less powerful than men (Rosenfeld, 1999). As a result, it is reasoned that women experience greater distress and are believed to be more vulnerable to the health consequences of stressful conditions because of relative lack of material and personal resources (Rosenfeld, 1999). This is further bolstered by the differential exposure hypothesis, which asserts that the greater demands and obligations in women's social roles account for their higher levels of depression and distress (Turner & Lloyd, 1999).

The way in which females and males are socialized, which is largely culturally determined, emerges early in adolescence. Social forces likely put pressure on girls to become increasingly interpersonally oriented as they enter the dating world, where submissiveness to males is valued on dating market, therefore resulting in a difference in socialization (Nolen-Hoeksema, 2004). Likewise, research indicates that parents are more unlikely to teach one's daughters rather than sons about problem-solving approaches to dealing with negative affect (Nolen-Hoeksema, 2004).

Furthermore, interpersonal dependency has been found to mediate the gender difference in depressive symptoms (Helgeson & Fritz, 1996). While men have been socialized to have mastery and independence, women have been raised to be collectivistic and interrelated.

Such a pattern is counter to the western ideals of individualism which target women's maladaptive styles, thus perhaps leading to depression of women in western societies (Helgeson & Fritz, 1996).

**Cognitive personality factors.** In addition to biological roots, ways in which men and women think and operate likely contribute to the gender gap in distress. For example, depression likely results from a negative cognitive triad in which individuals view themselves, the world, and the future in distorted and negative ways (Beck, Rush, Shaw, & Emry, 1979). Gender differences in the composition of this triad are unknown. Mixed results were also obtained as to whether negative self concept was more prevalent in females rather than males (Nolen-Hoeksema & Girgus, 1994).

**Coping differences.** Lastly, differences exist in the way with which women and men cope with life events. Rumination has been the focus of much of the coping literature, and implicated as a reason for which women may experience increased levels of depression. Rumination is the tendency to focus on one's symptoms of distress, and the possible causes and consequences of these symptoms, in a repetitive and passive manner rather than in an active, problem-solving manner (Nolen-Hoeksema, 2004). Rumination is a cognitive style that can predispose one to develop negative affect or depression through perseverating on memories of the past, interpretations of present, and expectations for the future become more negative and distorted (Lyubomirsky, Caldwell, & Nolen-Hoeksema, 1998) and ruminators generate less effective solutions to solve problems, and are less likely to take positive action. Based on findings from self-report studies as well as laboratory studies, women are more likely to ruminate. In fact, when rumination was held constant, gender differences in depression becomes insignificant. Instead, men are thought to implement distraction techniques to cope

(Nolen-Hoeksema, 2004) and are less likely to turn problematic feelings inward against themselves (Rosenfeld, 1999), which may have differential outcomes.

**Trends in the course of gender differences in distress.** A glimpse into the course of onset and emerging differences may provide some insight into when to best intervene and speak to some of the etiology surrounding depression. The literature suggests that gender differences in rates of depression emerge at early adolescence (Kovacs, Obsrosky, & Sherrill, 2003; Nolen-Hoeksema & Girgus, 1994). However, in childhood years, girls and boys show similar levels of depressive symptoms (Nolen-Hoeksema & Girgus, 1994). It is at age 12 that we start to see girls' rates of depression increase substantially, whereas boys either remain the same or increase slightly (Angold, Costello, & Worthman, 1998). The observed trend may be attributed to 'gender intensification', or social pressure to conform to gender roles increasing in adolescence (Nolen-Hoeksema, 2001). For females, there seems to be a reduction in choices and opportunities. Girls tend to be more restricted and are held to lesser expectations from their parents. There is also thought to be greater rejection by peers for girls at this age (Nolen-Hoeksema, 2001).

Research indicates that the gender gap in distress increases with age (McDonough & Stroschein, 2003). This widening gap reflects the progressive and cumulative nature of women's disadvantaged work and family roles (Mirowsky, 1996), explained by the cumulative disadvantage hypothesis. This hypothesis leads to research which found that the gap widened from the middle years of life (i.e. ages 45-54) and onward (McDonough & Stroschein, 2003). Therefore, there is a U-shaped relationship with distress: distress appears to be highest among the younger people and oldest people; at all ages, women appeared to be more distressed than men, yet the gap widened with age. It should be noted, however, that

employment status, housework, and childcare (responsibilities typically assumed by women) accounted for half of the variance in distress with age (McDonough & Strohschein, 2003).

### **Gender Differences in Cancer-Related Distress**

Gender differences in depression and other psychiatric conditions have been widely documented in the general population (Nolen-Hoeksema, 2006). Therefore, several studies have analyzed the differential gender-based adaptation of a cancer diagnosis. However, there seem to be contradictory results. While some studies have found there to be no gender differences in terms of cancer-related distress (Beresford et al., 2006; Deimling et al., 2006; Zabora et al., 2001; & Carlson et al., 2004; Matthews, 2003), other studies have found that females tend to display more anxiety and depressive symptoms (Mystakidou et al., 2005; Deimling et al., 2006). Interestingly, limited studies have reported men with higher levels of psychological distress when compared to women (Kaiser, Hartoonian, & Owen, 2009).

In considering the effects of gender on cancer-related distress, there are other factors that should be considered; for instance, is the cancer gender-specific? (E.g. breast, ovarian, cervical, prostate, testicular), or is the cancer gender-common? (E.g. lung, pancreatic, colon, etc.). While looking at distress rates within cancer types, it is important to consider the prognosis/ survival rate of different types of cancer. For example, perhaps women diagnosed with ovarian cancer, a serious form of cancer, will report higher levels of distress in relation to men diagnosed with highly treatable prostate cancer. This observation may be attributed to survival rate as opposed to gender.

Yet another factor to consider while examining gender differences in cancer-related distress rates are cultural determinants (Mehnert, Shim, Koyama, Cho, Inoi, Paik, & Koch, 2006). Some cultures may find it less socially acceptable for men to admit to distress, which may in turn

explain why females have been found to report higher levels of distress. For example, Wilson (1967) found that males are more willing to express certain types of emotions more than others. Women are more likely to express feelings of fear than men, and more likely to report fears that others may view as “silly” because it is not socially acceptable for men to do so (Wilson, 1967).

Findings concerning gender differences in cancer-related distress have largely varied based upon location and types of symptoms as well. For example, males have reported higher distress in the physical dimension of symptoms, but for females in the psychological dimension. However, females have reported higher distress in general (Herschbach, Book, Brandi, Keller, Lindena, Newohner, & Marten-Mittag, 2008). Moreover, females treated in University clinics and rehabilitation clinics reported significantly higher distress than their male counterparts in the same setting, yet distress rates varied in different settings (Herschbach, Book, Brandi, Keller, Lindena, Newohner, & Marten-Mittag, 2008). However, such results may be due to the complex confounding effects and stage of disease in these settings. Furthermore, across different cancer types, females have been found to be more distressed than males in each category. Highest distress rates were found in individuals with respiratory tract cancers for both males and females (Hershbach et al., 2008).

Finally, when gender differences are found to exist in terms of cancer-related distress, it is important to recognize that a cancer diagnosis may affect men and women uniquely and may trigger different coping methods. Therefore, intervention efforts may need to cater differently to men versus women. For example, research has demonstrated that females tend to experience more cancer-related pain than men, speculated to be accounted for by females being undertreated for such pain (Im, Chee, Guevara, et al., 2007). Further, females have tended to display more emotion-focused and social support seeking efforts compared to their male counterparts (Clarke, McCXarthy, Downie, Ashley, & Anderson, 2009).



## **Interventions Targeting Cancer-Related Distress**

**Effectiveness of psychosocial interventions targeting cancer-related distress.** Anxiety and depression are among the most commonly reported 'syndromes' accompanying cancer diagnoses in adults (Newport & Nemeroff, 1998; Stark & House, 2000), and symptoms may persist for years after diagnosis and treatment (Cordova, Andrykowski, & Kenady, 1995). Dangers to untreated distress (i.e. increased morbidity and mortality) have been documented (Bardwell et al., 2006), and are being paid more attention. Therefore, the focus is to develop interventions to alleviate such syndrome symptoms and should focus on dealing with the day-to-day issues concerning a cancer diagnosis as opposed to just end of life issues. However, research has sometimes left an unanswered question in terms of the actual efficacy of psychosocial interventions.

In terms of anxiety, systematic reviews have been equivocal in terms of perceived benefit of psychosocial interventions. Some studies have found positive effects including improved coping, lesser stress responses, etc. (Jacobsen & Jim, 2008; Jacobsen et al., 2006, Devine & Westlake, 1995; Osborn et al, 2006); however, not all findings have been so convincing (i.e. Uitterhoeve et al., 2004; Newell et al., 2002). Similarly, psychosocial interventions have demonstrated benefit in terms of alleviating depressive symptoms as well as mixed anxiety (Bottomely et al., 1998; Lovejoy et al., 1997; Sellick & Crooks, 1999; Barsevick et al., 2002; Uitterhoeve et al., 2004; Luebbart et al., 2001; Devine & Westlake, 1995; Osborn et al., 2006; & Jacobsen et al., 2006). Likewise, not all findings have found such advantageous outcomes or have been mixed (Newell et al., 2002; Sheard & Maguire, 1999; Williams & Dale, 2006; Rodin et al., 2007).

Research on outcomes is difficult given that there is no real standardization of outcome measures and given that there are always differences in the way that interventions are

facilitated, conducted, setting, duration, cancer type, and several individual differences to take into account. However, most of the evidence-based treatment studies have primarily focused on the efficacy of behavioral therapy, counseling/ psychotherapy, all combined with some sort of psycho education, with cognitive-behavioral interventions as the most heavily researched psychosocial interventions (Jacobsen & Jim, 2008). Steps have even been taken to cater to unique cancer-related needs such as resources based on type of treatment regimen and time of diagnosis, but few conclusions have been produced (Jacobsen & Jim, 2008).

**Differential effectiveness for men and women.** There are gaps in the literature regarding the benefits of psychosocial interventions for patients with certain demographic, disease, and treatment characteristics with particular oversight as to the effects of gender. For example, in a systematic review of psychosocial intervention effectiveness for cancer patients, men were included in only 5% of the studies (Jacobsen et al., 2006). In addition, sources of anxiety and depression and the psychosocial interventions needed to treat them may vary by gender as well as cancer type. Namely, Simpson et al. (2001) found that group Cognitive Behavioral Therapy for female breast cancer patients was effective, yet results cannot be generalized to other types of cancer and to men.

Interestingly, very few studies focus on effects or even interventions targeting men; yet studies that include men suggest that the benefits of participating in psychosocial interventions and support groups are quite significant (Rehse & Pukrop, 2002; Gregoire et al., 1997; Mishel et al., 2002; Penedo et al., 2006). Specifically, benefits have been found, including greater improvements in mental health, less interpersonal conflict, greater perceived control over health and functioning, greater benefit finding, higher quality of life and lower distress associated with cancer-related intrusive thoughts relative to controls (Lepore, 2001; Penedo et al., 2006). Men with the most inadequate social resources received the most benefit from the

intervention. However, the research is limited to small scale studies within single types of gender specific cancer (i.e. breast and prostate cancer), community-based and without an appropriate comparison group, and largely comprised of largely educated, older, white men (Anderson, 2002; Coreil & Behal, 1999), with the exception of a few (i.e. Penedo, Dahn, Molton, Gonzalez, Kinsinger, Roos, Carver, Schneiderman, & Antoni, 2003) examined an ethnically diverse sample of men and women.

### **The Internet as a Way of Providing Intervention**

Researchers, clinicians, and the oncology community as a whole are responding to the increased need for and efficacy of psychosocial interventions, and are attempting to individualize, specialize and improve the quality, efficiency, and ease of providing psychosocial services to the cancer community and beyond. The internet has emerged as a promising medium to help implement such goals.

The internet has penetrated almost every aspect of everyday life, from how we communicate, to how we learn, shop, and play (Benton Foundation, 1998; Dertouzos, 1997; Jackson, 1999a; Keller, 1996; Kiesler, 1997; Tapscott, 1996, 1998 U.S. Dept of Commerce, NTIA, 1995, 1997, 1999). The internet has opened up new possibilities in public health as well (Sorenson, 2001), with the number of people participating in computer mediated social support groups becoming increasingly popular (Horrigan, 2001; Fox et al., 2003). The internet has especially become a popular forum for breast cancer support groups (McTavish et al., 1995; Weinberg et al., 1995, Weinberg et al., 1996).

**Benefits of Internet as a Modality of Intervention.** Over the recent years, more and more research has been conducted to explore the efficacy of online interventions. The findings have showed promise, but are not without criticisms and skepticism. Benefits found include

lower depression scores (Shaw & Grant, 2002; Houston et al., 2002; Lieberman et al., 2003); decreased cancer-related trauma (Winzelberg et al., 2003); increased social support and information (Fernsler et al., 1997; Fogel et al., 2003; Gustafson et al., 2001; Klemm et al., 1998; Sharf, 1997; Weinberg, 1996); improved coping (Hoybue et al., 2005); and acceptance, motivation, understanding, and relief (McTavish et al., 1995). Much of the appeal surrounding online interventions lies in the ability to overcome many of the common barriers to participation in traditional face-to-face interventions. For example, there is often a lack of professionals available in many communities to provide care to cancer patients (Fallowfield, Ratcliffe, Jenkins, & Saul, 2001). Jacobsen & Jim (2008) recognized the need to increase access to evidence-based interventions, and acknowledged the internet as a promising venue to offer such services with ease of dissemination, cost, and decreased resources needed to address common barriers such as childcare issues and geography (Gustafson & McTavish, 1999).

**Criticisms of internet as a modality of intervention.** Despite the demonstrated advantages, several criticisms have been identified in terms of accessibility and feasibility, population served, detriments to interpersonal relationships, security and accuracy of information, and efficacy of the internet as a modality of intervention. Skeptics have expressed that time spent on the internet supplants the time that users could spend establishing and nourishing “real world” relationships, thereby breaking down users’ social support network (Kraut, Oaterson, Lundmark et al., 1998; Sanders, Field, Diego et al., 2000). Further, there is an ongoing debate about whether online relationships have the potential to be as meaningful as face-to-face relationships or if they are inherently less fulfilling (i.e. void of the face to face visual cues, etc) (Wolfradt & Doll, 2001). Similarly, the Internet Paradox Study (Kraut et al., 1998) warned users that the internet affects us negatively: internet use was positively correlated with diminishing communication between family members in the participant

households and reduction in local and distant social networks. The study also asserted that internet use was linked to loneliness, depression, and daily stress. However, several studies have refuted such assertions and found evidence to the contrary (Sanders et al., 2000; LaRose et al., 2001; Hamburger & Ben-Artzi, 2000).

Ease of accessibility has also come into question with respect to online interventions. Researchers have noted that finances and online literacy are likely barriers, especially to ethnic minorities, women, and the elderly. However, respondents to this criticism have responded by saying that when free access and training are made available, almost all people are equally likely to participate (Shaw et al, 2006). Furthermore, Weinberg et al. (1996) found that women with breast cancer encountered few problems with the computer program and participants quickly mastered the use of the support modality. In terms of satisfaction and usage, and characteristics such as age, educational level, and computer experience, was not shown to have any negative effect (Gustafson et al., 1993; McTavish et al., 1995).

Beyond these criticisms, online interventions have been known to sometimes post inaccurate or incorrect information (Finfgeld, 2000; Klemm et al., 1998), and the security and privacy of information on the net has been in question (Boehlefeld, 1996). It is also argued that online interventions tend to “make the healthy healthier” in that participants are typically high income, have lesser physical and psychological limitations, do not have as advanced cancer, and are highly educated (Fawcett & Buhle, 1995; Im, Chee, Tsai, Lin, & Cheng, 2005)

**Demographics of internet users.** There are more than 1 billion internet users worldwide (Miniwatts, 2007). This number is increasing due to a drop in cost of internet connections and improved high speed access, and the biggest penetration rate is in North America (roughly 70% (Miniwatts, 2007)). Currently, the largest increase in internet usage rate is highest among underserved population (i.e. elderly, lower educated, and women); therefore

previously noted gaps in internet usage are narrowing (Insites Consulting, 2005). However, that being said, compared to non-users, internet users tend to be younger, more educated individuals with higher incomes (Fogel et al., 2002b).

**Gender differences in internet use.** There are also marked gender differences in terms of internet use that are of interest. Historically, it was thought that men were more likely to have access to the internet than females (Graphics, Visualization, and Usability Center, 1994-1998) and there was a widespread belief that computers, and now the internet, are male-biased technologies (Morahan-Martin, 1998). However, recent research challenges this assertion. According to Jackson (1999c), females have been using the internet in increasingly staggering numbers: from its inception as a mass media technology in 1994, the percentage of women online in the U.S. has increased from 5% to 40% or more (depending on the survey). Likewise, In December 2000 and 2001, women outnumbered men online both years (50.4 million females vs. 48.2 million males in 2000; 55 million women vs. 49.8 million males in Dec 2001) (Nielsen, 2002).

Yet, even more contradictory findings have surfaced. Recent reports from the UCLA World Internet Project (2004) stated that the gender difference in usage may not have diminished as was thought; trans-world findings indicate that in the US, 73.1% of males reported using the internet compared to 69% of females; in the United Kingdom, the percentages reached 69% males to 63.9% females; and in Italy: 42% males to 22% females use the internet.

Despite the mixed findings with regards to who uses more, men or women, there are patterns concerning usage that have arisen which are important to take note of. While the number of women users are increasing, male users seem to be accessing the internet more frequently (21 log-ins average for males compared to 17 log-ins for females; average of 11 hours online and 801 different websites visited for males vs. an average of 9 hours online and 573 websites visited for females (note: statistics based on weekly usage)) (Nielsen, 2002; Odell,

Korgen, & Schumacher et al., 2000; Pew Internet and American Life Project, 2007; Fallows, 2007).

Finally, differences seem to exist in terms of how men and women use the internet. For example, males use the internet more for information searching and entertainment, whereas females use it more for communication purposes (Jackson et al., 2001a; Miller et al, 2001; Morehan-Martin, J. , 1998; Odell et al., 2000; Sherman et al., 2000; Teo et al., 2000; Weiser et al., 2000); such findings seem to be cross-cultural (Teo & Lim, 2000; Ho & Lee, 2001). Differences are beginning to emerge in access and usage, but the question remains, why do such differences exist? The following discussion will attempt to answer this question.

**Factors that may influence gender differences in online access/usage.** Several reasons may underlie the observed discrepancies in gender online use. One of the factors includes differences in attitude towards the internet. Females have been found to have less positive attitudes towards the internet than males (Sherman et al., 2000; Ford & Miller, 1996; Tsai et al., 2001; Li et al, 2001). Furthermore, females are less confident in their abilities in using the internet (Li et al., 2001) and are more anxious using the internet (Tsai et al, 2001). Cognitive factors also may play a role, such as self-efficacy: males are more self-efficacious with regard to computer technology than are females (Comber, Colley, Hargreaves, & Dorn, 1997; Fletcher-Flinn, & Suddendorf, 1996).

Additional psychological, affective, and social factors may also explain the discrepancy. For example, females were found to be more depressed than males, but males were discovered to be lonelier. Loneliness was associated with less email use, which is consistent with findings that males email less (Jackson et al., 2001; Kraut et al., 1998). However, higher email use was found to be associated with higher rates of depression (Kraut et al., 1998). Caution must be used in drawing conclusions from this finding; as it does not suggest that email usage is a cause of

depression, but rather likely a response to depression. These findings reiterate the pattern discussed previously that females seem to be likely to nurture and connect to others more as a coping mechanism (Taylor et al., 2000).

Moreover, a link between motives for using the internet (such as communication purposes, information gathering, and entertainment purposes), personality factors, and gender was observed. Hamburger & Ben-Artzi (2000) discovered that personality traits such as extraversion and neuroticism were linked to females' tendencies to seek out social interaction online. Conversely, extroverted personality for males was positively correlated to the entertainment motive, while neuroticism among males was found to be negatively correlated with information services. However, no link was discovered between males and social motive or between females and information seeking or information motives. This finding proves to be interesting, as it illustrates how different personality styles spawn differential online behaviors for the two genders.

Not all research indicated marked gender differences that may influence differential online usage. For example, no difference was discovered in terms of trust of the internet, concerns about internet privacy, or current computer ownership (Jackson et al., 2001). Likewise, no greater success has been reported in either gender when searching the web (Jackson et al., 2001; Morahan-Martin, 1998). Yet examining such findings will help pave the way to understand how/ why men and women differ in terms of usage, and thus how the internet can be used as a modality to appeal to both men and women for cancer interventions. To speak to such issues, a further examination of the internet as a previously tested and potentially superior way of meeting the needs of male and female cancer patients will be provided.

**Internet as a modality for cancer support groups.** Cancer support groups have existed for almost 30 years and were first reported in the 1970's. More recently, cancer patients have



utilized the internet as a means of support, and the number of internet cancer support groups has risen dramatically (Klemm et al., 1999; Madara & White, 1997). Thirty-nine percent of cancer patients use the internet, and approximately 2.3 million persons living with cancer worldwide are online (Eysenbach, 2003). Further, a study of cancer patients and their caregivers indicated that 80% were interested in treatment-related information on the internet, while 65% expressed an interest in online support groups (Monnier, Laken, & Carter, 2002). Online cancer support groups (OCSG's) have been described by patients, researchers, and clinicians alike as a convenient and effective way to provide information, personal and professional support, shared experience, and patient advocacy (Finfgeld, 2002).

### **Benefits found to OCSG Participation**

There are several potential ways that online interventions overcome many of the barriers traditional face to face interventions encounter. For example, research indicates that participation tends to reduce negative moods, including depression and cancer-related trauma (Winzelberg et al., 2003; Houston et al., 2002; Lieberman et al., 2003; Shaw et al., 2006; Sharf, 1997). Moreover, women in an online intervention of 60 women with breast cancer reported significantly better social support and greater information competence, despite non-significant findings with respect to quality of life (Gustafson et al., 2001). Owen and colleagues (2005), however, noted significant improvements in quality of life relative to emotional expression of negative emotions, in addition to improved health status of breast cancer survivors among those with poor health status at study entry. Contrary to the notion that benefits of OCSG's were limited to wealthy, white, highly educated males, results have also been beneficial for greater disadvantaged individuals (Gustafson et al., 2001).

Winzelberg and colleagues (2003) derived a comprehensive list of advantages that OCSG's hold over traditional cancer support groups. First, the modality of delivery is flexible because information can be delivered both synchronously and asynchronously. Next, there are also a variety of facilitation options such as scheduling flexibility, increased accessibility to individuals who otherwise could not have participated in such groups because of health status, residence in remote areas, and/or social anxiety. Also, fewer resources are required to moderate a group. Thus, cancer patients are getting necessary support through OCSGs even when they don't have transportation to participate in face-to-face groups, when they are awake alone in the night, and when they are too weak to function normally in their daily lives (Hoybye, 2002; Weis, 2003; Winzelberg et al., 2003). Online facilitation also avoids the visual distractions of age, gender, and social status, and has thus been described as "the great equalizer" (Madara & White, 1997). The internet support system also allows for greater anonymity (Fernsler & Manchester, 1997). Moreover, online support groups have become popular and essential among cancer patients, especially for those who live in geographically distant areas (Hoybye, 2002; Madara & White, 1997; Fernsler & Manchester, 1997; Sharf, 1997).

OCSG's may also be valued by people who suspect that they are unlikely to establish equal and honest relationships with their doctors in real settings because of their ethnicity. In fact, contrary to popular thought, ethnic minority cancer patients expressed greater interest in e-health than in their more affluent counterparts (Cline & Hayes, 2001; Mead, Varnam, Rogers, & Roland, 2003). However, there are still barriers that exist and populations that are not being reached. Namely, very few ethnic minorities are participating. In women-only groups, about 1% of participants were ethnic minorities (Im et al., 2005). It is thought that perhaps these women do not feel that such a group would be helpful to them because of the stigma of disclosing cancer to people outside of the immediate family, which is culturally taboo (Im et al., 2005).

