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SOCIAL SUPPORT RECEIVED ONLINE AND OFFLINE BY INDIVIDUALS
DIAGNOSED WITH CANCER

A dissertation submitted in partial fulfillment of the requirements for the degree of
Doctor of Philosophy at Virginia Commonwealth University.

by

Jessye Cohen,
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Regardless of what media people use to communicate, basic human emotions and motivations remain.

(Joinson, McKenna, Postmes, and Reips, 2007)

What should young people do with their lives today? Many things, obviously. But the most daring thing is to create stable communities in which the terrible disease of loneliness can be cured.

Kurt Vonnegut (source unknown)

*It's simple to wake from sleep with a stranger,
dress, go out, drink coffee,
enter a life again. It isn't simple
to wake from sleep into the neighborhood
of one neither strange nor familiar
whom we have chosen to trust. Trusting, untrusting,
we lowered ourselves into this, let ourselves
downward hand over hand as on a rope that quivered
over the unsearched.... We did this. Conceived
of each other, conceived each other in a darkness
which I remember as drenched in light.
I want to call this, life.*

from "Origins and History of Consciousness" (Adrienne Rich, 1993)

There are many forms of love and affection, some people can spend their whole lives together without knowing each other's names. Naming is a difficult and time-consuming process; it concerns essences, and it means power. But on the wild nights who can call you home? Only the one who knows your name.

Jeanette Winterson (1997)

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My interest in research on cancer-related coping and support was borne of personal sadness; however from that sadness emerged a passion for this work and a fervent desire to understand and contribute to the lives of individuals living with cancer. Despite moments of self-doubt and frustration, I am very proud of the two independent research projects I have conceptualized, implemented, and completed during my time in the doctoral program at VCU. All of the people I have mentioned here and others have helped me along the way.

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Abstract

SOCIAL SUPPORT RECEIVED ONLINE AND OFFLINE BY INDIVIDUALS DIAGNOSED WITH CANCER

By Jessye Cohen, M.S.

A dissertation submitted in partial fulfillment of the requirements for the degree of
Doctor of Philosophy at Virginia Commonwealth University.

Virginia Commonwealth University, 2011

Major Director: Kathleen M. Ingram, J.D., Ph.D.
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Life after treatment for cancer has become a primary focus for health service provider communities as the number of individuals living longer grows. The medical and psychosocial needs of cancer survivors have been prominent in the popular and scientific literature. A major focus for psychologists has been the relationships and social support networks of individuals diagnosed with cancer. The current study explored a recent phenomenon within this realm, the use of Internet resources for online support. The purpose of this study was to compare social support received online and social support received offline among people diagnosed with cancer who use the Internet for cancer-

related support. Specifically, the study first compared types of support received online and offline. Based on the existing literature, the study then explored relationships between offline and online social support and other psychological variables, including positive affect, health-related quality of life, and coping. The research design was cross-sectional, and self-report data were collected from 102 participants who had been diagnosed with cancer. Participants reported a variety of reasons for using cancer-related websites and online communities and provided information regarding types, frequency, and intensity of online activities. Most hypotheses were supported for traditional social support but were not supported for online support. Consistent with hypotheses, total social support received offline was higher than support received online. Emotional support and informational support were significantly higher offline than online. As predicted, participants experienced fewer unsupportive interactions online than offline. Also consistent with the hypotheses, emotional support received from the main support person was positively associated with positive affect and health related quality of life, whereas online emotional support was only positively associated with Focus on the Positive coping. Contrary to the hypotheses, hierarchical regression equations indicated that received informational support was positively associated with avoidant coping. This study contributes to the literature as one of the first studies to explore social support received online in a systematic manner. The results have important research and clinical implications for understanding the distinct and overlapping elements of social support received online and offline by individuals with cancer. Future research directions are also discussed.

Social Support Received Online and Offline by Individuals with Diagnosed with Cancer

Life after treatment for cancer has become a primary focus for health service provider communities as the number of individuals living longer grows. As of 2006, there were 11.4 million individuals, or nearly 4% of the U.S., who are cancer survivors (Horner et al., 2009). The medical and psychosocial needs of cancer survivors have been prominent in the popular and scientific literature. A major focus for psychologists and related professionals has been the interpersonal relationships and social support networks of individuals diagnosed with cancer. The current study explores a recent phenomenon within this realm, the use of Internet resources for online support.

The vast majority of adults in the U.S. have Internet access, and most adults have sought health information online (Fox & Jones, 2009). With each incremental technological development and expansion of resources on the Internet, the possibilities for obtaining information, forming social connections, and communicating with others increases. At the beginning of this decade, Sharp (2000) argued that the Internet changed not only the way cancer survivors received information but that it transformed the way survivors received support. In the 10 years that have followed, the number of social networks and online communities has exploded.

An assortment of popular media reports has emphasized the role of social media, social networks, and online social support. Whereas these sources do not provide us with empirical evidence of the benefits of online social support, they provide compelling anecdotal arguments for exploring these phenomena further. Two recent New York Times articles quoted individuals with chronic illness who claimed that online social

networks saved their lives and gave them a reason to go on by allowing them to connect with other individuals (Clifford, 2009; Miller, 2010). A brief Internet search reveals thousands of sites devoted to individuals with cancer.

As will be discussed in detail later in this document, there is a variety of options available for those seeking support online. These resources include support groups moderated by a professional, unmoderated peer support groups, individual weblogs, chat rooms and message boards, cancer services organization websites, information hubs, and listservs. The variety and omnipresence of these resources, in conjunction with the growing availability of Internet access, present vast possibilities for seeking and receiving support. Furthermore, there are resources available for individuals from pre-diagnosis to long-term survival.

There are distinct benefits of online support resources, including ease of access, the range of resources from purely information to intensive support, the possibilities for anonymity, and the possibilities for communication that does not require all participants to be in the same physical space at the same time. However, there are also potential disadvantages or risks involved in using these online support resources. The unfiltered nature of many of these resources and exchanges increases the risks of misinformation and potential negative interactions. For example, an individual newly diagnosed with Stage 1 breast cancer seeking reassurance may encounter a woman with Stage 4 uterine cancer who is extremely depressed and in terrible pain. The ensuing interactions could be difficult and have negative repercussions for both individuals. Such risks still exist offline but the nature of the Internet enhances these risks.

Social support has been a focus of the psychological literature on adjustment to cancer for several decades. Researchers have explored the subtypes of social support, the differences between received support and perceived support, the psychological and disease-related benefits of social support, among other topics. As individuals diagnosed with cancer have been a prominent group on the Internet, it would be natural to extend this field of study to online sources of support. Indeed, a small but growing body of research has explored the characteristics of individuals participating in particular online communities and activities, as well as the benefits of specific online interventions.

The existing research on the functions, benefits, and challenges of online social support is important and provides us with useful information for designing resources and interventions. However, very little theoretical work has been published exploring the structure of social support online, how online support relates to traditional social support, or the mechanisms of online support. One theory of online social support has been published from a nursing perspective (LaCoursiere, 2001), and several other authors have argued for the development of a theory of online social support. Despite the presence of individual studies investigating online social support or interventions, this literature is in its infancy.

The current study sought to contribute to further understanding the characteristics of online social support. Specifically, the study contains four research aims. First, social support received online was compared to social support received offline for this sample. Next, reports of unsupportive interactions online were compared to reports of unsupportive social interactions experienced offline in this sample. These first two aims will help understand the relationships between online and offline support. Third, the

relationships between social support and aspects of psychological well-being were explored. The first step of this process was to examine whether offline support is related to psychological variables identified in previous studies. The second step was to explore whether online support relates to these same psychological variables in this sample.

Literature Review

The Internet has been used as a resource for health information and social connection since its inception and accessibility in the mid-1990s. This chapter will review the various uses of the Internet by individuals with cancer and ways in which the Internet may serve as a source of social support. Next I will review existing theories of social support, and how these theories might be applied to online social support, and the existing theoretical literature related to online social support.

History of Use of Internet for Cancer Support

With the advent of the Internet came countless opportunities for individuals to obtain information, meet other individuals, explore new areas, and post personal information. As personal and home access to the Internet expanded, individuals began to spend more time online. As Internet resources have become more sophisticated and widely available, social interactions and online communities have become more popular. It is estimated that in 2009, 74% of U.S. adults had Internet access and 61% of adults looked online for health information (Fox & Jones, 2009). Sixty percent of individuals who looked for health information online reported that this information affected a decision about medical treatment.

In addition to vast informational sources, the Internet provides a wide range of social resources. Informal and formal social support networks have emerged in this

climate, and numerous resources are available for individuals with cancer. Sharp (2000) argued that the Internet was changing the way cancer survivors received support, citing the explosion of Internet discussion groups, listservs, and chat rooms. He cited 79 listservs hosted by a single cancer organization, the Association for Cancer Online Resources. Sharp anticipated the future of Internet support would include more specialized resources on the Internet targeting specific types of cancer or demographic groups. In the decade since Sharp published this editorial, the use of social networking sites and other online resources has ballooned and interactive technologies have advanced.