### **Material Included in OCSGs**

Like many of the traditional face-to-face psychosocial interventions for cancer patients, the goal of online support groups is to alleviate distress or anxiety/ depressive symptoms. However, as is common with much other internet use, information seeking is a common coping mechanism that is utilized heavily by OCSG's (Fernsler & Manchester, 1997). A content analysis of over 300 messages posted on an OFSG identified eight major categories of information shared: information giving/ seeking, personal opinions, encouragement and support, and personal experience (these accounted for 80% of the messages posted; Klemm et al., 1998). Weinberg and colleagues (1995) found that OCSG's offered the same therapeutic factors in face-to-face groups such as hope, group cohesion, and universality (Fobair, 1997; Cella & Yellan, 1993; Hosaka et al., 2001; Kogan et al., 1997; Koopman et al, 2001; Leavitt et al., 1996; Magan & Glajchen, 1999; McLeod, 1996; Mishel et al., 1984; Rutledge & Raymon, 2001; Samarel et al., 1997; Roberts et al., 1997; Simpson et al., 2001; Montazeri, 1996).

### **Predictors of Use in Online Psychosocial Interventions**

Although the Internet is growing as a popular resource for psychosocial support, little is known about the factors that predict who will choose to participate. Identifying the factors that may influence or appeal to those who participate may help better target currently unreached populations and appeal more to those already served. However, the findings have yielded mixed results. From what has been observed thus far, a study of an online intervention for breast cancer patients revealed the only significant predictors of participation were whether at pretest, the women considered themselves active participants in their healthcare, had better relationships with one's physician, fewer cancer-related worries, and higher energy levels (Shaw, Hawkins, Arora, McTavish, Pingree, & Gustafson, 2006). Such findings indicate that

health care self-efficacy is a strong predictor of participation while other factors previously thought to predict participation were not supported (i.e. higher education, health competence, information seeking, lower levels of preexisting social support, and more negative mood).

Fawcett & Buhle (1995) discovered that cancer patients whom participate in online cancer support groups tend to be highly educated, high income white males, as was similar to Im & Chee's (2004) findings. However, while Fawcett & Buhle claimed that participants tend to be healthier than cancer patients in face-to-face settings, Im & Chee found that online participants tended to be more seriously ill. Interestingly, Klemm & Hardie (2002) found that online participants when compared to face-to-face participants did not differ with respect to income, health insurance status, or time since diagnosis. However, researchers did find that participants did differ significantly in terms of levels of depression; online participants were found to have higher baseline depression scores than those participating in face-to-face groups (Klemm & Hardie, 2002). Hence, questions remain regarding the demographics of those who are most likely to participate in online support groups for cancer patients.

### **Gender Specific Factors in OCSG Participation**

Since non-gender specific factors yielded mixed findings, a closer look at gender-specific factors influencing participation in online cancer support groups may shed light on what appeals to participants. Furthermore, this knowledge can help to better individually tailor interventions to gender-specific needs. To date, there is very little research on gender differences in recruitment for interventions or clinical trials (Gotay, 1991). Findings are mixed concerning the gender that dominates OCSG participation, yet they indicate that significantly more women than men participate, perhaps due to the observation that more breast cancer online groups have been developed (Wright, 2002; Im, Chee, Tsai, Lin, & Cheng, 2005). Yet,

other studies argue that online support groups tend to have more gender balance than traditional face-to-face support groups (Klemm & Hardie, 2002, Klemm et al., 1998). Marked gender differences in the psychology, coping, cancer-related needs, recruitment method and targeted behavior, as well as intra-gender demographic differences provide the explanations for gender differences in interest to participate.

For instance, females are thought to have increased awareness and sensitivity to others, which are hallmarks of female psychology, and may predict higher levels of participation (Gilligan et al., 1986; Markus & Kitayama, 1991). Hobfoll & Vaux (1993) hypothesized that individuals more comfortable receiving support are usually more competent at obtaining it. This taps into culturally sanctioned gender roles where it may be more acceptable for women to seek support from others as opposed to men.

There may also be demographic differences within gender types that are associated with greater coping and help-seeking behavior, such as higher education (Epping-Jordan et al., 1999); white ethnicity (Gourash et al., 1978; Shaw et al., 2006); younger age (Epping-Jordan et al., 1999); married marital status (Shaw & Yun, 2000); and stage of cancer (Epping-Jordan et al., 1999).

### **Recruitment Method and Targeted Health Behavior**

Furthermore, different modes of recruitment strategy and topics of interest have yielded gender differences. For example, females as opposed to men were more drawn to participate in online interventions targeting physical activity recruited through such means as a brochure (Spittaels & De Bourdeauduij, 2007), Diabetes prevention intervention recruited via newspaper ads (Harvey-Berino et al., 2002; Tate et al., 2003), or obesity interventions recruited

major radio stations (McCoy et al., 2005). Thus, across types of interventions and recruitment, it appears as though women are universally more apt to participate.

### **Gender Differences in Coping**

Examining gendered coping differences may help shed light on why females rather than males are more drawn to participate in online interventions over males. As previously discussed, females are more apt to connect with others and express emotions via email or online venues, while men are more information seekers (Jackson et al., 2001a; Owen et al., 2004). This is in line with Spiegel (2003) findings, indicating that men often express affection and relatedness by doing things actively, while women seem to want to talk and be heard. Moreover, men tend to deny or diminish problems to avoid burdening others or being perceived as needy or vulnerable, to reduce or avoid negative affect, and to maintain a positive self image (Boehmer et al., 2001; Hess et al., 2000; Kosberg et al., 2002). Such findings may explain why Kiss & Meryn (2001) found that men with prostate cancer are less likely than their female counterparts to attend support groups or to share feelings with others, preferring informational exchanges (Kiss & Meryn, 2001). Conversely, it has been observed that women with breast cancer are more likely than men with prostate cancer to confide in several people (Harrison et al., 1995).

Thus, although it appears that women may participate more to cope by connecting and seeking emotional support from others, the internet also provides a promising venue for men as well to cope by gathering information about their disease in a fast, effective way (Klemm et al., 1998) in addition to reaping other psychosocial benefits such as connecting to others and expressing their thoughts and feelings in an open manner.

## **Gender Differences in Cancer-Related Needs**

Yet another factor that may affect gender differences in online participation interest is differences in cancer-related needs. Cancer patients needs have been defined as psychological, informational, physical, support, and communication needs (Foot, 1996). Psychological needs can be described as the patients' perceived needs with psychological and emotional issues; informational needs are those surrounding diagnosis, investigative tests, family, and financial issues; physical needs include coping with physical symptoms and side effects of treatment, performing daily tasks living, and self management of medical treatment routines; support needs are usually in relation to family, friends and health care professionals; and communication needs are those related to interpersonal relationships and interactional skills with health care professionals (Foot, 1996).

Researchers have documented that there are gender differences in diverse aspects of cancer-related needs (Sanson-Fisher et al., 2000; Thorne & Hallberg, 2004). For instance, it seems as though women report a significantly larger number of cancer-related concerns, including the illness itself, the future relating to the illness, concerns about the family, and physical concerns (Hill, Amir, Muers, Connolly, & Round, 2003). There are also differences in help-seeking behavior that have been observed which may imply differences in perceived needs for help. As previously mentioned, men are more information driven as opposed to female whom are more support and encouragement driven (Dale et al., Klemm, Hurst, Dearholt & Torne, 1999; Sharf, 1997). In similar fashion, men seem to have more concerns about the physical aspects of cancer (i.e. being able to carry out physical household demands or hold a full-time job and act as a breadwinner for the family) as opposed to women who express more psychologically related concerns (Feine, Bushnell, Miron, & Duncan, 1991; Vallerand, 1995), yet results are mixed (Erdington et al., 2004; Turk & Okifuji, 1999; Miakowski, 2004).

### **Observed Differences in How Men and Women Use OCSG's**

In addition to established gender differences in interest to participate in OCSG's, several gender differences regarding *how* men and women use the OCSG's have been observed. Such differences may be attributed to differences in communication styles (Coates, 2004), differing experiences with cancer (Harrison, Maguire, & Pitceathly, 1995), and emotional expressiveness differences (Davison & Pennebaker, 1997; Owen et al., 2004).

**Gender differences in cancer experience.** Primarily, gender differences in the experience of cancer have been thought to arise from biological profiles of individual cancers and from differing social expectations about the appropriate and stereotyped gender roles (Kiss & Meryn, 2001). The differing cultures of men and women's' cancer experience have been documented over the years through analyses of stories with people who have cancer (Harrison, Maguire, & Pitceathly, 1995). In qualitative and quantitative content analyses of newspaper reports accounting cancer experiences, women's' skills in emotional self transformation and ability to draw on support from others has been portrayed (Seale, 2002). However, men appear to be psychologically unchanged from the cancer experience, and remain stoical and isolated (Seale, 2002). Women seem to deal effectively through complex emotional communication, whereas men effectively cope by gathering the right medical information, asking incisive questions of doctors, maintaining tight personal control over treatment decisions (Seale, 2005a, b), and raising awareness of their form of cancer in public forums (Klemm et al., 1999; Seale, Ziebland, Charteris-Black, 2005). Moreover, different concerns arose for men and women in their cancer experience: men were more focused on diagnostic tests and physical symptoms than were women. However, while men seemed to focus on a more localized area of the body, women had a more holistic approach and expressed more body image issues (Seale et al., 2005)



Gooden & Winefield, 2007). Such differences may thus dictate what and how men and women communicate in an online venue.

**General communication differences between men and women.** Largely, differences have been observed with respect to how men and women communicate. Coates (2004) asserts that gender is constructed through communicative acts. Outside of the realm of online cancer support groups, several gender differences in communication styles are documented. For example, women are more frequently interrupted by men in mixed sex groups (Anderson & Leaper, 1998) and frequently have trouble getting in their chosen topics accepted in talk (DeFranciso, 1998). In addition, women are found to both give and receive more compliments (Holmes, 1995), apologize more, hedge statements with qualifying statements, and swear less. In same sex groups, women rarely asked questions to get information, but to draw others in the conversation; men tend to engage in contests for dominance and are more likely to use direct commands and imperatives (Goodwin, 1980; West, 1990).

**Gender differences in OCSG communication.** Within the online form of cancer support groups, marked gender differences are also observed in communication style and preferences. For example, in a keyword analysis, men seemed to utilize more emotionally inhibited speech; they used less “I” and family words, and used more single “wife” words (Seale et al., 2005; Davison & Pennebaker, 1997). Also, in mixed sex online discussion forums, men had overwhelming quantitative dominance in postings and reported to take this balance to be natural (Herring, Johnson, & DiBenedetto, 1995).

Finally, because men tend to focus on information and expert advice, men seemed to express interest in inviting outside members and doctors to be involved in support groups, whereas women seem to prefer small, intimate settings with no outside members, and informal structure (Gray et al., 1996). Women also seem to use humor in these venues differently than

men; women seemed to use humor in a brief way and relating to the disease, whereas men used more lengthy jokes and accounts to cope (Gooden & Winefield, 2007; Gray et al., 1996). Finally, women seem to encourage with an affectionate and nurturing nature, whereas men promoted strength and used battle-like terminology, as if they were in a war vs. cancer (Gooden & Winefield, 2007; Klemm et al., 1999).

**Emotional expressiveness: men vs. women.** Emotional expressiveness has become an area of interest in examining gendered communication styles, especially within the realm of distress and cancer. Level of emotional expressivity has often been linked to benefit finding within the cancer experience, which has been thought to lead to improved distress outcomes (Davison & Pennebaker, 1997). Boneva and Kraut (2002) concluded that expressiveness tends to characterize women's style, associated with emotional intimacy and sharing in personal relationships. Conversely, men's style is more instrumental, interested in making things happen and oriented around common activities. Consistent with this finding, Davison and Pennebaker (1997) discovered that female breast cancer patients, when contrasted with male prostate cancer patients, had the highest percentage of positive emotion words. Females tend to be more direct in clearly expressing emotions as well, whereas men imply emotions when communicating (Gooden & Winefield, 2007).

Within the culture of gender, there are additional cultural and language-specific nuances to take into account when analyzing differential communication types. Gender differences can take somewhat different forms in non-English speaking cultures (Oliveira, 2003; Panyamethekul & Herring, 2003). For instance, gendered behavior that varies from dominant norms in English speaking societies has been described in studies of experience of breast cancer (Pitts, 2004) and prostate cancer (Gray, Fitch, Fergus, Mykhalovsky, & Church, 2002). Hence,

findings from English speaking studies may not be generalizable across cultures and languages, and special cultural considerations need to be addressed.

### **Gender Differences in Outcomes or Efficacy of Online Interventions**

With gender differences documented in participation interest and usage, gender differences are likely expected in terms of outcomes. Yet with few randomized controlled trials to be able to extract accurate conclusions regarding and a lack of standardized outcome measurement techniques, conclusiveness is difficult. Most studies conducted to date have included pilot studies of online interventions (Klemm et al., 2003), within small groups of single types of gender-specific cancers (i.e. women with breast cancer) (Penedo et al., 2004; Klemm & Hardie, 2002). Limited findings have been equivocal concerning differential outcomes for men and women; Klemm & Hardie (2002) concluded that there were no differences between men and women in terms of outcomes in a mixed diagnosis group. Yet, Christensen, Griffiths, Groves, & Korten (2006) found that women were more likely to have lower depression at end of intervention after an online CBT intervention targeting depression. Therefore, with a lack of conclusive findings, further research concerning gender differences with improved methodology for accurately determining outcomes is warranted.

### **Theoretical Perspectives in the Research**

There appears to be a lack of theory modeling the gender differences in distress as well as recruitment, use, and outcomes of online cancer support groups. However, a few past studies have attempted to take on a more theoretical approach in understanding this phenomenon.

**Theory behind gender differences in distress.** Due to the fact that there are several factors to consider in regards to gender differences in distress, Nolen-Hoeksema, Larson, &

Grayson (1999) have proposed an integrative model to understand multifaceted distress discrepancies. This comprehensive model describes how situational factors (i.e. predisposition to encounter more negative life events such as sexual or physical assault, poverty), negative cognitive style, dependency on others, ruminating, or having genetic vulnerabilities, hormonal changes, and Hypothalamic Pituitary Axis (HPA axis) dysregulation could contribute to women's higher rates of depression. Such factors were described at length in the beginning of this paper, but shall be briefly reviewed here (See Figure 1).

Stressful experiences more specific to women can cause biological change that increase women's stress reactivity (Weiss et al., 1999). In addition, genetic vulnerability to depression, or to deregulation of neuroendocrine or neurotransmitter systems, could further enhance the negative effects of early stressors on these systems (Kendler, 1998). In turn, deregulation of the biological stress response could contribute to new episodes of depression both through biological mechanisms (e.g. by affecting serotonergic systems) and by affecting a woman's behavioral response to new stressors. Hence, this becomes a vicious cycle. Stressful experiences could also increase psychosocial vulnerability to depression in women by exacerbating a preexisting tendency to ruminate and by contributing to the development of interpersonal dependency or negative cognitive styles (Nolen-Hoeksema et al., 1999).

Several other models have been proposed to understand gender differences in distress, and are part of, but not as exhaustive as the integrative model. For example, the Feedback effects model (Nolen-Hoeksema et al., 1999) describes how women are thought to harbor a lower sense of mastery, experience more chronic strain, and are more prone to ruminate; all factors which interact and contribute to each other, keeping women bound in a cycle of low control over one's environments and thus producing frequent experiences of depressive

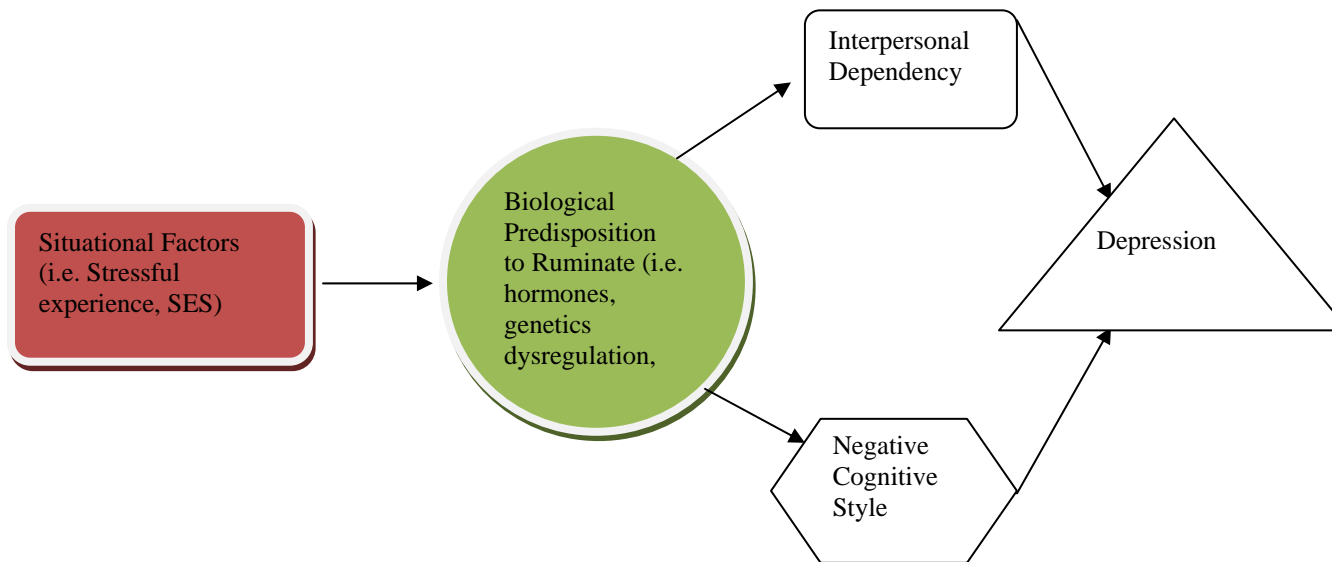


Figure 1. Integrated Model of Depression: Understanding Gender Differences (Nolen-Hoeksema, Larson, & Grayson, 1999).

symptoms. Next, the gender effects only model (Nolen-Hoeksema et al., 1999) links rumination, mastery, strain, and depressive symptoms to gender, but does not posit that these factors would predict each other over time. Furthermore, the depression effects model posits that people with more depressive symptoms would show more rumination and strain and lower master over time, because depression impairs people's functioning in many domains and enhances negative thinking (Nolen-Hoeksema et al., 1999). Finally, the interaction effects model describes how the interaction between rumination and chronic strain or between rumination and mastery would predict a significant variance in depressive symptoms over and above the individual variables.

**Theory describing internet use.** With continuously increasing usage rates of the Internet as part of the age of technology, researchers have begun to apply theory to the study of Internet use in order to better understand the predictors, patterns, and outcome of use. Jackson (1998) has developed a model including the motivational, affective, and cognitive factors that are both antecedents and consequences of use. Jackson asserts that people use the internet because it satisfies one's motives (e.g. communication, information), is associated with positive affect and because the cognitive requirements for use are compatible with their existing cognitive repertoire (i.e. they possess the requisite skills and attitudes). The Internet, in turn, has motivational, affective, and cognitive consequences in that use may increase or decrease social motivation, positive affect, and favorable attitudes toward the technology (Jackson, 1998). See Figure 2 Below.

**Gender and the model of internet use.** Findings indicating gender differences in internet use has inspired further research into the matter. Because it is thought that females and males have differential motives for internet use (informational for men vs. communication for women), females are thought to email more and males would use the web more than

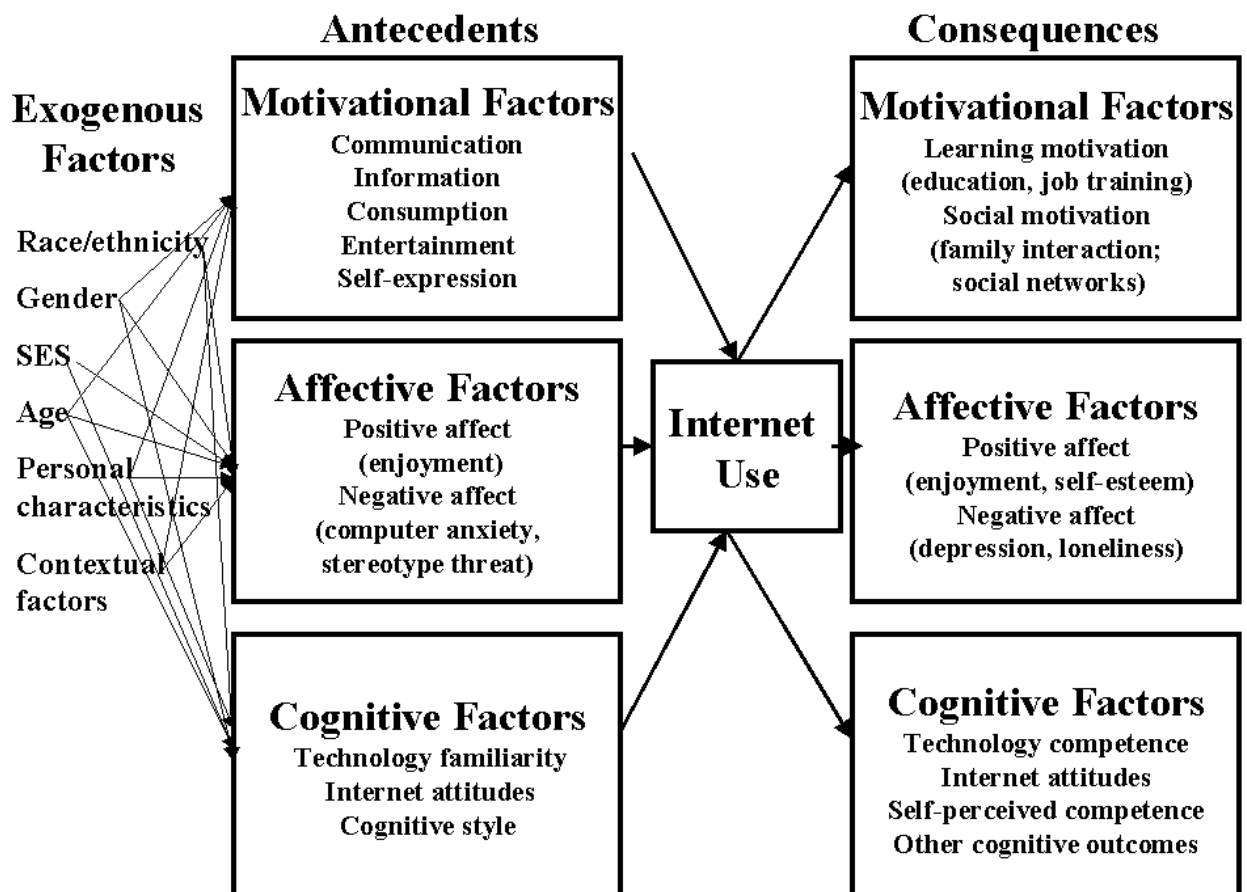


Figure 2. Model Predicting Internet Use (Jackson, 1998).

females (Jackson, 1998). In addition, women are likely to have less self efficacy, less favorable attitudes, and be less familiar with technology than men. Therefore, gender differences in affective and cognitive antecedents of internet use would moderate gender differences in use (Jackson, 1998).

**Internet usage by ethnic minorities and women.** Jackson (1998) has taken yet another step to further understand online cancer support group usage by the population believed to use the Internet less, ethnic minorities and females. To explain such patterns, Jackson (1998) has employed a feminist perspective. From a feminist perspective, gender and ethnicity are

considered significant characteristics that interact with other factors such as race, ethnicity, and class to structure relationships between individuals (Campbell & Wasco, 2000). Therefore, infrequent use of internet by ethnic minority women may reflect current constraints and oppressions as they exist in society currently. Also, use or lack thereof comes from people's continuous interactions with the real world and from biases reflecting the ways their and their health care providers view the real world (Campbell & Wasco, 2000).

**Participation in online cancer support groups.** Wright (2002) demonstrated the uses and gratification models to predict internet use (Ruggiero, 2000; Tewksbury & Althaus, 2000) in explaining participation in online support group. This theory is founded on the premise that audiences are active in their consumption of media content (Katz, Blumler, & Gurevitch, 1974; Palmgreen & Rayburn, 1985; Rubin, 1994). It is hypothesized that audiences use the media to meet a set of needs or goals (gratifications). Furthermore, individuals choose certain media according to the gratification they seek to meet and their perception of what the media offers (Palmgreen & Rayburn, 1985). Hence, online cancer support group members are thought to be active participants receiving gratification in their exchange with the offerings of the resource.

It is important to consider conceptual frameworks in the study of factors that influence gender differences in OCSG use in order to better understand how to recruit, develop, implement, and provide improved outcomes for men and women cancer survivors. Because OSSG's serve as a promising avenue for psychosocial interventions with easier accessibility, the lack of conceptually driven research in this area calls for further research to help explain their uses and success.



## **Limitations in the Existing Literature**

Although the existing research spanning gender differences in cancer-related distress and intervention methods to alleviate distress symptoms has been approached by several researchers from various perspectives, gaps in the literature remain. With new findings constantly emerging, new avenues for research unfold.

### *Gender Differences in Distress Literature*

Nolen-Hoeksema and colleagues have completed thorough research on the possible mechanism underlying gender differences in general distress. Yet, one of the major limitations that Nolen-Hoeksema and fellow researchers have noted is measurement tools of distress. Primarily, data has been often limited to self report, which can produce biased and inaccurate information. Furthermore, it is often difficult if not impossible to infer causation from correlation studies with distress, which is often the methodology employed. Finally, measures may contain phrases that are gender specific (i.e. “feeling blue” which may pertain to females more vs. “I feel like I want to injure someone” which males may relate to more). Hence, distress measures may be producing artificially elevated results for women, causing them to appear more distressed than may actually be the case (Nolen-Hoeksema, 2001). In addition, cultural considerations need to be taken into account when analyzing gender differences in distress. It is imperative to consider how culture and ethnicity might affect the gender differences in depression based on what stigmas exist surrounding mental health, etc.

**Cancer-related distress literature.** Although cancer-related distress has been widely studied in a variety of settings, results that have arisen from small-scale studies within single institutions and within single diagnoses of cancer have been contradictory and inconclusive. Similarly, much of the research conducted on distress among cancer patients has been completed on an inpatient basis, while individuals are still undergoing various forms of

treatment. However, much is unknown about the mental state and distress rates of those still living with cancer even years beyond diagnosis (Deimling et al, 2006).

Similar to the issue relating to gender differences and distress, limitations in the cancer-related distress literature lie within the quality of the measures of distress. Standard measures of distress capture global, generalized negative affect, but they may not measure affect specific to the cancer experience, and they capture many somatic effects which can be unrelated to psychological complaints. Improved measures will likely enhance the composition and quality of information derived in future research.

**Online cancer support group literature.** Few studies on internet-based programs have been published- and despite promise, internet-based recruitment and data collection pose considerable challenges in terms of access, eligibility, selection bias, participation rate, and data quality (Matano et al, 2000; Winzelberg et al, 2000; Tate et al., 2003). Further, the methodology, measurement, diversity in samples, and facilitation pose several limitations.

**Methodology limitations.** In terms of methodology, studies to date have been limited to small sample sizes (i.e. Penedo et al., 2004; Klemm & Hardie, 2002). Many of the studies are also limited to pilot studies and are composed of Caucasian women with breast cancer (Klemm et al., 2003). Moreover, there is a modicum of research employing randomized controlled trials comparing the effectiveness of online, face-to-face, and control groups. Without such data, little can be spoken for in terms of true differences or advantages. Also, it has been thought that there is a bias in terms of selection to groups in research studies, thus yielding biased results (Klemm & Hardie, 2002). Finally, much of the research on internet use in general has been limited to college convenient samples, which are not necessarily indicative of usage patterns in the adult cancer population.

**Measurement limitations.** Little is known about the short term and long term effects of participation in OCSGs (esp. long term effects). This is likely due to the fact that many studies do not take baseline and post hoc formal measures of distress. Limitations also lie in the inability to follow the participants longitudinally and identify drop-out patterns. Furthermore, in an online venue, it is often difficult to determine or analyze sentiments (i.e. verbal/ nonverbal), therefore interpretation of what people mean and are conveying is hard (Gooden & Winefield, 2007). Moreover, while the few randomized controlled trials in this area of research have yielded quantitative data, there is a lack of expressive or qualitative research in such studies (Klemm et al., 2003). Finally, there is no research conducted on potential harm online interventions might cause (i.e. isolation). Although likely minimal, research in this area is an important ethical obligation to participants. Along the same lines, there are several legal and ethical issues (i.e. privacy, HIPAA compliance and confidentiality) inherent with online facilitation of cancer support groups which again are minor, but have not been completely absolved.

**Sample composition limitations.** As has been noted throughout the paper, not enough men or ethnic minorities have been included in the existing research. That being said, however, approximately 89% of the U.S. Cancer Survivors are white (NCI, 2000), therefore homogenous samples of Caucasians may be best representative of the cancer demographic. Furthermore, variety in cancer diagnoses and physically/ psychologically compromised populations are not well-represented in studies (Classen et al., 2001; Hegelson et al., 1999; Magen & Glajchen, 1999; Michlec et al., 2004). This aligns with the argument claiming that OCSG's help "the healthy get healthier" in that participants tend to be highly educated with high incomes, and have many resources (Fawcett & Buhle, 1995; Im, Chee, Tsai, Lin, & Cheng, 2005).

**Facilitation limitations.** Critics of OCSG's often notice the lack of professional mediation or facilitation in Online Cancer Support Groups (Eysenbach, 2003; Gustafson et al., 1999;

McTavish et al., 1995; Sharf, 1997; Gustafson et al., 1993; Gustafson et al., 2001; Shaw et al., 2000; Lieberman et al., 2003; Shaw (n.d.). Therefore, many of the sites are strictly information giving or chat boards providing for interaction with other cancer patients, but may lack the professional resources needed to deliver optimal results and provide accurate information.

**Limitations in understanding gender differences in OCSG use.** Finally, very little is known about how to best target men and women separately for participation, cater to the separate genders in terms of topics, facilitation techniques, and uses of internet in order to provide the optimal outcomes. However, understanding such patterns is crucial to understanding etiology of distress as a whole and how to reach those who are not benefitting from use as well as further improve the quality of care for those already participating.

### **Research Plan**

In light of the established need for intervention and well-documented gender differences in biological, social, emotional, and cancer-related needs, the primary goal of the proposed study was to explore gender differences with respect to recruitment, utilization, and interest in an internet-based support group for cancer survivors. The current study adds to the existing literature in this field by evaluating an online intervention with multiple functions (i.e. live chat room, discussion board, guidance modules, private webmail, patient-to-patient contact, interactions with professional facilitators) among individuals of multiple cancer types, allowing for comparisons of men & women, through a randomized controlled clinical trial. Findings from the proposed study will help inform recruitment and intervention development efforts for web-based cancer support care in order to provide optimal and individualized care to distressed cancer survivors. In providing effective interventions, relieving distress will improve

quality of life for this ever growing and important population. To accomplish these goals, five specific aims and associated hypotheses were proposed.

**Aims and hypotheses.** In order to evaluate gender differences in distress in regards to cancer-related distress, recruitment, and participation in an online cancer support group intervention, the following aims and hypotheses were proposed:

Aim 1: To evaluate gender differences in distress post cancer diagnosis

Hypothesis 1: After controlling for health status, female cancer patients will report greater levels of distress when compared to male counterparts at baseline.

Aim 2: To evaluate gender differences in recruitment for participation in the online cancer support group.

Hypothesis 1: More females than males will elect to participate in the group. This will be analyzed at several stages of the recruitment process, including looking at the number of males vs. females we successfully contact from the registry, consent to go through the screening process, willingness to report distress (as part of eligibility), and completing online consent and baseline questionnaires.

Aim 3: To examine gender differences in Online Cancer Support group usage. (# of log-ins, time spent on website, personal pgs, etc.)

Hypothesis 1: When compared to their male counterparts, females will spend a greater average amount of time per log in session than men, but males will exhibit more frequent log-ins.

Hypothesis 2: Males and females will exhibit different interests in various topics explored during the intervention (i.e. coping, social support, self and body image, healthy lifestyle, communication with loved ones and health care professionals, competency and self-efficacy, goal setting, relaxation techniques, etc.). More

specifically, men will focus more on informational modules while females will exhibit greater interest in socially related and communicative functions. An exploratory hypothesis involving qualitative data obtained from retrospective interviews with clients will be analyzed using to determine differential interests and experiences for men and women. Content coding will be performed by an expert panel to determine consistent themes. Number (PERL measures) and nature (emotional expressiveness analyzed by LIWC) of postings related to given topics will be analyzed as well.

Hypothesis 3: Females will have more postings (i.e. on the discussion board and blog writings) and will exhibit a greater level of emotional expression when compared to male participants.

Hypothesis 4: Females and males will differ in their level of interaction with one another. Specifically, females will develop more tightly formed social bonds with fellow participants compared to males.

### **Summary and Conclusions**

Distress among cancer survivors is a prevalent and concerning issue. Dangers associated with untreated distress and concerns about the quality of life among cancer patients have been well-documented. In addition, several gender differences with respect to cancer-related distress exist based on biological, sociological, coping differences, differences in the experience of cancer itself, and so on. Therefore, intervention efforts should adjust accordingly in order to optimally serve the populations in need. Much of the intervention literature is highly inflexible and includes inherent barriers to care such as geography, cost, cancer type restrictions, rigid scheduling issues, among others. Yet in the recent years, the internet has become a promising

venue for delivery of psychosocial services providing ease, greater accessibility, and individually tailored features. While this phenomenon is catching on internationally, several areas still need to be addressed, including the development of randomized controlled trials examining efficacy, and groups reaching out to more ethnically/culturally/ gendered diverse populations, spanning more cancer diagnoses and levels of functioning.

## Methods

The methods outlined below are based upon a study currently underway by the Behavioral Oncology Research Lab under the direction of Dr. Jason Owen, and in collaboration with department research assistants and fellow doctoral candidates as part of various dissertation studies.

### Participants

Some of the potential participants were recruited from the Loma Linda University Medical Center Cancer Registry. Registry-based recruitment procedures seek to minimize harmful effects to patients (i.e. invasion of privacy) while promoting scientific usefulness (i.e. research and public health outreach) by educating patients about the registry (e.g. passively via web sites and brochures in doctors' offices or actively after a cancer diagnosis has been rendered), involving treating physicians (e.g. physician permission vs. notification), and initiating patient contact (e.g. opt in vs. opt-out) (Beskow et al., 2006a). All participants were at least 18 years of age, California residents, and first diagnosed with some form of cancer within the past 12 months. Loma Linda University Medical Center Physicians on record for each potential participant were contacted and notified of the researcher's intent to contact their patient. Passive permission was assumed if physicians do not contact the research lab within 2 weeks (Beskow et al., 2006b). Those eligible to participate in the initial screening process were mailed a letter describing the study, provided with a newsletter entailing information and features of the site, a colorful flyer advertising screen shots of the website, and explaining how the researchers identified them. Potential participants were given several ways to opt out of the study, including a toll-free number for the study, a confidential pre-paid postcard, website address, and e-mail



address. Those who decide not to opt out of the study via the methods aforementioned within a 3 week period were contacted by a research assistant via the telephone as well as given the option to enroll online. Trained research assistants conducted the informed consent process (if not done online via the website) and conducted a brief telephone screening process regarding accessibility to the internet, current health status, and current distress levels. Only those with regular access to the internet and those whom exhibited clinically-meaningful levels of distress (i.e., either  $<80$  on the Health Status Thermometer or a Distress Thermometer Score of  $\geq 4$ ) were eligible for randomization to either the wait-list control group or intervention group.

Revision to the IRB approval allowed for additional participants to be recruited nationwide using newspaper ads, cancer events, cancer listservs, and in-clinic recruitment at Loma Linda Oncology clinics.

### **Procedure**

Upon providing verbal telephone or online consent, all eligible individuals were directed to go to the website to complete the baseline survey on the website. At the completion of the survey, subjects were randomly assigned to receive access to the online treatment group or access to the online treatment group after waiting 12-weeks (wait list group). Members of both the wait list control and treatment group were contacted via telephone by one of the facilitators to welcome them to the group and address any concerns or questions. A start date for each cohort was assigned as soon as 10 subjects have been recruited into the cohort, at which time the online treatment group began. Individuals in the wait-list control group will continued to receive a study newsletter including pertinent journal articles, biographies of the facilitators, and cohort updates. At the completion of the 12-week treatment, each subject in the cohort was asked to complete a follow-up survey on the website. Post-intervention qualitative

interviews were also conducted to obtain information about the participants' experiences, interests, and deterrents (Note: Revision to IRB protocol was made for this, and subsequently accepted). After completing the first follow-up survey, wait list subjects began the online treatment group. Treatment subjects were asked to complete the web-based survey at weeks 0 and 12, while wait list subjects were asked to complete the survey at weeks 0, 12, and 24, providing data for a treatment-control comparison at 12-weeks and a within-subjects analysis of predictors of change for all subjects who completed the treatment group. Subjects were reimbursed with a \$10 gift card for completion of each survey at each time point.

### **Features of the Online Support Group (OSG)**

Health-space.net implements a structured, theory-based approach with active professional facilitation, and a social networking component.

**OCSG intervention.** The 12-week intervention is aimed at improving coping skills by facilitating active emotional, behavioral, and cognitive coping. Each week, a new relevant topic that will be introduced, including: 1. Introduction to the Group, 2. Overview of Coping, 3. Maintaining & Building Social Support Networks, 4. Self and Body Image, 5. Healthy Lifestyle Choices, 6. Preserving Domains of Competence & Self-Efficacy, 7. Communication with Partners & Healthcare Professionals, 8. Improving Coping Skills, 9. Developing Relaxation Skills, 10. Identifying and Disclosing Thoughts & Feelings, 11. Detoxifying Fears about Mortality, and 12. Goal-Setting & Benefit-Finding. Specified modules will include an audio and visual video to introduce and highlight important information from modules. In addition, other interactive features including mindfulness exercises and questions for thought and discussion will be included to encourage social interaction and synthesis of the guidance modules.

**Theoretical underpinnings of the intervention.** The intervention for health-space.net was based upon work from Fawzy et al. (1994); Spiegel, & Classen (2000); and Nezu et al. (1998) to facilitate active coping methods for individuals diagnosed with cancer. Additional material from the NuCare intervention (Watts & Edgar, 2004) was incorporated into the intervention. The basic theoretical foundation for the intervention methodology is based on Folkman & Greer's cancer specific Model of Stress and Appraisal Coping (2000). Folkman & Greer (2000) asserted that cancer patients undergo two simultaneous processes, including: 1) appraisal of the significance of the stressor and resources to handle the stressor, and 2) efforts to cope with the stressor, using a combination of thoughts, behaviors, and emotions that subsequently impact the stressor and/or appraisal of the stressor. According to this model, distress emerges when efforts to cope with a stressor are followed by unfavorable outcomes. The proposed intervention is designed to increase the engagement of stressor-specific coping efforts to increase the potential for favorable outcomes associated with coping efforts. Research in cancer survivors has consistently shown that avoidance-oriented coping efforts are related to more negative outcomes over time (Stanton & Snider, 1993; Stanton et al., 2002), whereas adopting active-behavioral (Tice, 2002), active cognitive (Lee et al., 2006), and active emotional (Owen et al., 2006; Austenfeld & Stanton, 2004) approaches to managing cancer-related difficulties appears to be associated with improvements in mood and quality of life (Stanton et al., 2000).

**Professional facilitation.** Each group was facilitated by doctoral candidates, whom are advanced students in a clinical psychology program from LLU. All groups were actively supervised by a licensed clinical psychologist (Dr. Jason Owen, Dr. Erin Bantum). The role of the facilitators was to encourage participants in the group, to promote discussion of weekly topics from the guidance modules, lead weekly active chats, and to provide individualized, supportive feedback to each participant. Trained research assistants and facilitators met weekly with the

supervisor to review progress over the previous week, identify any problems within the group, and make plans for actively facilitating discussion around the treatment module for the coming week. Individual online client progress notes were available to facilitators and supervisors strictly to keep an active web-based file for each participant, including relevant diagnoses, treatment, and participation needs. Technical support was offered on the website, through email, and by phone for around-the-clock tech support needs for participants.

**Social features of the website.** An open and interactive discussion board was posted for facilitators and active members of the group to post important updates, introduce points for conversation, and to post questions or thoughts to the facilitators for the group to share. A private webmail feature was available for cancer survivors and facilitators to interact in a more private setting if desired. A personal page was set up by each participant, including information about each individual (e.g. cancer type, cancer story, city of residence, photos, etc). On one's personal page (See Figure 3), a blog for journaling , expressive writing, and processing intervention content was available. On each profile, polls could be created and answered for getting anonymous feedback from the group. Visual feedback about the strength of social bonds with other group members (based upon frequency of interpersonal contact) was also provided. Ongoing self-monitoring of mood and distress was a part of each discussion board and personal webmail messages to help others better interpret one's feelings and context of messages. By providing increased opportunities for social engagement with peers confronting similar stressors and cancer-related distress, the intervention created enhanced opportunities for social modeling/ vicarious learning of active coping efforts and improved behavioral outcome expectancies associated with active coping efforts (Taylor & Carmack et al., 2007).

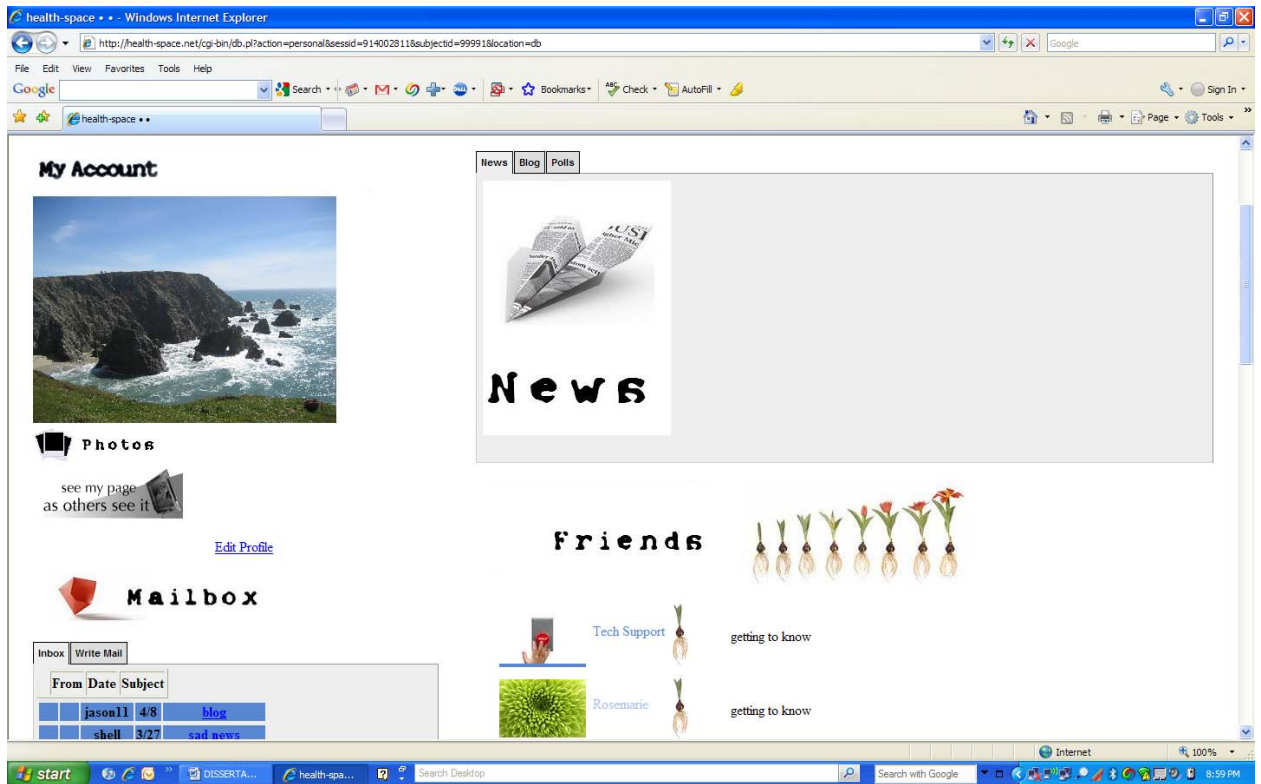


Figure 3. Personal Pages.

**Framework for health-space.net.** The intervention framework is built on a Linux server implementing Apache, PERL, PHP, and MySQL. Our program (health-space.pl, 521kb, 9133 lines of code) manages user security, survey administration, recruitment tracking, storage and retrieval of user-specific data, tailoring page content to individuals, linguistic analysis, and user interactions with the intervention website. The website was designed using principles associated with “web 2.0”: social participation, usability, open access, users adding content, and aesthetic appeal. The framework (including recruitment tracking system, intervention materials, social-networking CGI system, online survey administration, questionnaire scoring, MySQL database structure, and study flow tracking) has already been developed and is in working order.

## Measures

**Self-report data.** The instruments described below were performed online and all serve as self-report data wherein the participants subjectively report their experiences.

**Demographic and Cancer Data.** Demographic and cancer-related variables were obtained from the cancer registry in addition to self report format on the web. Cancer registry variables included gender, age, ethnicity, tumor site, date of diagnosis, and cancer staging information. Additional background information about the patient obtained through the website included education level, household income level, marital and employment status, whether or not they have ever used a support group for cancer previously (internet or face-to-face and frequency), computer proficiency (determined by frequency of internet usage, type of internet usage, and self-reported level of comfort with web-based use), physical limitations as a result of cancer illness, and treatment regimens undergone.

**Timing of surveys.** A brief, standardized battery of survey instruments was administered at entry into the study (baseline survey) and 12-weeks later (12-week survey) for both treatment and waitlist subjects. Because the 12-week survey is a pre-treatment baseline for the waitlist, they were also asked to complete a survey after completing the 12-week online intervention (24-week survey). All surveys were completed using the study website. Measures completed at baseline include demographics, CES-D, EQ-5D, IOES, and OQ-45. In group-assessment of trait measures (Time 1b) completed included the Courtauld Emotional Control Scale. The 12-week after baseline surveys completed (Time 2) included another CES-D, EQ-5D, IOES, OQ-45, and qualitative measures.

**Standardized measures.** *Quality of Life:* Quality of life was evaluated using four instruments:

1. The EuroQol-5D Health Status thermometer (Brooks, 1996). The EuroQol-5D is a standardized, non-disease-specific instrument for describing and valuing health-related quality of life. It has been purposefully developed to generate a generic cardinal index of health, aiming to capture physical, mental, and social functioning. There are four components of the instrument: A) description of the respondent's own health by means of the EuroQol classification. Respondents describe their own health on five dimensions- mobility (e.g. "I have no problem walking about", self-care (e.g. "I have some problems washing or dressing myself"), usual activities (e.g. "I am unable to perform my usual activities"), pain/discomfort (e.g. I have moderate pain or discomfort"), and anxiety/depression (e.g. "I am extremely anxious or depressed"). One of three levels is chosen for each dimension by placing a check mark in the box that best describes one's situation, and thus the resulting health state can be defined by a 5 digit number; B) rating of own health by means of the EuroQol thermometer. Respondents are asked to mark off their own current health statue on a thermometer calibrated from 0 (worst imaginable health state) to 100 (best imaginable health state). C) valuation and standard set of health stated defined by the EuroQol classification. The description and rating of one's own health state by the classification and thermometer approaches allow for comparisons of reference groups (i.e. other patients or the general population). Reliability estimates have been found in the .73-.78 range, and has been found to correlate highly with the SF-36 and HRQOL, other similar quality of life measures.

Emotional well-being will be measured using the 4 measures:

1. The Distress Thermometer (Roth et al., 1998): this is a visual analog scale rating of emotional distress, presented as a thermometer. Scores range from 0 ("no distress") to 10 ("extreme distress"), with a midpoint anchor of 5 labeled as "moderate distress". It was designed to

destigmatize reporting distress by presenting it in the form of a thermometer. This measure has been validated with cancer patients (Ransom, Jacobsen, & Booth-Jones, 2006), and a suggested cutoff score of 4 or higher is used to screen patients for distress. Participants will be prompted to complete the distress thermometer each time they post on the discussion board, which will provide a longitudinal measure of progress and link emotional expression analysis to distress thermometer ratings.