Estimates of rates of health-related Internet use by individuals with cancer range from 8 to 50% (Helft, Eckles, Johnson-Calley, et al., 2005). Others estimate that 28% of Americans using the Internet participate in online support groups related to medical conditions and personal problems (Beaudoin & Tao, 2007). Online cancer-related communities provide opportunities for information exchange, communication, and social support. Some forms of online resources are more conducive to social support and interactions, but nearly all sites offer some opportunity to connect with other individuals.

The Importance of Social Support

Helgeson and Cohen (1996) provided a rationale for the study of social support in the context of coping with cancer. They posited that the social environment is an important domain in the study of cancer for several primary reasons: (1) Aspects of the social environment can promote well being and protect against stress. (2) Cancer has an impact on interpersonal relationships. (3) Stigma, stress, and isolation resulting from cancer may affect an individual's access to social resources. There is vast diversity in

experiences with cancer but there are psychosocial issues shared by all persons with cancer (Helgeson & Cohen).

Constructs in Social Support

Several terms have been mentioned previously in the context of theories of social support. These constructs will be defined and their associated measures will be described in this section. Finally, the rationale for selecting specific constructs to measure in this study will be discussed.

The Internet provides unlimited potential for possible support; however, we do not have a large enough research base to know how this support is perceived or received. In fact, there is virtually no research measuring online social support. *Perceived support* refers to an individual's beliefs about the availability of support if it were needed. It concerns hypothetical support from supportive others. *Received support* (also called *enacted support*) concerns an individual's experiences of social interactions and what support he or she experienced. This type of support is more focused on specific supportive behaviors. Both perceived support and received support rely on an individual's perceptions. However, the latter relies on a person's perceptions of what *has* happened versus what *could* happen.

There is some controversy in the literature about whether to focus the study of social support on perceived or received support (Barrera, 1986; Helgeson, 1993; Wethington & Kessler, 1986). Researchers have debated whether the hypothetical availability of support (perceived support) or the "actual transfer of advice, aid, and affect" (received support) is more important in buffering the effects of stressful life events (Wethington & Kessler, p. 78). More data are available regarding relationships

between perceived support and psychological and health outcomes; however, it has also been suggested that measures of received support reflect social support more accurately than measures of perceived support (Haber, Cohen, Lucas, & Baldes, 2007). There is also controversy about the strength of the relationship between perceived social support and received social support (Haber et al., 2007). In an early influential study of social support, the correlation between perceived and received support was .01 (Haber et al.), and in a meta-analysis of studies of received and perceived support, correlations ranged from .15 to .64 (Haber et al.). The variability in social support measures may contribute to the weak and varying correlations between received support and perceived support.

This study focused on received support. Whereas perceived support is important and has been associated with positive health outcomes (Suls, 1982), I am less interested in the appraisal of possible support or available resources than I am in the actual social interactions individuals have experienced in their proximal networks and online. It is somewhat easier to quantify and measure received support than perceived support. Furthermore, social support interventions are more appropriate to received support than to perceived support. It is quite difficult to design interventions to modify individuals' perceptions. However, as we learn more about received support, we can design interventions to increase the received support. In comparing social support received online and through proximal networks, we can learn more about the differences between the two social contexts and the actual exchanges of social support, which will inform the development of future interventions.

Two additional terms will be used here to describe social support. In this document *proximal* support refers to off-line or in-person support that a person receives from friends and family. *Distal* support refers to social support received online.

Several types of social support are described in the literature. Some current measures of social support incorporate measurement of these types. The descriptions and terminology have shifted somewhat, but several authors have defined the following types (Helgeson & Cohen, 1996; House & Kahn, 1985; Thoits, 1985). *Emotional support* includes direct and indirect, verbal and nonverbal expressions of concern and caring. Emotionally supportive behaviors include listening, being present, reassuring, and comforting (Helgeson & Cohen, 1996). Emotional support can enhance self-esteem, reduce isolation, and permit the expression of feelings (Helgeson & Cohen). Finally, emotional support can provide meaning for the individuals experiencing a stressor. *Informational support* involves providing advice, guidance, or resources. Informational support can enhance a person's sense of control by providing options for action (Helgeson & Cohen). It can also provide clarification, reduce confusion, and improve coping. *Instrumental support* (also known as tangible support) involves the provision of tangible or material support, such as food, transportation, money, or assistance with tasks (Helgeson & Cohen). This type of support can also enhance an individual's sense of control by providing resources to manage circumstances. However, Helgeson and Cohen point out that this type of support may also contribute to a sense of dependence on others.