2. The Impact of Events Scale- Revised (IOES-R). The IOES-R was developed by Weiss & Marmar in 1997 and was adapted from the measure developed by Horowitz, Wilner, and Alvarez in 1979. It was developed to parallel DSM-IV criteria for PTSD to include the hyperarousal cluster of symptoms. It is a self-report measure designed to assess current subjective distress for any specific life event. It has 22 items and respondents are asked to rate each item on a scale of 0 (not at all), 1 (a little bit), 2 (moderately), 3 (quite a bit), and 4 (extremely) according to the past 7 days. The internal consistency of the 3 subscales was found to be very high (intrusion subscale = .87-.92; avoidance subscale = .84-.86; hyperarousal subscale = .79 -.90) (Briere, 1997). Test-retest correlation coefficients for the subscales include .57 for intrusion, .51 for avoidance, and .59 for hyperarousal. In terms of criterion (predictive) validity, the hyperarousal subscale has been found to have good predictive validity with regards to trauma (Briere, 1997). The intrusion and avoidance subscales, which are original IOES components, have been shown to detect change in respondents' clinical status over time and detect relevant differences in the response to traumatic events of varying severity (Weiss & Marmar, 1997; Horowitz et al., 1979).
3. Outcome Questionnaire-45 (OQ-45). The OQ-45 is a 45-item self-report measure that was designed for repeated assessment of client progress during the course of treatment (Lambert et al., 1996). It includes 3 subscales: symptom distress, interpersonal relations, and



social role performance. Each item is scored on a 5-point scale, and the total score yields a range from 0-180. The higher the score indicates a higher level of patient distress and pathology. Administration typically takes 5-7 minutes. It has adequate internal consistency ( $r = 0.93$ ), and 3-week test-retest reliability ( $r = 0.84$ ). Concurrent validity is moderately high (0.5-0.85) when correlated with measures most often used to evaluate psychotherapy outcomes (Lambert et al., 2004). Moreover, it has been shown to be sensitive to change in clients over short time periods (Vermeersch et al., 2000; Lambert, 2004). Using a formula developed by Jacobsen & Traux (1991), a reliable change index (RCI), and cutoff score for clinically significant change has been devised. The RCI was determined to be 14 points, and the cutoff score was set at 64 (this is 1 standard deviation above non-inpatient norms).

4. Center for Epidemiologic Studies Depression Scale (CES-D). The CES-D is a short self-report scale designed to measure depressive symptomatology in the general population (Radloff, 1977). For this reason, it differs from previous depression scales which have been used chiefly for diagnosis at clinical intake and/or evaluation of severity of illness over the course of treatment. It was designed to measure the current level of depressive symptomatology, with emphasis on the affective component, depressed mood. It consists of 20 items and respondents are asked to answer based on how they have felt over the past week ranging from: "rarely or none of the time" (<1 day), "some or little of the time" (1-2 days), "occasionally or a moderate amount of time" (3-4 days), and "most or all of the time" (5-7 days). Internal consistency has been found to be .85 in the general population and .90 in the patient sample group. Coefficient alpha has been found to be at .80 or above, and test-retest correlations were found to be moderate (.40 or above). Additionally, the CES-D has been found to discriminate between psychiatric inpatient and general population samples and discriminate moderately among levels of severity with patient groups. Four factors were

derived from the CES-D, including depressed affect, positive affect, somatic and retarded activity, and interpersonal.

**Emotional Expression Measure.** The following self-report measure was utilized to qualify the degree of emotional suppression.

1. Courtald Emotional Control Scale (CECS). The CECS was developed by Watson & Greer (1983) to measure emotional control in breast cancer participants. It evaluates the extent to which individuals report controlling the expression of anger, anxiety, and depression. Participants respond to phrases such as “When I feel angry...” by endorsing statements such as “I bottle it up” or “I say what I feel”. Chronbach’s alpha has been found to be about .91 for depressed mood and anxiety and .93 for anger.

**Qualitative Evaluation.** Qualitative interviews were conducted after conclusion of the 12-week interventions to gather information concerning the participant’s experience with the intervention. Four open-ended questions were asked via phone, including: “If you could envision the perfect online cancer support venue, what would it look like? (i.e. what types of features would it include, what topics would be discussed, etc.). “In what ways could a website like health-space.net better meet your needs?”, “What function of the website (i.e. chat room, discussion board, guidance modules) did you find the most/least useful?”, and for those who did not participate online as much: “What, if anything about the website or experience, kept you from wanting to be more involved in the group?”. Phone interviews were transcribed by interviewer.

**Behavioral and linguistic data.** A computer program written in Practical Extraction and Report Language (PERL) controls the intervention website. PERL is a high-level, general-purpose, interpreted, dynamic programming language. Perl was originally developed by Larry Wall as a general purpose scripting language to make report processing easier ([www.perl.org](http://www.perl.org)). The

language provides powerful text processing facilities, facilitating easy manipulation of text files. With health-space.net, it was used to capture specific, individual-level behavioral data, including (but not limited to): time spent interacting with the study's treatment manual, social affiliation with group members and facilitators, and written emotional expression. Internal timestamps and randomly-generated session identifiers were captured in PERL to measure time spent on each page of the website, and all of this data was stored in a mySQL relational database. Additionally, we have developed an algorithm for measuring the strength of social bonds with other group members by quantifying responses and interactions that take place between pairs of individuals on the website. Finally, we have developed a method for conducting linguistic analyses in real-time using a PERL implementation of Linguistic Inquiry and Word Count (LIWC; Pennebaker & Francis, 1996). A large number of studies have found that having individuals write or talk about deeply emotional experiences is associated with improvements in mental and physical health (e.g. Lepore & Smyth, 2002; Pennebaker, 1997). Text analyses based on these studies indicate that those individuals who benefit the most from writing tend to use relatively high rates of positive emotion words, a moderate number of negative emotion words, and an increasing number of cognitive words, and switch their use of pronouns from writing session to writing session (e.g., Campbell & Pennebaker, 2002; Pennebaker, Mayne, & Francis, 1997).

### **Data Analysis**

Quantitative hypotheses were evaluated using SPSS statistical software. Portions of the qualitative linguistic analyses were conducted using a PERL implementation of Linguistic Inquiry and Word Count (LIWC; Pennebaker & Francis, 1996). Exploratory qualitative analyses were

evaluated through content coding procedures of qualitative interviews using a panel of expert judges (see data analysis section below).

**Linguistic Inquiry and Word Count (LIWC).** Linguistic Inquiry and Word Count (LIWC) is a text analysis software program designed by James W. Pennebaker, Roger J. Booth, and Martha E. Francis. LIWC is able to calculate the degree to which people use different categories of words across a wide array of texts. Within emails, speeches, poems, or transcribed daily speech, LIWC allows you to determine the rate at which the authors/speakers use positive or negative emotion words, self-references, big words, or words that refer to specific topics. The program was designed to analyze simply and quickly over 70 dimensions of language across hundreds of text samples in seconds ([www.liwc.net](http://www.liwc.net)).

**How does LIWC work?** The LIWC2007 application relies on an internal default dictionary that defines which words should be counted in the target text files. LIWC2007 is designed to accept written or transcribed verbal text which has been stored as a digital file in one of multiple formats, including raw text, ASCII, unicode, or standard files from Microsoft's Word files. LIWC2007 accesses a single file or group of files and analyses each sequentially, writing the output to a single file. Processing time for a page of single-spaced text is typically a fraction of a second on both PC and Mac computers. LIWC2007 reads each designated text file, one target word at a time. As each target word is processed, the dictionary file is searched, looking for a dictionary match with the current target word. If the target word matches the dictionary word, the appropriate word category scale (or scales) for that word is incremented. As the target text file is being processed, counts for various structural composition elements (e.g., word count and sentence punctuation) are also incremented. With each text file, approximately 80 output variables are written as one line of data to a designated output file. This data record includes the file name, 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 LIWC dictionary.** The LIWC2007 Dictionary is the heart of the text analysis strategy. The default LIWC2007 Dictionary is composed of almost 4,500 words and word stems. Each word or word stem defines one or more word categories or subdictionaries. For example, the word *cried* is part of five word categories: sadness, negative emotion, overall affect, verb, and past tense verb. Hence, if it is found in the target text, each of these five subdictionary scale scores will be incremented. As in this example, many of the LIWC2007 categories are arranged hierarchically. All anger words, by definition, will be categorized as negative emotion and overall emotion words. Note too that word stems can be captured by the LIWC2007 system. For example, the LIWC2007 Dictionary includes the stem *hungr\** which allows for any target word that matches the first five letters to be counted as an ingestion word (including hungry, hungrier, hungriest). The asterisk, then, denotes the acceptance of all letters, hyphens, or numbers following its appearance.

**Psychometric Properties.** Psychometric properties of this program are tricky, but reliability coefficients have been found to range between .55 and .92, using intercorrelations of word use across several documents ([www.liwc.net](http://www.liwc.net)). In one of the first tests of the program's validity, Pennebaker & Francis (1996) conducted a study with college students writing about their experience at college. Results yielded good external validity as evidenced by high intercorrelations of judge's ratings and the LIWC program. LIWC has been identified to have a

sensitivity of .88 in a study with breast cancer patients, but a positive predictive value of .31 (Bantum & Owen, 2009). Compared to other computerized coding methods (i.e. Psychiatric Content Analysis and Diagnosis (PCAD), LIWC has been found to have both better convergent and discriminant validity (Bantum & Owen, 2009).

**Evaluation of research hypotheses.** Specific data analyses were applied to evaluate each of the proposed hypotheses.

**Hypothesis 1.** After controlling for health status, female cancer patients will report greater levels of distress when compared to male counterparts at baseline. In order to evaluate this hypothesis, independent samples t-tests or ANOVAs were run separately to compare men and women on a host of demographic variables (i.e. age, ethnicity, SES), cancer-related (i.e. cancer type, time since diagnosis), and health status (measured by Euro-QoL-5D). Such analyses determined important variables to covary for, which may account for gender differences in reported distress. From there, a regression analysis was employed to evaluate gender differences on emotional functioning measures (IOES-R, CES-D, OQ-45, DT) while controlling for variables found to significantly contribute to distress.

**Hypothesis 2.** More females than males will elect to participate in the group. This hypothesis was analyzed at several stages of the recruitment process, including looking at the number of males vs. females we successfully contact from the registry, consent to go through the screening process, willingness to report distress (as part of eligibility), completing online consent and baseline questionnaires, and total time spent online. Frequency statistics were tracked using a recruitment flowchart, separately for males and females. Frequencies were conducted in SPSS, and mean differences were compared to determine if the frequencies were statistically significant differences. A power analysis was conducted a priori to determine the sample size needed to obtain a power of .8 and an effect size of .35 (large effect size in

regression analyses). According to the power analysis, we would have needed to obtain a total sample size of 43 to attain this level of power and effect size. Moreover, a sensitivity analysis was conducted, using preliminary data on total time spent online, in order to determine the range of sample sizes and effect sizes that can be derived, while attaining sufficient power (.8) to detect gender differences. A 2-tailed test was conducted, to be conservative, using G-Power 3.0. Results of the sensitivity analysis indicated that in order to obtain a large effect size ( $ES = 1.30$ ), and power of .8, a total sample size of 22 (11 men, 11 women) would be needed. Further, in order to obtain a medium effect size ( $ES = .524$ ), and power of .8, a sample size of 118 (59 men, 59 women) would be needed. It is important to note that when conducting the analyses of gender differences in recruitment and usage differences, covariates were determined and controlled for, which may have accounted for differences in gender findings (i.e. age, income, education, employment status, etc).

***Hypothesis 3.*** Males and females will exhibit different interests in various topics explored during the intervention. More specifically, men will focus more on informational modules (i.e. coping skills, healthy lifestyle, self-efficacy, ways of thinking) while females will exhibit greater interest in socially related and communicative functions (i.e. social support, relationships, disclosing thoughts and feelings).

This hypothesis was evaluated using both qualitative and quantitative methods. The PERL program provided information concerning the amount of time spent on each module and application of the website. An exploratory hypothesis involving qualitative data obtained from retrospective interviews with clients was analyzed using to determine differential interests and experiences for men and women. The exploratory hypothesis was analyzed with no preconceived notions as to what findings will ensue, but will simply serve as an open-ended investigation of common themes derived. In following the principles of Grounded Theory (Glaser

& Strauss, 1967), analysis of the qualitative interview responses were open-coded in order to capture the detail, variation, and complexity of the basic qualitative material. This process can be also be called substantive coding, and entails writing down the material that emerges from the interviews (Glaser & Strauss, 1967). The ideas and content of the interviews was then combined into larger theme categories for conceptual similarities and differences by the expert rater (method of constant comparison, Glaser & Strauss, 1967). Once categories were created, reliability for this process was established by content coding of a larger panel of expert judges. This was accomplished by placing common theme index cards and excerpts from the interviews on index cards. Operational definitions of the themes were discussed by the panel of judges. Raters then placed the content of the interviews into the appropriate theme, and an interrater reliability was calculated. Comparisons and coding were continued until the point where no new insights were reached (Glaser & Strauss, 1967).

***Hypothesis 4.*** Females will have more postings (i.e. on the discussion board and blog writings) and will exhibit a greater level of emotional expression when compared to male participants.

Linguistic Inquiry/ Word Count (LIWC) program was used to evaluate level of emotional expressiveness and breadth of participation. In addition, level of cognitive processing was evaluated using this program. The Courtald Emotional Control Scale variables was also used to determine gender differences among emotional control, with regression-based analyses implemented to determine gender differences, while controlling for significant correlates determined in hypothesis 1. A sensitivity analysis was conducted, using preliminary data on time spent on the discussion board, in order to determine the range of sample sizes and effect sizes that could be derived, while attaining sufficient power (.8) to detect gender differences. A 2-tailed test was conducted, to be conservative, using G-Power 3.0. Results of the sensitivity



analysis indicated that in order to obtain a large effect size ( $ES = 2.66$ ), and power of .8, a total sample size of 8 (4 men, 4 women) would be needed. Further, in order to obtain a medium effect size ( $ES = .687$ ), and power of .8, a sample size of 70 (35 men, 35 women) was needed. It is important to note that when conducting the analyses of gender differences in discussion board usage differences, covariates were determined and controlled for, which may have accounted for differences in gender findings (i.e. age, income, education, employment status, etc).

***Hypothesis 5.*** Females and males will differ in their level of interaction with one another. Specifically, females will develop more tightly formed social bonds with fellow participants compared to males.

Social affiliation was measured through strength of the emotional bond measure of quantitative responses and interactions through PERL. Further, information regarding the number of private webmail exchanges was evaluated, and gender differences were analyzed quantitatively.

## Results

### Participants Demographics

**Total recruitment base (cancer registry, online advertisements, newspaper advertisements, flyers posted).** Participants from the current study were recruited from the Loma Linda University Medical Center Cancer Tumor Registry from the years 2007-2009. The 2007-2008 Loma Linda University Medical Center registry included all adults over the age of 18, California residents, those diagnosed with any type of cancer, and those who had not yet passed away. The 2008-2009 registry database that the present study drew from included individuals who were 18 and older, diagnosed with any type of cancer, still living, and who lived in the United States (note: the difference in inclusion criteria from 2007/2008 to 2008/2009 was based on grant funding from NCI beginning July 1, 2009). Therefore, the total number of individuals who were included for the purposes of the Health-Space study as of June 2010 from the LLUMC Cancer Registry was 2,160 adults. Fifteen (15) individuals were recruited from means other than the LLUMC Cancer Registry (i.e., via newspaper ads, internet searches, flyers posted). Thus, of the 2,175 individuals that were available to recruit for the current study, valid data on gender was provided for 2,158 individuals (missing gender data = 17, 0.8%). Of this total, 1,328 (61.1%) were male, and 830 (38.2%) were female (missing data = 17, 0.8%). Moreover, in terms of race, 1,518 of the total 2,175 individuals endorsed their race as “white” (70.3%); 336 were Hispanic (15.6%); 96 were black (4.4%); 47 were Asian (2.2%); 55 were “other” (2.5%); and 95 (4.4%) were unknown (in that race was not provided; missing data = 13, 0.6%). Age was available for 1,967 of the individuals; ages ranged from 18 – 97 ( $M = 61.73$ ,  $sd = 13.318$ ; Range = 79); missing data = 208, 9.6%. With respect to cancer types represented, the most represented group was prostate cancer ( $N = 813$ , 37.4%). Furthermore, 10.9% ( $N = 236$ ) were diagnosed with female

reproductive cancers (i.e., ovarian, vulvar, uterine); 9.2% ( N = 201) were diagnosed with breast cancer; 5.9% (N = 128) were diagnosed with blood/ lymph, kidney, bladder (genitourinary) cancers; 4.8% (N = 105) were diagnosed with lung cancer; 4.1% (N = 90), were diagnosed with colorectal cancer; 2.7% ( N = 59) were diagnosed with skin cancer; 23.9% ( n = 520 ) were diagnosed with “other” types of cancer (i.e., pancreatic, brain, etc), and 0.9% ( N = 20) were diagnosed with multiple forms of cancer (missing data = 3, 0.1%). Figure 4 depicts the recruitment flow chart described herein, including percentages within gender in each area of recruitment.

**Individuals who were attempted to be contacted.** Of the 2,175 (2,160 from the cancer registry and 15 individuals recruited via other means) available for the lab to contact, 1,318 have been attempted to contact at the time of this study. Of these 1,318 individuals, 769 (58%) were male, and 533 (40.4%) were female, missing data = 16 (1.2%). With respect to ethnicity, 899 (68.2%) were white, 190 (14.4%) were Hispanic, 24 (1.8%) were Asian, 52 (3.9%) were Black, 35 (2.7%) were proclaimed as “other”, and 86 were unknown (6.7%); missing data = 30, 2.3%. Age ranged from 18 – 97 ( $M = 61.81$ ,  $sd = 13.72$ , range = 79); missing data = 127, 9.6%. In terms of types of cancer, 129 (9.8%) were diagnosed with breast cancer, 456 (34.6%) with prostate cancer, 64 (4.8%) with lung cancer, 63 (4.8%) with colorectal cancer, 134 (10.2%) with female reproductive cancer, 71 (5.4%) with genitourinary cancer, 39 (3.0%) with skin cancer, 341 (25.9%) with “other” types of cancer, and 14 (1.1%) with multiple types of cancer (missing data = 8, 0.6%).

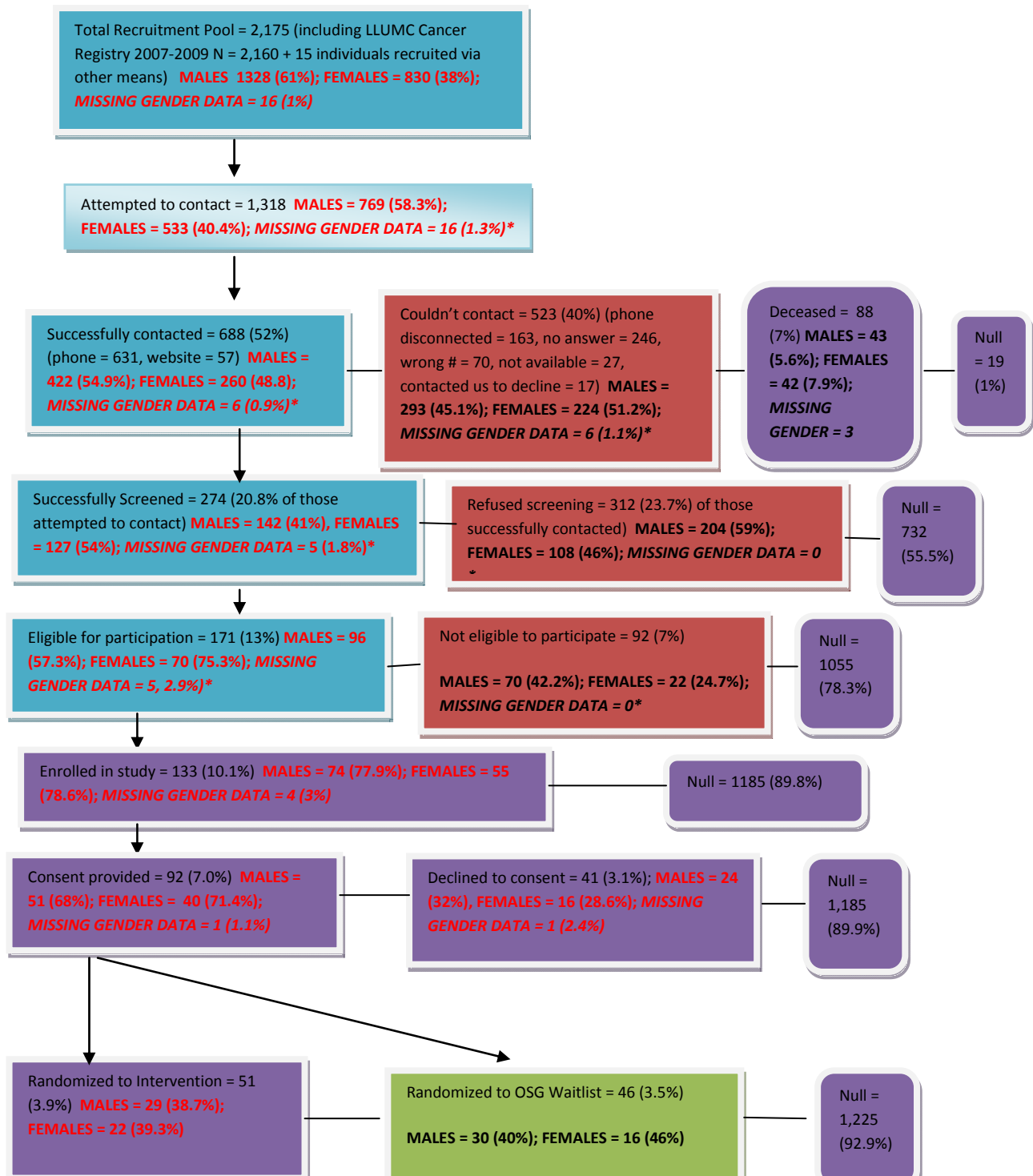


Figure 4. Recruitment Flow Chart Broken Down by Gender

Note: Percentages (%) reported for males and females are based on percentage *within* gender at each step of the recruitment process.

\*Indicates significance at the  $p < .05$  level.

Of these 1,318 individuals who were attempted to be contacted, 57 of these individuals were web-recruited (meaning they signed up through the internet independently after hearing about the study, and were not reached via phone). In contrast, six-hundred and eighty-eight ( $n = 688$ , 52% of those attempted to contact) were successfully reached over the phone (39.7% of those attempted to contact). In regards to demographic differences between those who were web-recruited, and those who were attempted to be recruited via the phone, there was a significant association between gender and recruitment method,  $\chi^2(1) = 10.356$ ,  $p = .001$ . More specifically, 6.4% of females were web-recruited, whereas 2.7% of males were web-recruited; and roughly similar percentages of men (97.3%) and women (93.6%) were phone recruited. There was also a significant difference in age between those who were web-recruited vs. those who were attempted to be recruited over the phone,  $t(1189) = 3.678$ ,  $p < .001$ . Notably, those who were web-recruited ( $M = 54.91$ ,  $sd = 13.33$ ) were significantly younger than those who were attempted to be reached over the phone ( $M = 62.13$ ,  $sd = 13.18$ ). However, there was not a significant association between ethnicity and recruitment method,  $\chi^2(1) = 9.14$ ,  $p = .104$  or ethnicity and cancer type,  $\chi^2(8) = 10.623$ ,  $p = .224$ .

In contrast, Five-hundred and twenty-three ( $n = 523$ ) of the individuals who were attempted to contact were not able to be contacted (i.e., phone disconnected = 163, no answer = 246, wrong # = 70, not available = 27, contacted us to decline = 17). Additionally, 88 of the individuals (7%) had passed away by the time the recruitment team had reached them (there were also 19 individuals wherein no attempt was made to call this person). Therefore, the total number of individuals who were not able to be contacted, for any reason, was 630 (47.8% of those attempted to be contacted). Those who were successfully contacted and not able to be contacted were compared with demographic variables to determine whether this sample of

individuals attempted to be contacted differed from one another. Results for this group comparison are depicted in Table 1. Briefly, significant associations were indicated among gender and contact status,  $\chi^2 (1) = 4.69, p = 0.03$ ; 54.9% of males were successfully contacted, whereas 48.8% of females were successfully contacted. There was also a significant association between race and contact status  $\chi^2 (1) = 32.061, p < .001$ ; 56.5% of white individuals were successfully contacted; whereas 39.3% of non-white individuals were successfully contacted. A significant age differences was also noted between those who were successfully contacted vs. not successfully contacted,  $t(1024.603) = 15.71, p < .001$ ; those who were successfully contacted ( $M = 62.99, sd = 12.66$ ) were significantly older than those who were not successfully contacted ( $M = 60.41, sd = 14.86$ ). Cancer site was also significantly associated with contact status,  $\chi^2 (8) = 28.506, p < .001$ ; 59.5% of prostate cancer survivors were successfully contacted vs. 60.1% of those who had other cancers were successfully contacted. Note: Cancer site is depicted in terms of prostate vs. other in Table 1, but the following results were broken down into additional categories of cancer type. The following percentages within cancer type were observed for those who were not successfully contacted: 49.5% of breast cancer survivors; 40.4% of prostate cancer survivors; 61.9% of lung cancer survivors; 44.4% of colorectal cancer survivors; 50.7% of female reproductive cancers; 43.7% of genitourinary cancers; 38.5% of skin cancer survivors; 58.8% of “other” types of cancer; and 50% of those with more than 1 cancer diagnosis.

Table 1

Group Differences at Each Step of the Recruitment Process

Those Attempted to be Contacted	Gender			Ethnicity			Cancer Type			Age		
	$\chi^2$	%male	%female	$\chi^2$	%white	%non-white	$\chi^2$	%prostate	%other	t	M	sd
Those Successfully Contacted ( n = 688)	4.69*	54.9%	48.8%	32.06**	56.5%	39.3%	16.46**	59.6%	60.1%	15.71**	62.99	12.66
Those Not Successfully Contacted ( n = 523)		45.1%	51.2%		43.5%	60.5%		40.4%	52.1%		60.41	14.86
<b>Total = 1318</b>												
▼												
Screening	Gender			Ethnicity			Cancer Type			Age		
	$\chi^2$	%male	%female	$\chi^2$	%white	%non-white	$\chi^2$	%prostate	%other	t	M	sd
Those Successfully Screened ( n = 274)	9.516**	41%	54%	5.17*	40.7%	51.8%	19.68*	34%	53.1%	.287	61.91	13.46
Those Who Refused Screening ( n = 312)		59%	46%		59.3%	48.2%		66%	46.9%		63.34	12.65
<b>Total = 586</b>												
▼												
Eligibility	Gender			Ethnicity			Cancer Type			Age		
	$\chi^2$	%male	%female	$\chi^2$	%white	%non-white	$\chi^2$	%prostate	%other	t	M	sd
Those Deemed Eligible ( n = 171)	7.88**	57.3%	75.3%	.003	61.1%	61.5%	13.38**	51.7%	73.8%	5.88**	58.91	12.33
Those Deemed Ineligible ( n = 92)		42.2%	24.7%		38.9%	38.5%		48.3%	26.2%		63.98	9.94
<b>Total = 262</b>												
▼												
Enrollment	Gender			Ethnicity			Cancer Type			Age		
	$\chi^2$	%male	%female	$\chi^2$	%white	%non-white	$\chi^2$	%prostate	%other	t	M	sd
Those Who Enrolled in the Study ( n = 133)	.011	77.9%	78.6%	.003	75.2%	73.9%	.599	74.6%	79.8%	-.311	58.94	11.75
Those Who Did Not Enroll ( n = 36)		22.1%	21.4%		25.8%	26.1%		25.4%	20.2%		58.22	14.08
<b>Total = 169</b>												
▼												
Consent	Gender			Ethnicity			Cancer Type			Age		
	$\chi^2$	%male	%female	$\chi^2$	%white	%non-white	$\chi^2$	%prostate	%other	t	M	sd
Those Who Consented Online ( n = 92)	.178	62%	71.4%	.005	71.4%	70.6%	.039	68.2%	69.9%	2.72**	57.10	12.01
Those Who Didn't Consent Online ( n = 41)		38%	28.6%		28.6%	29.4%		31.8%	30.1%		63.10	10.08
<b>Total = 133</b>												
▼												
Participation	Gender			Ethnicity			Cancer Type			Age		
	$\chi^2$	%male	%female	$\chi^2$	%white	%non-white	$\chi^2$	%prostate	%other	t	M	sd
Phone Recruit ( n = 39)	6.15*	58.7%	31.6%	.165	50%	50%	.471	51.9%	43.9%	-2.37*	61.32	1.76
Web Recruit ( n = 45)		41.3%	68.4%		55.4%	44.6%		48.1%	56.1%		54.29	15.19
<b>Total = 84</b>												

Note: \* indicates significance at the  $p < .05$  level

**Individuals who were screened.** Two-hundred and seventy-four (274) (39.8% of those successfully contacted) individuals were successfully screened. In contrast, there were 312 individuals who refused screening (45.3% of those individuals successfully contacted). Those who agreed to be screened and those who did not agree to screening were compared with demographic variables to determine whether this sample of individuals differed from one another (See Table 1). Notably, there were significant associations between gender and whether or not individuals consented to be screened,  $\chi^2 (1) = 9.516$ ,  $p = .001$ ; 41% of males agreed to be screened, whereas 54% of females agreed to be screened. Ethnicity (whites vs. “other” due to large number of white individuals in cancer registry) and screening status was also significantly associated,  $\chi^2 (1) = 5.17$ ,  $p = 0.015$ ; 40.7% of whites agreed to be screened, whereas 51.8% of non-whites agreed to be screened. A significant association was also documented among cancer type and screen status,  $\chi^2 (8) = 26.55$ ,  $p = 0.001$ ; 34% of prostate cancer survivors agreed to be screened, whereas 53.1% of those with other types of cancer agreed to be screened. (\*Note: although Table 1 depicts comparisons for prostate vs. “other” types of cancer, the following provides percentages within cancer type of those who agreed to be screened for more comprehensive cancer types: 58% with “other” types of cancer; 55.4% with female reproductive cancer; 55.3% with genitourinary cancer; 53.3% with colorectal cancer; 41% of breast cancer survivors; 40% with multiple types of cancer; 38.9% with skin cancer; 38.1% with lung cancer; and 33.7% of prostate cancer survivors.

**Individuals eligible for participation.** For those individuals who agreed to be screened, eligibility for participation was assessed based on a Distress Thermometer score of  $\geq 4$  OR a health status score of  $\leq 80$  on the Euro-QOL (Note: after July 1, 2009, eligibility for participation was based solely on a DT score of  $\geq 4$  due to changes in grant funding). One-hundred and seventy-one (171) individuals were deemed to be eligible (70.1% of those individuals who were



successfully screened), In contrast, there were 92 individuals (33.6% of those who were successfully screened), who did not meet eligibility criteria. Table 1 depicts results from the comparison of the two groups (eligible vs. ineligible) on demographic variables. Notably, there was a significant association between gender and whether or not individuals were eligible for enrollment in the study,  $\chi^2(1) = 7.875, p = .003$ ; 57.3% of men were eligible for participation, whereas 75.3% of women were eligible for participation. A significant association was also noted among cancer type and eligibility status,  $\chi^2(1) = 13.381, p < .001$ ; 51.7% of prostate cancer survivors were eligible for participation whereas 73.8% of survivors with other forms of cancer were eligible for participation. There was a significant age difference among those who were eligible vs. not eligible,  $t(223.121) = 5.879, p = .002$ , wherein those who were eligible ( $M = 58.91, sd = 12.33$ ) for participation were significantly younger than those who were ineligible, ( $M = 63.98, sd = 9.94$ ).

**Participants who enrolled in the study.** One-hundred and thirty-three (133) of the 171 individuals who were eligible for participation actually enrolled in the study. However, there were 36 individuals (13.6% of those eligible) who did not enroll in the study despite being eligible. Group comparisons (enrolled vs. did not enroll) in terms of demographic variables are depicted in Table 1. Notably, no significant group comparisons were noted.

**Participants who consented online to participate in the group.** Of the 133 individuals who enrolled in the study, a total of 92 individuals consented online to participate in the group (69.2% of those enrolled). Those who consented and those who did not consent online to participate in the study were compared with demographic variables to determine whether this sample of individuals differed from one another (See Table 1). Notably, there was a significant difference in age between those who consented and those who did not,  $t(125) = 2.72, p = .007$ .

Specifically, those who consented online were younger ( $M = 57.10$ ,  $sd = 12.01$ ) than those who did not consent online ( $M = 63.10$ ,  $sd = 10.08$ ).

**Individuals who participated in the online intervention.** A total of 84 individuals (91.3% of those who consented) participated in the online group intervention at the time of this study. Of these 84 individuals, 38 (45.2%) were female, and 46 (54.8%) were male. Age ranged from 23 to 88 years old ( $M = 57.46$ ,  $sd = 13.73$ ; missing data = 2, 2.4%). In regards to education, 21 individuals (25%) had an equivalent of a high school education or less; 41 (48.8%) had an equivalent of a college education; and 22 (26.2%) attended education above college, or earned a higher education degree. In addition, 58 (69%) of individuals in the group were married, and 26 were unmarried (31%, including those who are divorced, widowed, and unmarried). With respect to employment status, 19 (22.6%) were unemployed, 21 (25%) were retired, 13 (15.5%) were employed for less than 30 years, and 31 (36.9%) have been working for more than 30 years. In terms of ethnicity, 65 (77.4%) were White, 7 (8.3%) were Hispanic, 2 (2.4%) were Asian, 4 (4.8%) were Black; and 5 (6%) were of "other" ethnicity (missing data = 1, 1.2%). In addition, 27 (32.1%) earned under \$50,000 per year; and 26 (31%) earned more than \$50,000 per year (missing data = 31, 36.9%).

In regards to cancer variables, 9 (10.7%) had breast cancer, 27 (32.1%) had prostate cancer, 1 (1.2%) had lung cancer, 3 (3.6%) had colorectal cancer, 6 (7.1%) had female reproductive cancer, 3 (3.6%) had genitourinary cancer, 4 (4.8%) had skin cancer, 25 had "other" forms of cancer (including pancreatic, thyroid, meningioma, brain, tongue, adenoid cystic carcinoma, tracheal, parotid gland, astrocytoma, adenocarcinoma, Hodgkins Lymphoma, chordoma, squamous cell carcinoma, condrosarcoma, chordoma, and non-B-cell Lymphoma), and 6 individuals had multiple forms of cancer (7.1%). With respect to staging of cancer, 11 (13.1%) of the survivors had cancer in situ (not at all spread to anywhere beyond original tumor

site), 17 (20.2%) had stage 1 cancer, 11 (13.1%) had stage 2 cancer, 8 (9.5%) had stage 3 cancer, 6 (7.1%) had stage 4 cancer, and 31 (36.9%) were unsure of the stage of their cancer. The average time of diagnosis was 65.8 months (approximately 5.5 years,  $sd = 68.1$  months, range = 22 months to 377 months). In terms of distress, the average on the distress thermometer was 4.75,  $sd = 2.8$  (range = 0-10; missing data = 8, 9.5%, which represents those who participated online, but did not fill out 12-week follow-up data (time 1 surveys); Note: cutoff for clinically significant distress is a score on the DT of 4 or more).

### **Demographics by Recruitment Method Within Web-Use Data**

Of the 84 individuals who participated in the online group, 45 (53.6%) were web recruited, and 39 (46.4%) were phone recruited. Demographic variables were compared for web recruits versus phone recruits for those who ended up participating in the online support group. Specifically, there was a significant association between gender and recruitment method (phone vs. web),  $\chi^2 (1) = 6.152$ ,  $p = .012$ ; 68.4% of females were web-recruited whereas 41.3% of males were web-recruited. In contrast, 31.6% of females were phone-recruited, whereas 58.7% of males were phone-recruited. In regards to ethnicity, there was not a significant association between ethnicity and recruitment method,  $\chi^2 (1) = .165$ ,  $p = .443$ . In terms of marital status, 28 of the individuals who were married in the group (48.3% of the total individuals married in the group) were web recruited, whereas 17 of the individuals who were unmarried (65.4% of the total unmarried) were web-recruited. There was not a significant association, however, between marital status and recruitment method,  $\chi^2 (1) = 2.113$ ,  $p = .117$ . In terms of education, 11 of the individuals with a high school equivalent or less (52.4% of the total individuals with the same level of education) were web recruits; 22 of those with a college education (53.7% of those with a college education in the group) were web recruits; and 12 of the individuals with education

beyond college (54.5% of those who had greater than a college degree) were web recruits. However, 10 of those with a high school education or less (47.6% of those with the same level education) were phone-recruited; 19 of those with a college education (46.3% of those with a college education in the group) were phone-recruited; and 10 of those with an education beyond college (45.5% of those with an education beyond college in the group) were phone-recruited. There was not a significant association between education level and recruitment method,  $\chi^2 (2) = .020$ ,  $p = .990$ . In regards to income, 16 of those who earn less than \$50,000 per year (59.3% of all those who earn this amount of money yearly) were web recruited; while 14 of those who earn more than \$50,000 annually (53.8% of those who earn over \$50,000 per year enrolled in the group) were web recruited. However, 11 of those individuals who make less than \$50,000 per year (20.8% of individuals in this income bracket) were phone recruited, and 12 of those individuals who make over \$50,000 annually (46.2% of those in this income group and enrolled in the intervention) were web recruited. Thus, there was not a significant association between income and recruitment method,  $\chi^2 (1) = .158$ ,  $p = .452$ . Furthermore, employment status (categorized by employed or not) was analyzed with respect to the association with recruitment method. There was not a significant association among recruitment method and employment status,  $\chi^2 (1) = .063$ ,  $p = .488$ . Specifically, 22 individuals who were not working were web recruited (55% of the total in the group not working); whereas 23 individuals who were employed (52.3% of the individuals in the group working) were web-recruited. In contrast, 18 of the individuals not working were phone recruited (45% of the individuals who were not working); whereas 21 (47.7% of those currently working) were phone recruited. Moreover, there was a significant difference in age among those web recruited vs. phone recruited,  $t(80) = -2.374$ ,  $p = .02$ , whereas those who were web-recruited were younger ( $M = 54.29$ ,  $sd = 15.188$ ) than those who were phone-recruited ( $M = 61.32$ ,  $sd = 1.758$ ). However, there was not a

significant difference in time since diagnosis among those who were web vs. phone recruited,  $t(57.130) = 1.230$ ,  $p = .224$ . Lastly, there was not a significant association between cancer type (categorized as prostate vs. other types of cancer, OR prostate cancer vs. breast cancer),  $\chi^2 (1) = .471$ ,  $p = .325$  and  $\chi^2 (1) = 2.40$ ,  $p = .122$ , respectively.

### **Hypothesis 1: Gender Differences in Distress at Baseline**

It was hypothesized that female cancer survivors would report greater levels of distress when compared to male counterparts at baseline (time of recruitment). More specifically, it was asserted that these gender differences in distress would remain after controlling for health status (as measured by the Euro-QOL). It is also notable, however, that health status data was only available for 64 individuals. However, for those who did have valid health status data, values ranged from 0 – 100 ( $M = 68.59$ ,  $sd = 22.95$ ). There was not a significant difference between males and females with respect to reported levels of health status  $t(59.84) = .655$ ,  $p = .515$ . Specifically, data was available for 27 males ( $M = 70.74$ ,  $sd = 3.65$ ), and 35 females ( $M = 67.00$ ,  $sd = 4.40$ ).

Initially, it was important to determine whether those who were eligible for participation but never enrolled or participated in the group (based on a Distress Thermometer Score of  $\geq 4$ ) differed from those who participated in the online group (and completed T1 analyses). An independent samples t-test indicated that there was a significant difference in distress between those who did and those who did not participate in the group,  $t(133) = -2.56$ ,  $p = .01$ . Notably, those who enrolled and participated in the group had significantly lower distress levels ( $M = 4.64$ ,  $sd = 2.96$ ) than those who screened positive for significant distress, but did not enroll/ participate ( $M = 5.89$ ,  $sd = 2.54$ ). Therefore, there was actually a bias in those who did

not enroll, but screened positive for distress, as those who were more distressed declined to participate when asked over the phone.

In regards to distress (as measured by the Distress Thermometer) differences by gender, there was not a significant gender difference reported at time of recruitment,  $t(255) = -2.57$ ,  $p = .09$  ( $M$  distress males = 3.67,  $sd = 3.17$ ;  $M$  females = 4.4,  $sd = 3.24$ ),  $D = 0.23$ . Unadjusted regression analyses also were not significant,  $F(1, 256) = 3.09$ ,  $p = .08$ . Therefore, there was no need to covary for other variables (demographics, health status, etc) which may have driven the relationship between gender and distress.

In addition, gender differences in distress on other emotional measures were determined for those who actively participated in the group. Analyses were conducted using the following as testing variables for independent samples t-test: CES-D, Distress Thermometer, IOES, FACT-G, and Outcome Questionnaire. However, no significant gender differences were observed with respect to any of these testing variables: CES-D,  $t(74) = .154$ ,  $p = .878$ ; DT,  $t(79) = -.014$ ,  $p = .929$ ;  $t(55.47) = -1.19$ ,  $p = .229$ ; IOES,  $t(68.61) = .634$ ,  $p = .528$ ; OQ,  $t(50) = .724$ ,  $p = .423$ . Although significant gender differences were not documented, females generally yielded higher scores on distress variables (CESD  $M$  females = 20.06,  $sd = 7.87$ ,  $M$  males = 19.5,  $sd = 7.08$ ,  $D = .07$ ; IOES  $M$  females = 20.34,  $sd = 14.93$ ,  $M$  males = 18.29,  $sd = 13.21$ ,  $D = .14$ ; DT  $M$  females = 4.71,  $sd = 2.93$ ,  $M$  males = 4.71,  $sd = 2.73$ ,  $D = 0$ ; OQ  $M$  females = 64.68,  $sd = 21.56$ ,  $M$  males = 60.47,  $sd = 20.14$ ,  $D = 0.20$ ).

## **Hypothesis 2: Gender Differences in Decision to Participate in the Group**

Figure 3 depicts the breakdown of gender at each step of the recruitment process, and this flow is described above in the Participants section. Briefly, there was a significant association between gender and those attempted to be contact (percentage of males >

females); those successfully contacted (percentage of males > females); successfully screened (percentage of females > males); and eligibility (percentage of females > males). Therefore, results confirmed the hypothesis that more females would be willing to be screened (and thus expressed greater interest in the group), as well as eligible to participate (based partially on greater willingness to report distress).

In terms of web usage, no significant gender differences were significant with respect to web usage, which as contrary to what was hypothesized (See Table 2, which also denotes effect sizes for each gender comparison). Notably, there was no significant difference between men and women with respect to total time spent online,  $t(45.91) = 1.55$ ,  $p = .127$  ( $M$  men = 8471.59 seconds,  $sd = 11054.88$ ;  $M$  women = 16194.37 seconds,  $sd = 28945.93$ ); total number of log-ins,  $t(42.31) = 1.61$ ,  $p = .115$  ( $M$  men = 14.37 logins,  $sd = 21.361$ ;  $M$  women = 33.97 logins,  $sd = 72.56$ ); total time spent on the discussion board,  $t(42.428) = 1.738$ ,  $p = .089$  ( $M$  men = 1255.44 seconds,  $sd = 3476.14$ ;  $M$  women = 4666.89 seconds,  $sd = 1167.91$ ); total time spent on others' personal pages,  $t(43.106) = 1.506$ ,  $p = .139$  ( $M$  males = 1379.76 seconds,  $sd = 3226.80$ ;  $M$  females = 3977.42,  $sd = 10218.72$ ); total time spent on coping modules,  $t(82) = -.440$ ,  $p = .661$  ( $M$  males = 42.50 seconds,  $sd = 163.387$ ;  $M$  females = 30.11,  $sd = 64.62$ ); time spent blogging,  $t(67.92) = 1.16$ ,  $p = .25$  ( $M$  males = 11.61 seconds,  $sd = 51.88$ ;  $M$  females = 27.24 seconds,  $sd = 68.39$ ); or total time spent in the chat rooms,  $t(82) = .494$ ,  $p = .622$  ( $M$  males = 185.65 seconds,  $sd = 947.05$ ;  $M$  females = 281.74 seconds,  $sd = 807.18$ ).

Table 2

*Gender Differences in Website Usage*

	<i>t</i>	<i>df</i>	<i>p</i>	<i>M</i> males ( <i>sd</i> )	<i>M</i> females ( <i>sd</i> )	<i>ES</i> ( <i>D</i> )
<b><i>TIME SPENT ONLINE FOR DIFFERENT FEATURES OF THE SITE</i></b>						
Total time spent online (in seconds)	1.55	45.91	.127	8471.59 (11054.88)	16194 (28945.93)	0.27
Total Number of log-ins	1.61	42.31	.115	14.37 (21.361)	33.97 (72.56)	0.27
Total time on discussion board (in seconds)	1.738	42.43	.089	1255.44 (3776.14)	4666.89 (1167.91)	2.92
Total time spent on other participants' personal pages	1.506	43.106	.139	1379.76 (3226.80)	3997.42 (10218.72)	0.26
Total time spent on coping modules (in seconds)	-.440	82	.25	42.50 (163.387)	30.11 (64.62)	0.08
Total time spent in chat sessions (in seconds)	.494	82	.622	185.65 (947.05)	281.74 (807.18)	0.12
Total time spent blogging (in seconds)	1.16	67.92	.25	11.61 (51.88)	27.24 (68.39)	0.23
<b><i>TIME SPENT ON INDIVIDUAL INFORMATION MODULES</i></b>						
Introduction	1.386	68.021	.170			
Social Support	.199	64.041	.199			
Self and Body Image	1.472	42.269	.148			
Healthy Lifestyle	-.178	82	.859			
Self-efficacy	.000	82	.999			
Relationships	.333	82	.740			
Ways of thinking	-.383	82	.703			
Self-talk	.708	82	.481			
Relaxation & Imagery	1.192	38.87	.240			
Discussing Thoughts & Feeling	.683	82	.497			
Goal setting	.914	50.343	.365			
Benefit Finding	1.348	37	.186			



### **Hypotheses 3: Gender Differences in Topic Interest and Website Functions**

It was hypothesized that males and females would exhibit different interests in various topics explored during the intervention. More specifically, it was proposed that men would focus more on informational modules (i.e., coping skills, healthy lifestyle, self-efficacy, ways of thinking), while females would exhibit greater interest in socially related and communicative functions (i.e., social support, relationships, disclosing thoughts and feelings). However, contrary to what was hypothesized, no gender differences were noted in terms of time spent on any of the different informational modules (in terms of quantitative analyses). Notably, there was no significant gender differences in terms of time spent on the introductory model,  $t(82) = -.387, p = .715$ ; mindfulness and coping page,  $t(68.021) = 1.386, p = .170$ ; social support,  $t(64.041) = .199, p > .05$ ; self and body image,  $t(42.269) = 1.472, p = .148$ ; healthy lifestyle,  $t(82) = -.178, p = .859$ ; self-efficacy,  $t(82) = .000, p = .999$ ; relationships,  $t(82) = .333, p = .740$ ; ways of thinking,  $t(82) = -.383, p = .703$ ; self-talk,  $t(82) = .708, p = .481$ ; relaxation and imagery,  $t(39.87) = 1.192, p = .240$ ; disclosing thoughts and feelings,  $t(82) = .683, p = .497$ ; goal setting,  $t(50.343) = .914, p = .365$ ; and benefit-finding,  $t(37) = 1.348, p = .186$ . These null findings may be accounted for the fact that despite gender, males and females as a whole did not spend a lot of time on the information modules in general (overall  $M$  for time spent on all coping modules = 9.25 seconds,  $sd = 37.825$ ; range = 0 -76).

**Qualitative data analyses.** Qualitative interviews were conducted in order to evaluate the hypothesis that males and females will exhibit differences with respect to the preferred features of the website (i.e., chat room, discussion board, private webmail, coping modules); topics explored online (i.e. coping skills, healthy lifestyle, self-efficacy, ways of thinking, social support, relationships, disclosing thoughts and feelings); and deterrents/ incentives to

participate. Specifically, four open-ended questions were asked via phone, and responses were transcribed. A total of 20 individuals (12 men and 8 women), were interviewed over the phone, taking approximately 10-15 minutes for each interview. In line with the principles of Grounded Theory, this hypothesis was analyzed with no preconceived notions as to what findings would result, but served as an open-ended investigation of common themes derived (Glaser & Strauss, 1967). Sixty percent (60%, n = 12) of the participants were active on the site, and 30% (n = 6) of the total participants were currently undergoing treatment for cancer. Appendix A provides transcribed responses for questions 1, 2, and 4 (see below) for all participants. Table 3 provides percentage of category mentioned within each gender, as well as results from Chi-Square Analyses.