Another important issue to consider when exploring social support is that of unsupportive interactions. Concurrent with an increase in socially supportive interactions, unsupportive or negative social interactions can occur. At times, even well-

intentioned actions or statements are received as unsupportive. As Sharp (2000) discussed, the potential for unsupportive or negative interactions exists online as it does in face-to-face social exchanges. Unsupportive social interactions are unsupportive or upsetting responses received from other people concerning a stressful life event (Ingram, Betz, Mindes, Schmitt, & Smith, 2001). Several studies have found that unsupportive interactions are related to an increase in psychological distress and a decrease in psychological well-being (Figueiredo, Fries, & Ingram, 2004; Manne, Taylor, Dougherty, & Kenney, 1997).

Four types of unsupportive social interactions that an individual may experience during a stressful event were identified by Ingram and colleagues (2001). *Distancing* involves disengaging from the individual emotionally or behaviorally. *Bumblng* involves behaviors that are inappropriate and appear to be driven by the idea that the person under stress can be “fixed.” *Minimizing* an individual’s fears or concerns is another form of unsupportive interaction and may include forced optimism or cheer. Finally, *blaming* entails criticizing or finding fault with the person experiencing the stressful situation (Ingram et al., 2001). There is evidence that these unsupportive responses are distinct from social support and are important to include in the study of social support. In their initial research on unsupportive responses, Ingram and colleagues found that after controlling for stress and social support, unsupportive social interactions accounted for a significant amount of variance in psychological distress and physical symptoms. Figueiredo, Fries, and Ingram (2004) found similar results in a study of women with breast cancer.

Finally, a new area of exploration is the effectiveness of social support. The evidence regarding beneficial relationships between received social support and various health and psychological outcomes is mixed. Recently researchers have explored why received support may not always be helpful. One hypothesis is that the types, quantity, and form of social support may not match the needs of the individual experiencing a stressor (Cutrona, 1990). As a result, social support varies in its effectiveness depending on how it is received and perceived. Rini and Dunkel-Schetter (2006; 2010) have begun to investigate social support effectiveness in a systematic way. The goal of this approach is to “systematically capture the various reasons some support attempts are more effective than others” (2010, p. 27).

Social Support and Cancer

Psychosocial factors and interventions for individuals with cancer have been researched widely. Many researchers have explored the relationship between various psychosocial factors and health, both broadly and specifically. The majority of research has examined relationships between social support and psychosocial factors such as depression, quality of life, and positive affect. The breadth of this work is too vast to summarize in this section, but a significant subset of research has focused on social support as it pertains to diagnosis, adjustment, and survivorship for individuals with cancer.

Broadhead and Kaplan reviewed the literature on social support and cancer in 1991. They suggested that social support needs of individuals with cancer will vary based on the “adaptive tasks they confront” (p. 794). For example, they posited that more tangible support is needed during hospitalization, whereas emotional support may be

more important during the dying process. They also emphasize the importance of various sources of support. Many of the recommendations for the study of social support and cancer are still necessary today and echoed in the more recent literature, including the need to expand the outcomes studied, the need for sound, specific measures, and the need for longitudinal research.

Helgeson and Cohen (1996) published a review of research on social support related to cancer. Although this review is nearly 15 years old, no similar updated review has been published, and this article provided an overview of issues to consider.

Helgeson and Cohen (1996) organized their review based on types of research, focusing first on descriptive and correlational research and then on experimental intervention research. They discovered contradictory findings in these literatures and explored ways to reconcile these contradictions. Overall, few studies included in the review distinguished between types of support. However, the results of the studies that differentiated the types of support are summarized here.

Social support and adjustment to cancer. Researchers have attempted to quantify the effects of social support on psychological well-being and other outcomes. Social support has been found to buffer the negative effects of cancer (Cohen & Willis, 1985). It has also been associated with higher quality of life (Boehmer, Luszczynska, & Schwarzer, 2007; Northouse et al., 2002).

In addition to exploring relationships between social support and psychological variables with cross-sectional research, a number of investigators have attempted to tease apart the different types of social support and which types are most helpful. This researcher's previous qualitative study (Cohen, 2009) contains extensive descriptions of

the perceived value of emotional and instrumental social support behaviors. Across a series of descriptive and correlational studies, emotional support was found to be the most helpful kind of support (Helgeson & Cohen, 1996). Furthermore, the absence of emotional support was more harmful than the absence of other types of support.