Table 3

*Percentage within Gender for Qualitative Categories Mentioned*

**Question #1: If you could envision the perfect online cancer support venue, what would it look like? (i.e., what types of features would it include, what topics would be discussed, etc.)**

<b>Categories of Responses</b>	$\chi^2$	<b>Percentage of times mentioned by males</b>	<b>Percentage of times mentioned by females</b>
Information	4.44	20%	20%
Technological Ease	.702	5%	0%
Personal Contact	.000	25%	25%
Ability to Participate When First Diagnosed	.065	12.5%	16.7%
Positive Support	0.357	25%	37.5%
Cancer-specificity	0.693	25%	25%

**Question #2: In what ways could a website like health-space.net better meet your needs?**

<b>Categories of Responses</b>	$\chi^2$	<b>Percentage of times mentioned by males</b>	<b>Percentage of times mentioned by females</b>
Cancer-specificity	.000	25%	25%
More group interaction	---	---	---
Technological Ease	1.046	8.3%	25%
Information	.093	8.3%	12.5%
Less Structure	.065	12.5%	16.7%
More Chat Times	.093	12.5%	8.3%
Personal Contact	.065	12.5%	16.7%

Table 3 continued

**Question #3: What is your Most/ Least Favorite Feature(s) of the Website?**

Features	$\chi^2$	Percentage of times mentioned by males	Percentage of times mentioned by females
<b>MOST FAVORITE</b>		$\chi^2 (8) = 10.417, p = .237.$	
Nothing Mentioned	---	33%	12.5%
Blog	---	0%	12.5%
Discussion Board	---	16.7%	25%
Support From Others	---	8.3%	12.5%
Surveys	---	0%	12.5%
Email notifications	---	0%	12.5%
Coping modules	---	16.7%	0%
Chat Sessions	---	25%	0%
<b>LEAST FAVORITE</b>		$\chi^2 (7) = 6.458, p = .487$	
Nothing	---	50%	0%
Private webmail	---	0%	12.5%
Coping Modules	---	50%	0%
Surveys	---	8.3%	0%
Chat Sessions	---	8.3%	0%
No men's issues discussed	---	8.3%	0%

Table 3 Continued

**Question #4: “What, if anything about the website or experience, kept you from wanting to be more involved in the group?”**

<b>Categories of Responses</b>	<b><math>\chi^2</math></b>	<b>Percentage of times mentioned by males</b>	<b>Percentage of times mentioned by females</b>
Others not active	3.33	0%	25%
No personal contact	1.579	0%	12.5%
Too busy	0.469	25%	12.5%
Technological barriers	0.093	33.3%	0%
Medical barriers	3.33	8.3%	12.5%
Not distressed/ sick	2.353	25%	0%
Not specific to my cancer	0.159	33.3%	25%
Avoiding depression	0.093	8.3%	12.5%

**Question # 1.** The first question asked included: “If you could envision the perfect online cancer support venue, what would it look like? (i.e. what types of features would it include, what topics would be discussed, etc.). Upon multiple reviews and considerations of the content of the data, the following themes emerged from the responses to question #1:

MAJOR THEME	MINOR SUBCATEGORIES OF THEME (OPERATIONAL DEFINITIONS)	Examples of Responses from Participants to reflect theme
INFORMATION	<ul style="list-style-type: none"> <li>-Long-term follow up advice (I.e., check-ups, diet, exercise)</li> <li>-Access to medical professional for medical advice</li> <li>-Advances in cancer treatment</li> </ul>	<p>“...One of the topics [that would be of interest] would be ongoing update info on cancer treatment and where you can get help/ information – not just the website, but local places you can go sit down and be able to talk in person...”</p>
TECHNOLOGICAL EASE	<ul style="list-style-type: none"> <li>-easy to access/ use</li> </ul>	<p>“...Ease of accessibility more than any one single thing-“</p>
PERSONAL CONTACT	<ul style="list-style-type: none"> <li>-ability to contact someone via phone in urgent situations</li> <li>-option to also meet in person</li> </ul>	<p>“The instant messaging great, but in times when I am in a deep hole, I want someone to talk to- [I would love the] option to call somebody – not all of the time, but when you hit that hard spot and u want to sit and talk... I wish a facilitator could contact if they get a text from that person...”</p>
PARTICIPATE WHEN FIRST DIAGNOSED	<ul style="list-style-type: none"> <li>-target those who are recently diagnosed when distress is highest from diagnosis and cancer treatment period</li> </ul>	<p>“...I was treated for cancer at Loma Linda. Everything went according to plan. I was doing well, so there was nothing that I needed- no hang-ups – no distress. Distress was right after diagnosis....I think probably – if you catch people when they are first diagnosed- people need encouragement at this time...”</p>
POSITIVE SUPPORT	<ul style="list-style-type: none"> <li>-have more people involved</li> <li>-venue that helps people stay positive when it is difficult to do so</li> <li>-open to talk about whatever you want, even if it is taboo (i.e., guilt)</li> </ul>	<p>“I am a firm believer in being positive- I have had colon and thyroid cancer, I have never lost faith and things have gone well- I always make my Dr. appointments, and follow</p>

		instructions- its is not the end when you get diagnosed – being positive and following Dr.’s advice is what is key”
CANCER SPECIFICITY	-Advice/ support specific to cancer type -Different venues (i.e., chats, db) for males and females to process topics related to each sex separately	“[I would prefer if the site would be specific to] types of cancer- more specific to my cancer- I can’t relate to others with other cancer types....I understand cancer but [a lot of this is ] not specific to me”.

Subsequently, an expert panel of 4 raters gathered to discuss the operational definitions of the common themes, and each rater coded the responses to 3 of the 4 questions (note: 1 of the questions did not require content coding, and simple frequencies were calculated). Interrater reliability was calculated in order to determine the agreement between raters on the assignment of categories. The interrater reliability for the first question ranged from kappa = .814,  $p < .001$  (rater 2 \* rater 4) to kappa = .876,  $p < .001$  (rater 1 \* rater3); the overall kappa was thus .845,  $p < .001$ . Based on the results of the 4 expert raters, 20% ( $n = 4$ ) of females mentioned the theme of “Information” in their responses regarding what would be included in their ideal online cancer support venue, while 20% ( $n = 1$ ) of males also mentioned “Information” (i.e., long-term follow up advice, access to medical professional for medical advice advances in cancer treatment); however, there was not a significant association between gender and whether or not they mentioned information as an essential features ( $\chi^2 (1) = 4.44$ ,  $p = .058$ ; approaching significance). Furthermore, only 5% of males ( $n = 1$ ) mentioned “technological ease” as an essential feature, while no females mentioned this; again, no significant association was found between gender and mention of technological ease ( $\chi^2 (1) = .702$ ,  $p = .60$ ). With respect to opportunities for personal contact (either in person or over the phone), 25% ( $n = 2$ )

of females mentioned this, while 25% (n = 3) of males also mentioned this as a desired feature, with no significant association found between gender and personal contact mention ( $\chi^2 (1) = .000, p = .678$ ). Twelve-point-five (12.5) percent of females (n = 1) and 16.7% of males (n = 2) mentioned that they would have liked to have the opportunity to participate when they were first diagnosed (i.e., when distress was the greatest, and they were undergoing treatment) ( $\chi^2 (1) = .065, p = .656$ ; no significant association). Moreover, 25% of males (n = 3) and 37.5% of females (n = 3) mentioned that they would like positive support from others, where they can remain focused on the good and talk about anything ( $\chi^2 (1) = .357, p = .455$ ; no significant association). Finally, 25% of women (n = 2), and 25% of men (n = 3) mentioned that the most desired feature of an online cancer support group would be a venue that provides information as well as individuals who have been diagnosed with the same type of cancer that they have ( $\chi^2 (1) = .000, p = .693$ ; no significant association).

Whether or not the participants were currently undergoing treatment for cancer was also evaluated with respect to desired features of an online cancer support venue. Results indicated that of those undergoing treatment, 33.3% (n = 2) mentioned information; 16.7% (n = 1) mentioned technological ease; 33.3% (n = 2) mentioned personal contact; 50% (n = 3) mentioned positive support; 0 mentioned ability to participate when 1<sup>st</sup> diagnosed; and 0 mentioned cancer specificity. For those NOT currently undergoing treatment for cancer, 21.4% (n = 3) mentioned information; 0 mentioned technological ease; 21.4% (n = 3) mentioned personal contact; 21.4% (n = 3) mentioned the ability to participate when first diagnosed; 21.4% (n = 3) mentioned positive support, and 35.7% (n = 5) mentioned cancer-specificity. However, there was no significant associations between cancer treatment status and preference for any of the features (Information  $\chi^2 (1) = .317, p = .483$ ; Technological Ease  $\chi^2 (1) = 2.456, p = .300$ ;



Personal Contact  $\chi^2 (1) = .317, p = .483$ ; Ability to Participate when first diagnosed  $\chi^2 (1) = 1.513, p = .319$ ; Positive Support  $\chi^2 (1) = 1.633, p = .225$ ; Cancer Specificity  $\chi^2 (1) = 2.857, p = .129$ .

**Question # 2.** The second question asked included: “In what ways could a website like health-space.net better meet your needs?” Upon multiple reviews and considerations of the content of the data, the following themes emerged from the responses to question #2:

The interrater reliability for the second question ranged from kappa = .822,  $p < .001$  (rater 2 \* rater 3) to kappa = .881,  $p < .001$  (rater 1 \* rater4); the overall kappa was thus .851,  $p < .001$ . Results from the expert panel ratings indicated that 25% of both males ( $n = 3$ ) and females ( $n = 2$ ) mentioned cancer specificity as a way that the website could better meet their needs (i.e., provide information and have fellow group members that have the same diagnosis). There was no significant association between gender and whether or not one mentioned cancer specificity as a way to better meet their needs ( $\chi^2 (1) = .000, p = .693$ ). However, 25% of women ( $n = 2$ ), and only 8.3% of males ( $n = 1$ ), indicated that they would like to see more frequent interaction from a larger group ( $\chi^2 (1) = 1.046, p = .344$ ; no significant association). With respect to preference for more technological ease (e.g., easier to access and navigate website), no men or women mentioned this as a way to better meet their needs (however, this was coded as something that was mentioned seldom, but not as a salient theme). Moreover, 12.5% ( $n = 1$ ) of women, and 8.3 % of men ( $n = 1$ ) mentioned that additional information (i.e., regarding recent advances in cancer treatment, diet and exercise recommendations, etc), would be a way that Health-space.net could better meet their needs ( $\chi^2 (1) = .093, p = .653$ ; no significant association). In terms of wanting less structure (i.e., shorter surveys, open-ended topics), 12.5% ( $n = 1$ ) of women , and 16.7% ( $n = 2$ ) of men mentioned this as a way the website could better meet their needs ( $\chi^2 (1) = .065, p = .656$ ; no significant association). Twelve-point -five (12.5) percent (%) of females ( $n = 1$ ), and 8.3% ( $n = 1$ ), indicated that the website could better meet

MAJOR THEME	MINOR SUBCATEGORIES OF THEME (OPERATIONAL DEFINITIONS)	Examples of Responses from Participants to reflect theme
CANCER-SPECIFICITY	<ul style="list-style-type: none"> <li>-separation of site by prognosis (i.e., those in treatment vs. those in remission)</li> <li>-separation by cancer-type</li> <li>-target those recently diagnosed</li> </ul>	“Male or prostate cancer specific [information and participation]”
MORE GROUP INTERACTION	-having more active members (lots of people enrolled, but few who regularly check in)	“[It would be nice if there were] More people who could join up in the conversations”
TECHNOLOGICAL EASE	-lots of technical difficulties: easier to access and upload photos/ update profile	“Easy access and easy participation, otherwise creates frustration”.
INFORMATION	-more info regarding recent advances in cancer treatment, diet and exercise recommendations	“[ I would like if there were available] long-term follow-up care advice, information regarding treatment, and physical and mental health guidelines”.
LESS STRUCTURE	<ul style="list-style-type: none"> <li>-ability to talk openly about whatever is on their mind</li> <li>-shorter surveys</li> <li>-emoticons don’t accurately reflect emotions</li> </ul>	“More open-ended representation of emotional status rather than the current emoticons”
MORE CHAT TIMES	-can never make chat; would be good to have a.m. and p.m. chat	“I have missed the chat rooms but I am interested in doing this – I would like to participate in those, but the timing is never right”
PERSONAL CONTACT	-ability to contact group members or facilitators by phone or meet in person	“No not really- just face to face interactions (I am currently not going through anything –in terms of treatment- but waiting) ; Face to face interaction is what I prefer – but I think it is a fantastic idea...I do read it- but I don’t always participate- if I were in treatment, it would be more helpful to me”

their needs by having more options for chat sessions ( $\chi^2 (1) = .093, p = .653$ ; no significant association). Finally, 12.5% of females ( $n = 1$ ), and 16.7% of males ( $n = 2$ ), indicated that they would like to have the opportunity to contact a facilitator or group member by phone or in person, as a way that the website could better meet their needs ( $\chi^2 (1) = .065, p = .656$ ).

For those that were currently active on the site, 16.7% ( $n = 2$ ) mentioned cancer specificity, 16.7% ( $n = 2$ ) mentioned more group interaction, none mentioned technological ease, 16.7% ( $n = 2$ ) mentioned additional information, 8.3% ( $n = 1$ ) mentioned less structure, 16.7% ( $n = 2$ ) mentioned additional chat times, and 16.7% ( $n = 2$ ) mentioned opportunity for personal contact as the ways that Health-space.net could better meet their needs. However, for those who were not currently active on the site, 37.5% ( $n = 3$ ) mentioned cancer specificity, 12.5% ( $n = 1$ ) mentioned more group interaction, 0% ( $n = 0$ ) mentioned technological ease or additional information, 25% ( $n = 2$ ) mentioned less structure, 0% ( $n = 0$ ) mentioned additional chat times, and 12.5% ( $n = 1$ ) mentioned opportunity for personal contact as ways that the site could better meet their needs. Notably, there were no significant associations among activity status on the site and ways that the website could better meet their needs (Cancer specificity  $\chi^2(1) = 1.111, p = .296$ ; More group interaction  $\chi^2(1) = .065, p = .656$ ; Technological ease = n/a; Information  $\chi^2(1) = 1.481, p = .347$ ; Less structure  $\chi^2(1) = 1.046, p = .344$ ; More chat times  $\chi^2(1) = 1.481, p = .347$ ; Personal contact  $\chi^2(1) = .065, p = .656$ ).

Whether or not one was currently undergoing treatment for cancer was also evaluated in regards to the association with ways that participants mentioned that health-space.net could better meet their needs. For those currently undergoing treatment for cancer, none (0%) mentioned that cancer specificity, technological ease, or opportunity for personal contact would be ways that the site could better meet their needs. However, 16.7% ( $n = 1$ ) mentioned that more group interaction would help better meet their needs. Thirty-three point three percent

(33.3%, n = 2) mentioned that a less structured venue would better meet their needs. Finally, 33.3% (n = 2) of those currently undergoing treatment indicated that more chat times would be a way that the website could better meet their needs. Moreover, with respect to those who were NOT currently undergoing treatment for cancer, 37.5% (n = 5) mentioned cancer-specific topics as a way that the site could better meet their needs. Fourteen point three (14.3%, n = 2) indicated that they preferred to have more group interaction. None of those not currently undergoing treatment mentioned cancer specificity; yet 7.1% (n = 1) mentioned that additional information would be a way that the site could better meet their needs; 7.1% (n = 1) mentioned less structure as a way the site could better meet their needs; none mentioned more chat times; and 21.4% (n = 3) mentioned personal contact as a way that the site could better meet their needs. Notably, no significant associations between cancer treatment status and mention of the ways that the site could better meet one's needs were noted (Cancer specificity  $\chi^2(1) = 2.857$ ,  $p = .129$ ; More group interaction  $\chi^2(1) = .019$ ,  $p = .691$ ; Technological ease = n/a; Information  $\chi^2(1) = .423$ ,  $p = .521$ ; Less structure  $\chi^2(1) = 2.260$ ,  $p = .202$ ; More chat times  $\chi^2(1) = 5.185$ ,  $p = .079$ ; Personal contact  $\chi^2(1) = 1.513$ ,  $p = .319$ ).

**Question #3.** All participants were also asked about their most and least favorite feature of the website (i.e., blog, chat sessions, discussion board, private webmail, coping modules). Because the responses were close-ended, they were not coded by the expert panel for qualitative responses, but rather simple frequencies were conducted by gender. For women, 12.5% (n = 1), did not mention anything as their favorite feature; 12.5% (n = 1) mentioned the blog as their favorite feature; 25% (n = 2) mentioned the discussion board as their favorite feature; 12.5% of women (n = 1) mentioned support from others; 12.5% (n = 1) mentioned surveys; 12.5% (n = 1) mentioned the convenience of the online venue; and 12.5% (n = 1) mentioned the anonymity that the online venue provides. In contrast, 37.5% (n = 3) did not

mention anything as their least favorite feature; 12.5% (n = 1) mentioned the coping modules; 12.5% mentioned the discussion board; 12.5% (n = 1) mentioned email notifications; 12.5% (n = 1) mentioned the surveys as their least favorite feature; and 12.5% (n = 1) mentioned private webmail as their least favorite feature.

For males, 33.3% (n = 4) did not mention anything as their favorite feature; 16.7% (n = 2) of males mentioned the coping modules as their favorite feature; 16.7% (n = 2) mentioned the discussion board; 8.3% (n = 1) mentioned support from others as their favorite feature of the site, and 25% (n = 3) mentioned the chat as their favorite feature. In contrast, 50% (n = 6) did not mention anything as their favorite feature; 25% (n = 3) mentioned the coping modules as their least favorite feature; 8.3% (n = 1) of males mentioned surveys; 8.3% (n = 1) mentioned the chat sessions as their least favorite; and 8.3% (n = 1) mentioned the fact that men's issues (i.e., specific to prostate cancer and treatment) were not discussed on the site as their least favorite feature.

Notably, there was not a significant association between gender and favorite feature of the website  $\chi^2 (8) = 10.417, p = .237$ . There was also no significant association among gender and least favorite feature of the website,  $\chi^2 (7) = 6.458, p = .487$ .

**Question #4.** Question #4 was attempting to obtain information from those who were less active on the website. The question included, "What, if anything about the website or experience, kept you from wanting to be more involved in the group?" Upon multiple reviews and considerations of the content of the data, the following themes emerged from the responses to question #4:

MAJOR THEME	MINOR SUBCATEGORIES OF THEME (OPERATIONAL DEFINITIONS)	Examples of Responses from Participants to reflect theme
OTHERS NOT ACTIVE	-few people active on the site	“[ I would participate more if] .. people to post more on the board”
NO PERSONAL CONTACT	-no ability to meet in person or contact someone via phone	“[ I would participate more if I had the] ability to contact people live- immediate gratification”
TOO BUSY	-not enough time/ not a priority	“[I] just has a lot going on in his life right now- I’m just a procrastinator”
TECHNOLOGICAL BARRIERS	-not comfortable using computer or internet on a regular basis -too many technical difficulties	“...I just don’t use the computer very much”...
MEDICAL BARRIERS	-to sick to participate (due to tx or terminal illness)	“I have been so busy with treatment, I have had no time... I go to bed so early, I am so tired”.
NOT DISTRESSED/SICK	-don’t fee in need of support -don’t consider oneself a cancer “patient” currently	“To be honest, yes, I am a prostate cancer survivor and so I don’t come face to face with more severe terminal types of cases in general- I have friends who I have lost – but for me, and this is personal, it may not be the same for everyone- dealing with prostate cancer, it is a good prognosis, so I am not wrestling with a terminal illness and not needing closure”
NOT SPECIFIC TO MY CANCER	-information doesn’t pertain to me	“[I] would like discussions about mens’ issues- I have nothing in common with the participants because they do not talk about issues specifically for men”
AVOIDING DEPRESSION	-don’t want to bring myself down with others stories -trying to stay “positive”	“I don’t always like to get myself involved because I don’t want to bring myself down and depressed where I always think about that- I don’t always want to put myself back in there”

Because not everyone was coded on the final question, only 2 raters were included on the calculation of kappa for this item. The interrater reliability for the fourth question was kappa = .885,  $p < .001$ . Results from the expert panel indicated that 25% ( $n = 2$ ) of females mentioned the fact that few people were active on the site as a deterrent to participation; In contrast, no males mentioned this as a deterrent to participation. There was not a significant association between gender and others not being active as a deterrent to participation ( $\chi^2(1) = 3.333$ ,  $p = .147$ ). Furthermore, 12.5% of females ( $n = 1$ ), and no males mentioned that the fact that no personal contact was available as a deterrent to participation ( $\chi^2(1) = 1.579$ ,  $p = .400$ ). Twelve-point-five percent (12.5%,  $n = 1$ ) of females indicated the fact that they were too busy as a deterrent to participation; whereas 25% ( $n = 3$ ) of males implicated this as a reason for less active participation ( $\chi^2(1) = .469$ ,  $p = .465$ ). Furthermore, no females and 33.3% ( $n = 4$ ) of males mentioned technological barriers (e.g., no regular access to computers/ internet) as reasons they did not participate more frequently ( $\chi^2(1) = .093$ ,  $p = .653$ ). Medical barriers (e.g., being too sick or busy with treatment) was mentioned by 12.5% ( $n = 1$ ) of females, and 8.3% ( $n = 1$ ) of males ( $\chi^2(1) = 3.333$ ,  $p = .102$ ). Moreover, no females, but 25% of males ( $n = 3$ ) mentioned the fact that they were not distressed or currently ill as the reason they did not actively participate in the site ( $\chi^2(1) = 2.353$ ,  $p = .193$ ). Twenty-five percent ( $n = 2$ , 25%) of females, and 33.3% ( $n = 4$ ) mentioned the fact that the site was not cancer-specific as a reason they did not participate more ( $\chi^2(1) = .159$ ,  $p = .545$ ). Lastly, 12.5% ( $n = 1$ ) of females, and 8.3% ( $n = 1$ ) of males mentioned the fact that they did not want to be “brought down” by depressing stories from others as the reason they did not participate more ( $\chi^2(1) = .093$ ,  $p = .653$ ).

For those who were not currently active on the site, none mentioned the fact that more people were not active as reasons for why they were not more active on the site. Twelve-point five percent (12.5%,  $n = 1$ ) mentioned the fact that there was no opportunity for personal

contact as the reason for why they could not participate more; 25% (n = 2) mentioned the fact that they were too busy; 12.5% (n = 1) mentioned technological barriers; 12.5% (n = 1) mentioned medical barriers; 25% (n = 2) mentioned that they were not distressed or sick as deterrents to participation; 27.5% (n = 3) mentioned the fact that the site was not cancer-specific as reasons for why they did not participate more; finally, 12.5% (n = 1) mentioned the fact that they did not want to be “dragged down” or become depressed by others as reason for why they did not participate more.

For those currently undergoing treatment for cancer, 16.7% (n = 1) mentioned the fact that more others were not active as the reason for why he was not more active on the site; none mentioned the fact that there was no opportunity for personal contact; 33.3% (n = 2) mentioned the fact that they were too busy; 33.3% (n = 2) mentioned technological barriers; 33.3% (n = 2) mentioned medical barriers; none mentioned the fact that they were not distressed or sick, the site was not specific to their type of cancer. For those who were NOT currently undergoing treatment for cancer, the following frequencies were noted in terms of reasons for why they were not more active on the site: 7.1% (n = 1) mentioned the fact that more people were not active on the site; 7.1% (n = 1) mentioned the fact that there was no opportunity for personal contact; 14.3% (n = 2) mentioned the fact that they were too busy; 14.3% (n = 3) mentioned technological barriers; none mentioned medical barriers; 21.4% (n = 3) mentioned the fact that they were not distressed or sick; 42.9% (n = 6) mentioned the fact that the site was not specific to their cancer; and 14.3% (n = 2) mentioned the fact that they did not want to become depressed by others’ stories/ experiences. Again, there was no significant association between cancer treatment status and reasons for why they did not participate more (Others not active  $\chi^2 = .423$ ,  $p = .521$ ; No personal contact  $\chi^2 = .451$ ,  $p = .700$ ; Too busy  $\chi^2 = .952$ ,  $p = .343$ ; Technological barriers  $\chi^2 = .952$ ,  $p = .343$ ; Medical barriers  $\chi^2 = 5.185$ ,  $p = .079$ ; Not



distressed/ sick  $\chi^2 = 1.513$ ,  $p = .319$ ; Not specific to my cancer  $\chi^2 = 3.673$ ,  $p = .077$ ; Avoiding depression  $\chi^2 = .952$ ,  $p = .479$ ).

#### **Hypothesis 4: Gender Difference in Online Postings and Level of Emotional Expression**

It was hypothesized that females would have more postings on the discussion board, and blog writings. Gender differences on these variables are shown in Table 4. There was not a significant gender difference in number of overall discussion board posts,  $t(41.46) = 1.87$ ,  $p = .068$  ( $M$  females = 5.89,  $sd = 14.619$ ,  $M$  = males = 1.33,  $sd = 3.94$ ) or amount of time spent posting discussion board messages,  $t(41.095) = 1.626$ ,  $p = .112$  ( $M$  amount of time spent posting discussion board message for males = 377.24 seconds,  $sd = 1346.821$ ;  $M$  amount of time spent posting discussion board message for females = 1789.24,  $sd = 5210.201$ ). Similarly, there was not a significant gender difference with respect to the amount of time spent blogging,  $t(37.28) = 1.278$ ,  $p = .209$  ( $M$  amount of time spent blogging for males = 23.48 seconds,  $sd = 141.496$ ;  $M$  amount of time spent adding blogs message for females = 496.11,  $sd = 2276.495$ ).

With respect to emotional expression, it was hypothesized that females would be more expressive. Table 4 displays the results described herein. Overall, females in the group had an average word count of 1541.16 words ( $sd = 3714.67$ ); while males had an average word count of 474.74 ( $sd = 163.31$ ). There was not, however, a significant difference between the total word count between males and females,  $t(42.45) = 1.708$ ,  $p = .095$ . There was also not a significant difference between the number of affective words that males and females used, as calculated by LIWC,  $t(41.396) = 1.726$ ,  $p = .092$ ;  $M$  number of affective words for males = 20.24,  $sd = 48.59$ ;  $M$  number of affective words for females = 72.53,  $sd = 181.42$ ). Moreover, no significant gender differences were observed with respect to the number of negative affect words,  $t(24) = 1.264$ ,  $p = .218$  ( $M$  number of negative affect words for males = 25.75,  $sd = 27.46$ ;  $M$  number of negative

Table 4

*Gender Differences in Online Postings and Emotional Expression*

	<i>t</i>	<i>df</i>	<i>p</i>	<i>M</i> males ( <i>sd</i> )	<i>M</i> females ( <i>sd</i> )	<i>ES</i> ( <i>D</i> )
<b>ONLINE POSTINGS</b>						
Total number of discussion board posts	1.87	41.46	.068	1.33 (3.94)	5.89 (14.619)	0.32
Time spent posting discussion board posts (in seconds)	1.626	41.095	.112	377.24 (1346.82)	1789.24 (5210.201)	0.27
Time spent blogging (in seconds)	1.278	37.28	.209	23.48 (141.496)	496.11 (2276.495)	0.21
<b>EMOTIONAL EXPRESSION</b>						
Total word count	1.708	42.45	.095	474.74 (163.31)	1541.16 (3714.67)	0.29
Number of affective words used	1.726	41.396	.092	20.24 (48.59)	72.53 (181.42)	0.29
Number of negative affect words used	1.264	24	.218	27.55 (27.46)	57.93 (84.15)	0.36
Number of positive affect words used	1.852	15.68	0.083	41.33 (43.983)	129.47 (179.01)	0.49
Courtald Emotional Control Scale (CECS Total Score)	-2.582*	49	0.013	48.20 (8.82)	41.476 (9.616)	0.76

Note: \* denotes significance at  $p < .05$  level

affect words for females = 57.93, sd = 84.115); or positive emotion words,  $t(15.68) = 1.852$ ,  $p = .083$  ( $M$  number of positive affect words for males = 41.33, sd = 43.983;  $M$  number of positive affect words for females = 129.47, sd = 179.01). Because initial analyses were not statistically significant, there was no need to conduct adjusted analyses, covarying for demographic or other factors such as stage of cancer, time since diagnosis, cancer type, or total number of words expressed.

In contrast, however, there were significant gender differences noted with respect to emotional suppression as measured by the Courtald Emotional Control Scale (CECS). Consistent with what was hypothesized, males exhibited higher scores on the CECS, suggesting a greater level of emotional suppression,  $t(49) = -2.582$ ,  $p = .013$ ;  $M$  CECS score for males = 48.20, sd = 8.82;  $M$  CECS score for females = 41.476, sd = 9.616).

Because significant gender differences were noted on independent samples t-tests (with respect to CECS scores), appropriate covariates to include in adjusted analyses were determined. Therefore, gender was compared on a host of demographic and cancer-related variables to determine where significant associations occurred, and thus what covariates needed to be included. Notably, there was a significant association among gender and employment status,  $\chi^2(3) = 12.194$ ,  $p = .007$ . Of note, more females tended to be unemployed ( $n = 12$  females vs. 7 males), whereas more males tended to be retired ( $n = 15$  males vs. 6 females); and males tended to be employed longer ( $n = 21$  males employed for more than 30 years as opposed to 10 females employed more than 30 years;  $n = 10$  females employed less than 30 years vs. 3 males employed less than 30 years). There was also a significant association between cancer type and gender,  $\chi^2(1) = 44.864$ ,  $p = <.001$ . In addition, there was a significant difference between males and females in terms of age,  $t(80) = -2.87$ ,  $p = .005$ . Specifically, males tended to be older than females ( $M$  age for males = 61.24, sd = 12.56;  $M$  age for females = 52.86, sd =

2.28). There was also a significant difference among males and females in terms of time since their cancer diagnosis,  $t(82) = 2.113$ ,  $p = .038$ . Notably, females were further away from diagnosis time rather than males ( $M$  time since diagnosis for males = 51.8 months,  $sd = 29.16$ ;  $M$  time since diagnosis for females = 82.71 months,  $sd = 93.96$ ). Thus, age, time since diagnosis, and employment have been determined to be necessary covariates for adjusted analyses. In contrast, however, gender was not determined to be significantly associated with ethnicity,  $\chi^2(4) = 4.027$ ,  $p = .402$ ; education,  $\chi^2(2) = 1.34$ ,  $p = .512$ ; income,  $\chi^2(1) = 1.602$ ,  $p = .162$ ; marital status,  $\chi^2(1) = 2.358$ ,  $p = .097$ ; stage of cancer,  $\chi^2(5) = 5.43$ ,  $p = .366$ .

Therefore, adjusted analyses were conducted, including age, time since diagnosis, and employment as covariates, and CECS scores as the dependent variable. Results revealed, however, when covariates were included, analyses were no longer significant,  $F(4, 50) = 2.39$ ,  $p = .06$ , Adjusted  $R^2 = .100$  (note: no individual significant predictors were identified).

### **Hypothesis 5: Gender Differences in Social Connectedness**

The final hypothesis asserted that gender differences would occur in terms of the level of interaction with other participants. Specifically, it was proposed that females would develop tighter social bonds with fellow participants compared to males. This hypothesis was evaluated by the number of webmails exchanged with other participants, replies to others' discussion board posts, and replies to participants' blogs. Please note that there was only social bond data for 30 of the individuals who were actively engaged in the group (35.7% of the total online usage data). However, because data was also collected regarding the level of connectedness to facilitators, data will be presented for level of connectedness among participants themselves, degree of connectedness with facilitators, and degree of connectedness overall (Please see Table 5).

Table 5

*Gender Differences in Social Connectedness*

	<i>t</i>	<i>df</i>	<i>p</i>	<i>M</i> males ( <i>sd</i> )	<i>M</i> females ( <i>sd</i> )
<b>INTERACTIONS WITH ALL OTHERS (PARTICIPANTS AND FACILITATORS)</b>					
Number of Individuals replied to db posts for	3.089*	18.05	.006	1.23 (1.09)	3.5 (2.5)
Total number of db replies	2.834*	15.7	.012	1.5 (1.61)	5.64 (5.15)
Number of individuals exchanged webmails with	1.495	18.027	.152	1.77 (3.14)	1.36 (3.13)
Total number of webmail exchanges	1.510	15.328	.151	3.38 (3.18)	8 (10.95)
Number of individuals replied to blog posts for	1.639	16.384	.120	0.31 (0.63)	1.14 (1.79)
Total number of blog replies	.854	25	.401	0.77 (2.2)	1.79 (3.72)
<b>INTERACTIONS WITH OTHER FACILITATORS (EXCLUDING PARTICIPANTS)</b>					
Number of facilitators for whom replied to discussion board posts for	1.914	20	.07	0.22 (0.44)	1.0 (1.15)
Total number of replies to facilitator discussion board posts	2.589*	15.67	.02	0.22 (0.44)	1.23 (1.15)
Number of facilitators with whom exchanged webmails with	1.541	19	.140	1.27 (0.65)	2 (1.41)
Total number of webmail exchanges with facilitators	1.174	18	.256	3.09 (2.55)	6 (7.76)
<b>INTERACTIONS WITH OTHER PARTICIPANTS (EXCLUDING FACILITATORS)</b>					
Number of participants for whom replied to discussion board posts for	2.413*	17.892	.027	1.56 (0.73)	2.77 (1.59)
Total number of replies to participant discussion board posts	2.304*	15.272	.036	2 (1.32)	4.85 (4.16)
Number of participants with whom exchanged webmails with	2.612*	11.878	.023	0.82 (0.75)	2.4 (1.78)
Total number of webmail exchanges with other participants	2.306*	8.184	.049	0.91 (0.83)	6.33 (7.02)

*Note: \* denotes significance at  $p < .05$  level*

Specifically, when not accounting for whether interaction was with facilitators vs. other cancer survivors, significant gender differences were documented in terms of the number of other individuals that participants replied to discussion board posts for,  $t(25) = 3.01$ ,  $p = .008$ , as well as the number of discussion board replies overall (regardless of the number of individuals replied to),  $t(25) = 2.748$ ,  $p = .001$ . Of note, females replied to more individuals' discussion board posts ( $M$  females = 3.5 other participants,  $sd = 2.50$ ;  $M$  males = 1.23,  $sd = 1.09$ ); as well as the number of overall discussion board replies ( $M$  females = 5.64,  $sd = 5.15$ ;  $M$  males = 1.54,  $sd = 1.61$ ). In contrast, there were not significant gender differences with respect to the number of individuals webmails were exchanged with,  $t(25) = 1.456$ ,  $P = .158$ ; the total number of overall webmails exchanged,  $t(25) = 1.462$ ,  $p = .156$ ; number of people individuals replied to blog posts for,  $t(25) = 1.590$ ,  $p = .124$ ; the overall number of blog replies,  $t(25) = .834$ ,  $p = .401$ . In terms of bond strength with facilitators, the only significant gender difference was noted in terms of the total number facilitator blog replies,  $t(15.67) = 2.59$ ,  $p = .02$ . Specifically, females replied to significantly more blog replies than males ( $M$  for females = 1.23,  $sd = 1.30$ ;  $M$  for males = .22,  $sd = .44$ ). No significant gender differences were noted in terms of the number of facilitators blogs replied to,  $t(20) = 1.91$ ,  $p = .07$ ; number of facilitators webmails were exchanged with,  $t(19) = 1.54$ ,  $p = .14$ ; overall number of webmail exchanges with facilitators,  $t(18) = 1.17$ ,  $p = .256$ . However, when interactions with only other cancer survivors (excluding facilitators) were considered, there were significant gender differences between the number of other participants that individuals replied to discussion board posts for,  $t(17.89) = 2.41$ ,  $p = .027$  ( $M$  for females = 2.77,  $sd = 1.59$ ;  $M$  for males = 1.56,  $sd = .73$ ); overall number of discussion board replies,  $t(15.272) = 2.304$ ,  $p = .023$  ( $M$  for females = 4.85,  $sd = 4.16$ ;  $M$  for males = 2.0,  $sd = 1.32$ ); number of participants individuals sent private webmails to,  $t(11.88) = 2.61$ ,  $p = .023$  ( $M$  for females = 2.4,  $sd = 1.78$ ;  $M$  for males = .82,  $sd = .75$ ); and number of overall private webmails

exchanged with (regardless of number of people exchanged with),  $t(8.18) = 2.31$ ,  $p = .049$  ( $M$  for females = 6.33,  $sd = 7.02$ ;  $M$  for males = .91,  $sd = .83$ ).

## Discussion

Results were mixed in that they both confirmed and disconfirmed hypothesized gender differences. Specifically, null findings were documented with respect to gender differences in distress, but results indicated that those who enrolled in the study tended to be less distressed than those who were eligible but did not elect to participate. In regards to the recruitment process, a significant preponderance of females agreed to be screened and were eligible for participation, yet equal gender distributions were observed in terms of enrollment. Moreover, in terms of web usage, slight (but not significant differences) were noted (i.e., females spent more time online, time on the discussion board, personal pages, time spent blogging, and greater number of logins). Finally, significant differences in social connectedness (females were more connected to other participants, whereas males and females equally interacted with facilitators).

### Recruitment Base

The sample obtained in this study is somewhat unique in that Loma Linda University Medical Center is one of the main proton therapy treatment centers nation-wide for the treatment of prostate cancer, and thus prostate cancer was the most prevalent type of cancer represented in the sample (37.4%). As a result, prostate cancer was over-represented in the sample when compared to nationwide trends (American Cancer Society, 2010). Because the sample in the current study is largely comprised of prostate cancer survivors, this study inherently includes more men, and thus is a departure from other studies examining gender dynamics within cancer support groups wherein the majority of samples have been female (Jacobson et al., 2006). The lack of men represented in online cancer support studies has thus made it difficult to generalize findings to males (Simpson et al., 2001), and thus little is known



with respect to males' interest in online support, how males use online support, and whether males benefit from participation. Although few studies have focused on interventions targeting men, those that have included men have suggested that the benefits of participating in psychosocial interventions and support groups are quite significant (Rehse & Pukrop, 2002; Gregoire et al., 1997; Mishel et al., 2002; Penedo et al., 2006). Specifically, benefits have been found according to studies of an all-men prostate cancer support group, including greater improvements in mental health, less interpersonal conflict, greater perceived control over health and functioning, greater benefit finding, higher quality of life and lower distress associated with cancer-related intrusive thoughts relative to controls (Penedo et al., 2006). Therefore, this study provided a unique opportunity to allow men to communicate their experiences and benefit from participation through their interactions with the site and other cancer survivors. Data from this study can thus be used to better illuminate whether online interventions are of interest to men, even when not in the context of an all men, cancer-specific support group. Moreover, the sample obtained in the current study was relatively ethnically diverse, with approximately 30% of participants identifying themselves as a minority. This representation is generally commensurate with nationally representative data, wherein over 80% of U.S. Cancer Survivors are identified as "White" (Alterkruse, Kosary, Krapcho, Neyman, Aminou, Waldron et al., 2010). Similarly, this percentage of White cancer survivors is consistent with the distribution of White individuals living in the U.S., which has been estimated to be 79.6% as of 2009 (U.S. Census Bureau, 2009). White ethnicity has also been identified as the most prevalent ethnic group diagnosed with prostate cancer (Alterkruse et al., 2010). In regards to ethnic minority representation in online cancer support groups, ethnic diversity has been found to be lacking within these groups (Im et al., 2005). Therefore, generalizability of the

findings of this study may be somewhat limited in terms of the ability to understand recruitment processes and participation for ethnic minorities.

### **Gender Differences in Regards to Recruitment and Group Participation**

Examination of demographic (specifically gender) differences at each step in the recruitment process revealed how this sample may have been biased. Specifically, the proportion of males within the registry was larger compared to females, and this is perhaps why more males were successfully contacted. However, consistent with what was hypothesized and despite the larger number of males available to contact, a higher percentage of females agreed to be screened for eligibility to participate. This trend suggested that females demonstrated more interest than males in participating, which is consistent with the extant literature indicating that more females express interest in participating in support groups (Wright, 2002; Im et al., 2005). In addition, more females were web-recruited than males. In general, internet users have been found to be younger than non-internet users (Fogel et al., 2002b), and because the female sample described herein was generally younger than the males, this may account for why more females were internet-recruited than males.

When it came to eligibility for participation (based on a Distress Thermometer Score of 4 or more AND access to internet), more females were eligible for participation, which is again consistent with what was hypothesized. Interestingly, however, there was not a significant difference with respect to distress at the time of recruitment. This finding is consistent with some studies, which have found distress levels to be similar in male and female cancer survivors (Beresford et al., 2006; Deimling et al., 2006; Zabora et al., 2001; & Carlson et al., 2004; Matthews, 2003). Similarly, in population-based studies of cancer survivors, gender does not appear to be associated with distress after controlling for other individual differences (Kaiser,

Hartoonian, & Owen, 2009). The lack of gender differences in distress among cancer survivors differs substantially from what is known about gender differences in distress in the general population, wherein females are identified as more distressed than their male counterparts (Nolen-Hoksema, 2006; Kessler, McGonagle, Swartz, Blazer, & Nelson, 1993). However, a number of studies within cancer survivors and those with other chronic health conditions (e.g., diabetes, heart disease; Kaiser et al., 2009) have yielded similar null findings with respect to gender differences in distress (Beresford et al., 2006; Deimling et al., 2006; Zabora et al., 2001; & Carlson et al., 2004; Matthews, 2003). Reasons for the observed lack of gender differences in distress is likely multifaceted. For instance, research has indicated that although women seem to have greater rates of initial onset depression than men, once males have had an initial episode of depression (which could be spurred by a cancer diagnosis), men and women seem to have episodes of similar duration and equal propensity to experience recurrence of depression (Kovacs, Obrosky, & Sherril, 2003). Moreover, it has been established that there may be differential predictors of distress within cancer survivors rather than the predictors of distress in the general population (Kaiser, Hartoonian, & Owen, 2009). Namely, younger age, not having health insurance, and social support characteristics (i.e., being responsible for younger children and living without older adults), have been found to be predictors that magnify distress in cancer survivors relative to the general population (note: gender was NOT found to predict differential distress in cancer survivors). It may also be that health status, or disease severity drives distress among cancer patients (e.g., Hagedoorn, Buunk, Kuijer, Wobbs, & Sanderman, 2000), which was not able to be analyzed in this study given limited data on cancer stage and health status information. Disease severity must also be taken into account within gender specific cancers (i.e., ovarian cancers specific to women have a lower 5 year survival rate as compared to prostate cancer specific to men, which has a higher 5 year survival rate.

Although there were no significant gender differences with respect to distress, females did endorse slightly higher levels of distress compared to males. Small effect sizes (around 0.20) in terms of differences between males and females were determined in regards to current differences in subjective distress (as measured by the IOES and OQ), and reported depressive symptomatology (as measured by the CES-D). This assertion is consistent with literature indicating that men and women may experience cancer differently (Harrison, Maguire, & Pitceathly, 1995), and thus have differing needs surrounding a cancer diagnosis (Sanson-Fisher et al., 2000; Thorne & Hallberg, 2004). Specifically, it has been determined that women report a larger number of cancer-related concerns regarding cancer itself, the future relating to the illness, concerns about the family, and physical concerns (Hill, Amir, Muers, Connolly, & Round, 2003). Similarly, there were no significant gender differences with respect to access to internet or usage as reported at time of recruitment, consistent with what recent literature has revealed (Nielsen, 2002; Jackson, 1999c). Hence, in light of the lack of significant gender differences with respect to distress or reported internet access, it is unclear as to why gender differences in terms of eligibility existed. Speculatively, whereas the higher percentage of women eligible for participation may have been partially influenced by the judgment of the recruiter, subtle gender differences in distress may have been influenced by biases in the measures of distress used herein. For example, previous findings have indicated biases in measures of distress, which are thought to contain language more specific to females and thus women may falsely appear to be more distressed (Nolen-Hoeksema, 1987).

Although gender differences were not documented with respect to baseline distress levels, there was a significant difference in distress between those who did and did not elect to participate in the group. Therefore, our sample was somewhat biased for those who were not as distressed. This is not to say that participants were not at all distressed, as all those who were

eligible for the study needed to produce a Distress Thermometer Score of 4 or greater, which has been determined as a moderate level of distress (Roth et al., 1998), and Ransom et al. (2006) have identified a cutoff of 4 within cancer patients as revealing clinical levels of distress. This finding of comparatively less distressed individuals participating is similar to what Fawcett & Buhle (1995) discovered, as they claimed that participants in online support groups tend to be healthier and thus less distressed than those who are more seriously ill/distressed, and thus perhaps unable to participate. This is somewhat surprising, as it would seem intuitively that the internet would provide an ideal venue for those who are not able to attend in-person groups due to illness factors. In fact, certain studies have indicated that online participants tend to be more seriously ill and distressed (Im & Chee, 2004; Owen, Boxley, et al., 2010). This pattern within the current sample was also interesting considering that in qualitative interviews, a large proportion of individuals interviewed identified the fact that they were not acutely ill or distressed as reasons why they did not participate more. Therefore, collectively, these findings indicate that while less distress may predict enrollment in groups, quality and quantity of interaction may more influenced by severity of illness and distress level.

Despite the finding that more females agreed to be screened and were eligible when compared to males, roughly an equal number of males and females enrolled in the study. Such a pattern is consistent with what limited studies to-date have revealed in terms of online cancer support groups having more gender balance than traditional face-to-face support groups (Klemm & Hardie, 2002; Klemm et al., 1998). The current study is thus unique in that it represents a heterogeneous group in terms of cancer types, whereas many of the studies to-date have consisted of gender specific cancer (e.g., breast cancer), consisting of mostly females (Im et al., 2005; Wright, 2002). In regards to the reasons behind a more equal dispersion of females and males who enrolled, perhaps more gender-balance was demonstrated when

compared to the gender dispersion in face-to-face groups in that the internet provides more anonymity and perhaps less shame than face-to-face interaction. This taps into culturally sanctioned gender roles where it may be more acceptable for women to seek support from others as opposed to men (Gilligan et al., 1986; Markus & Kitayama, 1991; Hobfoll & Vaux, 1993). Demographic differences within gender type must also be considered when interpreting online cancer support group participation. For instance, those who participated tended to be younger, white, roughly 70% were married, and 76% of those who participated had a minimum of a college degree. These findings support those in the literature, whereas factors identified to be predictive of participation included higher education (Epping-Jordan et al, 1999), white ethnicity (Gourash et al., 1978; Shaw et al., 2006), younger age (Epping-Jordan et al., 1999), and being married (Shaw & Yun, 2000).

Additional gender-specific patterns were demonstrated in terms of usage of the website and the different modalities the site had to offer. While many analyses did not result in statistically significant findings per se (likely due to the considerable within-group variability noted), the magnitude of the differences in some cases provided a clearer picture of the gender trends. Namely, small effect sizes (.10 - .30) were noted in terms of time spent online, time on personal pages spent, number of logins, time spent on the coping modules, time spent in the chat room, and time spent blogging; a large effect size was noted in terms of the time spent on the discussion board (>1.0). Largely, females had greater values on nearly all of the aforementioned measures, with the exception of time spent on the informational modules, wherein males spent moderately more time on the modules compared to females. It is therefore unclear as to whether true gender differences with respect to utilization of coping modules exist, as the current study was limited by the fact that coping modules were highly underutilized. Hence, gender differences with respect to interest in coping modules may be

better evaluated by studies wherein informational modules are the exclusive feature of online interventions. Findings herein are thus similar to those of Kiss & Meryn (2001), wherein men with prostate cancer were less likely to participate extensively in online cancer support groups, rather they prefer informational exchanges rather than social support. Furthermore, as previous studies indicated that males tended to log-in more frequently (Pew Internet and American Life Project, 2007; Nielsen, 2002; Odell, Korgen, & Schumacher et al., 2000; Fallows, 2007), this was not the case with respect to the current findings. To further disseminate the lack of statistically significant findings, cursory analyses were run within the group of active users (e.g., those that posted at least one discussion board message, participated in one chat, posted a blog, created a profile as opposed to those who enrolled and consented but never actively participated). However, despite selecting for those active in the group, no significant gender findings were discovered. Likewise, there were no gender differences were discovered in terms of the time spent (and thus demonstrated interest) on the various coping modules. It was originally hypothesized that males would spend more time on informational-related modules (i.e., i.e. coping skills, healthy lifestyle, self-efficacy, ways of thinking) while females would exhibit greater interest in socially related and communicative functions (i.e. social support, relationships, disclosing thoughts and feelings). The lack of significant findings may have been hampered by the fact that in general, the coping modules were a highly underutilized feature of the website. However, although differences were not noted in terms of individual topics, men did tend to spend more time on these pages than females, which supports the current understanding of male online support group usage wherein they are not as interactive or socially driven as the females are, but rather more informationally driven.

## **Qualitative Findings**

Qualitative interviews with select participants provided a greater level of depth concerning gender differences in interest and usage of the site, although statistical differences between males and females were not noted (as many of the analyses did not have great enough power). Themes were identified that spoke to gender-common and gender-specific needs, interests, and perhaps coping styles with respect to their cancer diagnosis and intervention styles. Generally, in terms of interests in what online cancer support groups could offer, males tended to express interest in cancer-specific (and male-specific) forums where they could gather information from health professionals and other survivors. In contrast, females expressed more interest in support and interactions with others. This is again consistent with what previous studies have indicated and hence what was hypothesized at the outset of the current study in that males are more information-seeking whereas females are more socially and emotion seeking (Kiss & Meryn, 2001; Clarke, McCarthy, Downie, Ashley, & Anderson, 2009; Jackson et al., 2001a; Miller et al, 2001; Morehan-Martin, J. , 1998; Odell et al., 2000; Sherman et al., 2000; Teo et al., 2000; Weiser et al., 2000; Jackson et al., 2001a; Owen et al., 2004). This trend also supported the notion that men seem to have more concerns about the physical aspects of cancer as it effects their ability to fulfill their gender roles (i.e., being able to carry out physical household demands or hold a full-time job to provide for their family, as well as perform sexually) (Feine, Bushnell, Miron, & Duncan, 1991; Vallerand, 1995). Moreover, this may also provide additional insight into gender differences with respect to the cancer experience, cancer needs, and coping differences. Specifically, while males are seeking specific information regarding their cancer and side effects of treatment, females do not necessarily focus as much on their type of cancer, but wish to seek support from others with varying degrees of illness and types of cancer. In addition, several females tended to mention a desire to connect with others (fellow participants or



facilitators) over the phone or in person. This was not as frequently mentioned among males, but again indicates the need for females to be more interpersonally connected.

Males tended to mention technological barriers as deterrents to participation more often than females, which may be a function of the fact that the female participants were younger than their male counterparts, and hence were perhaps more technologically savvy. Similarly, males tended to mention the fact that they were not distressed or acutely sick as reasons for why they did not participate more. However, this was mentioned less frequently by women. Such a finding may shed light on further gender differences in regards to gender-specific cancer needs, in that regardless of where females were in terms of the cancer trajectory, they valued support and participation in the group (as females were also, on average, further from time of diagnosis than male participants were). In contrast, males expressed more of a desire to be enrolled in the group when they first learned of their diagnosis and were more acutely distressed. Such a pattern likely informs intervention development for men and women, suggesting targeting newly diagnosed and distressed males as those who would most likely participate and perhaps benefit from intervention. This critical period may not be as pronounced for females.

Nonetheless, there were gender-common themes that emerged in terms of desired features of online cancer support groups, including information, technological ease, opportunities for personal contact outside of the website with facilitators and/or fellow survivors, ability to participate within proximity of diagnosis, positive social support, and discussion of cancer-specific topics. Therefore, while distinct gender differences emerged, the responses of participants indicated that there are likely gender-common needs in regards to support for a cancer diagnosis.

## **Gender Differences in Emotional Expression and Connectedness to Others**

Again, limited analyses yielded statistically significant gender differences. This lack of significant findings may have been attributed to the fact that the analyses were slightly underpowered, as at the time of data analysis, there were limited individuals who are consistently active on the website. Regardless, the lack of significant findings was perhaps less interesting than the magnitude of differences observed. Specifically, while no significant gender differences were noted, females did tend to use more words in general, as well as more affective words (negative and positive), had more discussion board posts, and more blog writings when compared to males. Therefore, the findings from the current studies were consistent with the previous findings documented in the literature (Davison & Pennebaker, 1997; Seale et al., 2005). Similarly, significant gender differences were noted in terms of the level of emotional suppression reported by males and females (as measured by the Courtauld Emotional Control Scale). Such differences may be explained by normative expectations for sex differences that arise as a result of male and female social roles, which may extend beyond sex differences in self-report and may suggest difference in the physiological experience of emotion (Grossman & Wood, 1993). However, when covariates were included in the model predicting emotional suppression, gender no longer significantly predicted emotional suppression. Thus, further research may be warranted to determine what drives the relationship between gender and emotional suppression.

In regards to the degree of social relatedness, distinct gender differences were documented in terms of their interaction with other participants as well as facilitators which sheds light on gender differential utilization within the online cancer support group venue. Specifically, in terms of interaction with other participants, it was determined that females generally replied to discussion board posts (for other participants and facilitators) more for

other individuals than males did. However, when interactions with only other participants were examined (excluding facilitator interaction), females were significantly more connected with other participants (as evidenced by significantly more discussion board replies with more individuals and more webmail exchanges with more participants). Therefore, although females and males didn't appear to significantly differ with respect to interactions with facilitators per se, females were significantly more connected with other participants. This finding supports the hypothesis that females would demonstrate a greater level of social connectivity. However, it also demonstrates the fact that males tend to interact with facilitators more so than other participants. This finding is supported by literature suggesting that females tend to prefer to confide in several other individuals in a supportive and informal structure (Harrison et al., 1995; Gray et al., 1996), whereas men tend to express interest in inviting outside member and health care professionals to be involved in support groups (Gray et al., 1996). Hence, although it appears that females may cope by connecting and seeking emotional support from others, the internet also provides a promising venue for males as a way to cope through gathering more information about their disease in addition to reaping psychosocial benefits such as connecting with others and expressing their thoughts/ feelings in an open manner (Klemm et al., 1998). This finding speaks to the unique feature of this study in that it includes professional facilitation, which is distinct from the structure of many online cancer support groups that are peer-led. Furthermore, the presence of this feature has provided knowledge in terms of the gender differences in interest and utilization of these professional vs. non-professional resources.

### **Limitations and Suggested Areas of Future Research**

Although the current study adds an important dimension to the cancer support group literature, it is not without limitations. Notably, the participants from this study come mainly

from a single cancer center registry (Loma Linda University Medical Center). While this is part of an ongoing study wherein recruitment methods are being extended beyond those described herein, it is unclear as to how the results of this study would generalize to cancer survivors outside of the Loma Linda area; to the state of California or the nation as a whole of cancer survivors as a whole. In regards to research methodology, although this was designed as a randomized controlled trial, the data collected for the purposes of the current study were largely part of the pilot or preliminary data collection, wherein continuous enrollment took place and thus no real comparison groups were available for analysis. Moreover, there were members who were participants in the group for several months, and some who had been members for a few weeks (in other words, this was not a set 12-week intervention wherein cohorts who spent the exact amount of time in the intervention); this fact may have impacted differential levels of participation and connectedness. However, since the current study did not set out to evaluate outcomes of the intervention, this will not affect the results of the research described herein. This fact leads to the next limitation, in that outcomes data were not yet available for this preliminary study of gender differences. Instead, the focus of the current study was on recruitment and web usage. Future research could benefit by understanding differential outcomes for men and women, and thus in turn inform how intervention development may adapt to fit the trends revealed. Similarly, there is no simultaneous evaluations of face-to-face groups, which would be an essential next step to determine how face-to-face groups (utilizing the same recruitment methods and intervention material as the internet groups) compare in regards to interest, recruitment patterns, participation, and outcomes. Such a study could potentially speak well to what an online cancer support group has to offer uniquely in terms of benefits or shortcomings rather as compared to face-to-face interventions. Additionally, in regards to statistical analyses, many of the analyses evaluating gender differences in terms of

social connectedness, emotional expression, and qualitative analyses were underpowered. Therefore, larger sample sizes may have been better able to illuminate true gender differences with regards to these constructs. Likewise, analyses may have been impacted by the fact that data included those who were extremely active in the group as well as lurkers (those who sign in but don't interact) and those who consented and enrolled, but never participated. Therefore, there was a lot of variability which may have hampered analyses to determine true trends within active users. In regards to the data itself, many of the variables analyzed were part of the cancer registry, which was very limited and in turn effected the range of the variables, completeness of the data, as well as the way that data could have been analyzed. Finally, one of the biggest strengths of the study as including various cancer types, can also be a limitation. For instance, it is not clear as to how this type of intervention may work differently for individuals with different types of cancer (in terms of interest, usage, and outcomes), and it was often identified as a weakness by those who were interviewed.

In summary, the current study offered data from a multifaceted online intervention, facilitated by individuals with professional backgrounds, and a large sample size of cancer patients with a variety of cancer diagnoses utilizing both quantitative and qualitative methods. These attributes have combined to provide a rich body of information regarding gender differences in distress levels, recruitment processes, and participation in online cancer support groups. The current research also adds to the literature in that much of the cancer support group research has been completed on an inpatient basis while individuals are still undergoing various forms of treatment. However, little has been done to examine the mental state and distress rates of those living with cancer years beyond diagnosis (Deimling et al., 2006). Moreover, few studies in this area have yielded quantitative data and lack expressive of qualitative research in such studies (Klemm et al., 2003). However, critical next steps for

research include evaluating differential outcomes in interventions for men and women utilizing a true randomized controlled trial methodology could help better speak to efficacy of OCSGs. In addition, analysis of larger sample sizes in terms of qualitative data and web-usage data may better illustrate true gender differences in utilization and interest.

The data developed herein can help to inform future intervention development, perhaps targeting male and female cancer survivors differently in terms of recruitment strategies and intervention style. More specifically, the current study suggests that inclusion of gender and/ or cancer-specific forums may be of interest, especially for males, wherein they can obtain information and support from fellow cancer survivors as well as trained health-care professionals. In contrast, females may prefer to connect more with other females, regardless of cancer type, in a more supportive, less-structured environment. Tailoring interventions in this way uniquely serves gender-specific needs and interests, likely improving distress symptomatology. This is not to say, however, that mixed gender and cancer groups are contraindicated; but rather, providing specialized forums or discussion times may help enhance the current intervention. Moreover, this research provides a better understanding of how the genders may differently experience cancer, and to best understand their needs. Online interventions are part of a cutting edge trend in providing healthcare, making interventions more convenient, more cost effective, and more widely disseminated. Therefore, the current study provides an important glimpse into how similar interventions are effective in terms of recruitment and reaching cancer survivors.

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## Appendix

### Responses to Qualitative Questions

<b>Responses to Question #1: If you could envision the perfect online cancer support venue, what would it look like? (i.e. what types of features would it include, what topics would be discussed, etc.)</b>
<p>-list of questions- some things that you want to discuss to give you more ideas instead of what you come up with yourself (eg list of FAQ – send a survey- if you could ask 5 questions, what would they be)</p> <p>-would like to be able to use the chat room (issues)- need to have tech support ; give people the option to talk about absolutely anything they might think is bad for having certain thoughts (i.e., when very sick, everyone is calling you) – feeling bad for feeling that way</p> <p>-taboo topics- ways to intro topics that no one likes to talk about</p>
<p>-instant messaging great, but in times when I am in a deep hole, I want someone to talk to- option to call somebody – not all of the time, but when you hit that hard spot and u want to sit and talk</p> <p>-wishes supervisor could contact if they get a text from that person</p>
<p>-Don't know- not sick; when was sick with chemo and radiation, had a lot of family support</p>
<p>-I am a firm believer in being positive- one thing I have had colon and thyroid cancer, I have never lost faith and things have gone well- always make my dr. appts, and follow instructions- its is not the end when you get diagnosed – being positive and following dr advice</p> <p>-make sure you get the check ups – people have supported me I am not afraid</p>
<p>-Ease of accessibility more than any one single thing-</p> <p>-In terms of subjects- can be random- doesn't really matter</p>
<p>Quality of life (look at) , coping mechanisms , a good support system (like a family), continuing education, psychoeducation, links to relevant links of important information</p>
<p>-I told the people that I didn't think I would enjoy it bc it doesn't fit my personality- I don't consider myself that I am a cancer pt- don't want to hear about everyone else's depression/ cancer</p> <p>-I am a google girl- I researched a lot- I would have liked something specific to my type of cancer (thyroid) – I was in with such a broad group of people, hard to navigate with that many people</p>

<p>-Don't know- was treated for cancer at Loma Linda. Everything went according to plan. I was doing well, so there was nothing that I needed- no hang-ups – no distress. Distress was right after dx, was okay after proton radiation</p> <p>-I think probably – if you catch people when they are first diagnosed- people need encouragement at this time</p>
<p>The only thing- if they had an emergency # to talk to somebody if things were getting really bad- like when I found out I had 4 tumors, I couldn't sleep all night-</p>
<p>-For me personally, there was a difference between male and female members- that had to do with the type of cancer that the person experienced.</p> <p>-Prostate cancer is male, that was my issue- for me that was the biggest issue – I wasn't able to talk to anyone – it was just cancer in general- and um, I had surgery, it was a done deal, I wasn't going through ongoing tx and so some of the questions and issues presented weren't relevant</p> <p>-You would think more women are interested in this- which makes sense in terms of the need for emotional support- men are having more anger issues – I am a high school teacher, I am good at reading emotions</p>
<p>-One of the topics would be ongoing update info on cancer tx and where you can get help/ information – not just the website, but local places you can go sit down and be able to talk in person</p> <p>-Lots of people who have bc are older and are not too computer literate, would rather go to a face to face group to be around other people</p>
<p>Don't know, Im on another one where we post questions, people answer (about side effects/ tx)- this one is only active with 3 or 4 people so it is still kinda new</p>
<p>I think your topics are good- a place where people gather and learn st new about the dx- my cancer was very short lived and hopefully will not come back, but I have another dx and it fits with it too –</p>
<p>I think it is good the way it is- somebody to talk to and feel more comfortable – nothing new that I need – good place to vent and discuss probs you have</p>
<p>There is a website that I have- its dedicated to prostate cancer survivors- it is a wonderful site (yananow.net)- my story is there- I can go back and update but everyone that is on there has had some sort of prostate ca tx- it is organized by tx's and I could list my email/ phone- so if someone wanted to contact me abt my tx I could give them info about my tx (so... something that is more tailored to cancer type and tx- I can't relate to breast ca or other type of cancer- I find myself in a whole different world) – I have no pain and anxiety</p> <p>-It is different for each cancer type- like learning about new examination techniques – set up by ca</p>

type
-Opportunities to meet face to face  -But it does encourage a lot of people- there was someone who contacted me abt a tx I had which was nice
Types of cancer- more specific to my cancer- I can't relate to others with other cancer types – I understand cancer but not specific to me
-One thing I really love about this form is that although they tried to be structured at first, the facilitators have loosened reigns and have let those participating choose what they want to discuss – its been nice to have an open forum to talk about whatever – I just like it being open, no structured topic discussed
-I would like to see a place where if you had a medical question, you could ask that question to a med dr. and get a response back- i.e., about a certain drug – medical questions back and forth  -The last time I commented this lady was gonna get a port- she was scared and I told her it was the best thing that happened to me- there are some things that go on between the people, but it would be nice to get info from a dr. – medical needs met (about side effects of meds)
-If there were a way to connect with someone with your particular type of cancer for one – even though u survived cancer – there is still ongoing lifestyle changes u need to maintain to make sure there is no recurrence- that would be helpful for as well

<b>Responses to Question #2: In what ways could a website like health-space.net better meet your needs?</b>
-Chat room fixed- other than that, easy  -A lot of “active” people- but a lot don't participate  -I happen to be in remission and the other members are very sick- she feels bad cuz she is not very sick
-NO- plz see above (response from #1: <i>list of questions- some things that you want to discuss to give you more ideas instead of what you come up with yourself (eg list of FAQ – send a survey- if you could ask 5 questions, what would they be); would like to be able to use the chat room (issues)- need to have tech support ; give people the option to talk about absolutely anything they might think is bad for having certain thoughts (i.e., when very sick, everyone is calling you) – feeling bad for feeling that way; taboo topics- ways to intro topics that no one likes to talk about</i> )

No recommendations, doesn't use the internet very much
Keep the surveys short- if it is more than 10 mins, I get tired
Premise is very good, but have had great support at home- haven't felt a need to reach out, I leave in a retirement community – a lot of support
I didn't spend much time, but I liked the feedback I got- I responded to fred's story and I got some feedback from others- Facilitate rather than sharing – use the friendliness of it (facilitation) – I know there is a survey checking in which is good, depends on where individual is in terms of medically/ psychologically ; Surveys need to be user friendly and not long- it discourages people from using – don't want it to be seen as a task, even though it is useful; Easy access and easy participation, otherwise creates frustration
It has been so long- I know they have different thyroid websites to learn about what #'s mean- links to more relevant info about certain cancer types- grouping people together by not even cancer type, but more severe vs. less severe, those in remission, etc. – not always good for those who have gone through it to do it again
Catching people just after diagnosis – when you are most stressed
They are already doing an evening chat this wed- that was one thing I recommended
Male or prostate cancer specific
Through more information regarding updated info on cancer tx's, new progress on different types of tx ...I was HER-2 – there was no tx at the time – just read they developed something else, but I don't know if they do have a cure for mind- it wasn't FDA approved- info like that would be helpful / Diet and exercise recommendations/ mental healing stuff to
More people join up- conversations- I have missed the chat rooms but I am interested in doing this – I would like to participate in those
Can't think of anything- it meets my needs
No I noticed this time that he put some things on about new developments in cancer- and I thought that was good
Don't think so
No not really- just face to face interactions (I am currently not going through anything –in terms of tx- but waiting) ; Face to face interaction is what I prefer – but I think it is a fantastic idea...I do read it- but I don't always participate- if I were in tx, it would be more helpful to me

<p>There is a letter coming thru for veterans for agent orange- there are letters that come through to me and I like to see if it is useful- it is good education to touch the bases that pertain to my health- like subject matters that are more specific and pertinent to me ; My time is valuable so chatting with others that doesn't benefit me is kind of a waste</p>
<p>I would love if we could all meet people in face- but there is also st nice about the anonymity- there are some who are really going through some very difficult times that I don't think will be on the site very long – and I would love to meet them (but maybe they don't have that need- who knows)</p>
<p>Im okay- I made a suggestion that all those pics don't really describe some of your feelings (emoticons) – something that is more open ended- they are pretty precise</p>
<p>Wasn't interested in what people were talking about- personal stuff like shopping and vacation- it was casual conversation</p> <p>-More interested in finding out how people are coping- talking about exercise and diet ; I would have liked to interact with people who had similar tx (I had prostate removal) who I can connect with ; Really interested in lifestyle changes to help recurrences- maintenance ; Maybe a site for those who are in remission vs. those who are active</p>

<p><b>Responses to Question #4: For those who did not participate online as much: “What, if anything about the website or experience, kept you from wanting to be more involved in the group?”</b></p>
<p>people to post more on the board (last one is May 30<sup>th</sup>).. today is June 2<sup>nd</sup></p>
<p>Ability to contact people live</p>
<p>-The only thing- I would like to be involved, I like talking to people- it is inconvenient to spend so much time, cuz I am a busy person</p>
<p>-Have a face to face gathering of people- can arrange schedule – this would be really valuable, I like talking to people</p>
<p>Just has a lot going on in his life right now</p>
<p>Good support at home</p>
<p>To be honest, yes, I am a prostate cancer survivor and so I don't come face to face with more severe terminal types of cases in general- I have friends who I have lost – but for me, and this is personal, it may not be the same for everyone- dealing with prostate cancer- good prognosis, not wrestling with a terminal illness and not needing closure- I thought I was dealing with my dx and tx well, but when I am in an environ with more severely ill people, I tend to be more depressed; While I need to participate in a group – I felt myself shrinking back, feeling more pain because I am surrounded by terminal people – I am not dying, it is a focus of qol, being hopeful, positive . I wrestled with terminal</p>

part early on in dx, but now I am focused on the future- living in the moment helped me the most- I have done my tx, managed symptoms, it has been stressful, post-tx is stressful and can make me feel worse medically

I don't dwell on things, I don't look at it as a long-term process – so I unconsciously withdrew from the process ; I also wasn't able to participate as much cuz I am a student

I think program is excellent, facilitation is good- it should continue with it – I am looking forward to participating ; I needed to put input in earlier so I could be more connected to the group- I do support others well in managing illness, but more hard with terminal experience – I do not have experience with this – I am a pastor- never dealt with this myself – we can always compartmentalize ourselves

Being more specific to my cancer type- just group people differently based on stage or experience

Not really- more about where I was in terms of my dx

pretty active- nothing at all kept me from participating

-A few times I got locked out- I got really frustrated, I didn't realized how much I depended on it- I cant tell my family how I feel- that would scare them... have other people who have been through the same thing is nice to have. Jason was really quick to respond any time I had trouble with the site.

-Just what I have already mentioned- the male issues not being addressed – males just don't talk about these things, and I am willing to talk about it. They don't wanna talk about- these are still issues I am dealing with – perhaps better in a group setting ; I found one in Riverside but I live in Hemet, so I didn't want to drive (a male support group for prostate cancer survivors)

Anything else: they did make the attempt at having a chat room- that ended up being okay once in a while, very seldomly – hard finding a time- one time I did it while I was at work, which was not convenient. It was a cool feature, but difficult a good time. Overall, it was a very nice program, I enjoyed it for what it was. I like getting the emails and seeing what is going on, but again, it is primarily female participants and issues.

-Simply because I have not had the time to do that- I wouldn't mind doing it- I would like to know how other people feel but I don't always like to get myself involved because I don't want to bring myself down and depressed where I always think about that- I don't always want to put myself back in there.

-I do volunteer at the cancer center, I am an advocate and listen to others, I understand what they are going through, but I separate myself from the emotions of it – I have moved on and passed on – I don't want to relive it. I just want to help you guys with the ongoing survival experience

Anything else: Yes, we should include a resource center or a # somebody can call to talk to someone



<p>No, just that there is not a lot of discussions – I like that it is local people, it is nice- other website is from people all over (cancer survivor network and inspire)- I like to know what options I have (Tarceva)</p> <p>-Anything else: no, I like it – glad there is local people- some of us have the same dr. which is nice</p>
<p>No – I don't think so I have been really happy with the site</p>
<p>-Can't really say that – sometimes the inconvenience of lunch time with the chats- better at night</p> <p>-Anything else: I did have some trouble getting on going to chat- kept telling me I wasn't connected, don't know what was causing that- I use 2 browsers – it didn't work in either one – that was frustrating</p>
<p>-When I was setting up my homepage- I put everything up and pics, and it didn't save- I was so frustrated and I kind of gave up</p> <p>-Also, I am unemployed and I spend all my time and energy applying to jobs</p> <p>-on every email that comes in, it says click here- and there is no link – it is not active – it becomes very time consuming</p> <p>-LOTS of technical difficulties – some getting started advice</p>
<p>I did have one gentleman contact me thru the site- he wanted to do private interaction thru email, not on the website with everyone- so that was nice</p> <p>-I am not going thru tx, so it is not as pertinent to me</p>
<p>Would like discussions about mens issues- nothing in common with bc survivors- more specifically for mens issues (like a mens chats)</p> <p>Anything else: Any news worthy items coming out of LLUMC in terms of tx would be nice to have- new developments – I am excited about proton tx and electronic scalpel- I like to stay up on it ; It opens ur eyes to have a dx- I didn't know what a prostate was until I had this cancer</p>
<p>Well, actually it is a time constraint for me- I am going thru personal stuff with my mother who has end stage of Alz dx- and I am working a lot, so it is just so busy – now they have begun chat wed evenings which is good</p> <p>-I really have enjoyed participating very much – I have gleaned so much from other participants, and they have my upmost admiration (1 is my hero) and I enjoy conversing with facilitators- they are all good people</p> <p>-It has helped all of us a place to share- it is like being a parent, until someone is there, that is the</p>

only time you can really understand (if you have had cancer) – that is what I appreciate most of all

-I think it is a great thing and I hope it continues

-My treatment- I read then I go back to bed- I am exhausted – I used to use it a lot before the tx's went to twice a month, but I still read others stuff

The \$10 gift card is very appreciated!!!

Time for chat I am usually sleeping or in the hospital- so having a new chat time

Casual conversations in the chat room – about shopping and vacation- there was no info pertinent to me