Emotional support was helpful when received from anyone in the social network. In contrast, informational support was helpful from professionals but not friends and family (Helgeson & Cohen, 1996). In interviews with breast and colorectal cancer patients 7-20 months after diagnosis, instrumental support was mentioned least often as helpful (Dunkel-Schetter, 1984).

In a study of 102 breast cancer patients and their significant others at two time points: entry into the study (roughly four months after diagnosis) and six months later, Bolger and colleagues found that significant others provided enacted support (defined as instrumental and emotional support) in response to their partners' physical impairments; however, they found that support decreased in the face of emotional distress (Bolger, Foster, Vinokur, & Ng, 1996). These authors suggest that future research address the changes in and effectiveness of social support offered by significant others to persons with cancer. They posited that individuals experiencing distress may seek social support outside their primary intimate relationships due to the ineffectiveness of or dissatisfaction with the support received within this relationship. This suggestion provides support for the need to explore varied and nontraditional sources of social support.

A set of studies revealed a positive link between emotional support and both well-being and adjustment to cancer (assessed using measures of mood, distress, and psychosocial functioning). Other studies explored the possibility of coping as a mediator

between emotional support and adjustment. Emotional support inhibited “poor coping strategies” (Helgeson & Cohen, 1996, p. 138) and was thereby associated with adjustment. Emotional support was also associated with reduced distress. Overall, emotional support was the type of support most desired and most strongly linked to adjustment.

Taylor, Falke, Shoptaw, and Lichtman (1986) provided an early review of literature on support groups for individuals with cancer. They summarized studies that reported beneficial physical effects (to be reviewed later) and studies of support group participation that demonstrated psychosocial benefits, including fewer phobias, less tension, improved coping, and decreased depression. Many researchers have speculated about why individuals join support groups, including the possibilities that other support is not available, other sources do not provide appropriate support, and that individuals turn to group support when relationships with providers are unsatisfactory. In an effort to characterize individuals with cancer who participated in support groups, Taylor and colleagues surveyed 667 adults with cancer in southern California (60% of whom had participated in a support group). The results of their study indicated that those more recently diagnosed were less likely to have attended a support group. Females of higher socioeconomic status were more likely to attend support groups. In this study, it did not appear that inadequate social support was a motivator for attending a support group. Individuals who attended support groups tended to use more social support resources of all kinds than non-attenders (Taylor, Falke, Shoptaw & Lichtman, 1986).

In addition to exploring the relationships between types of social support and outcomes, a number of researchers have conducted experimental research to identify the

effects of social support interventions. Most intervention studies included in the Helgeson and Cohen review (1996) focused on social support provided by peers (others with cancer), either in dyads or groups. Group interventions usually consisting of one or both of the two following components: discussion or education. Often discussion aimed toward providing emotional support, whereas education provided informational support. Helgeson and Cohen reported a number of methodological flaws in these studies. However, they reported some findings consistent across studies.

Educational interventions increased knowledge and psychological adjustment compared to no-treatment controls in several studies. Three studies comparing educational interventions to group discussion interventions demonstrated the superiority of education over group discussion. The fourth study in that group did not find effects but also did not randomize. Educational interventions may enhance self-esteem, optimism, and sense of control.

Benefits (or potential benefits) of group discussion included enhanced self-esteem, increased optimism, and the identification, and exploration, and acceptance of emotions. However, Helgeson and Cohen (1996) report that these interventions have as much potential for adverse effects as they do to have positive effects. They describe the different effects of upward and downward comparison and the possibility of feeling more stigmatized in a group of persons with cancer.

Helgeson and Cohen (1996) described five potential mechanisms of social support. Others have described these in slightly different ways. These mechanisms are: (1) enhancement of self-esteem; (2) restoration of perceived control; (3) instilling of optimism about the future; (4) provision of meaning for the experience; and (5) fostering

of emotional processing. These potential mechanisms are promising. Unfortunately, Helgeson and Cohen did not expand their discussion of these mechanisms. In fact, there is still limited information on how social support produces positive effects.

Social support and disease progression. Most controversial has been the research attempting to link social support to survival and medical outcomes. This subject and related controversies will be reviewed briefly here; however, the present study is concerned with psychosocial factors and will not attempt to measure biological or disease markers, and therefore discussion of this topic will be limited. Beginning in the 1970s, David Spiegel and his colleagues conducted research on the effects of participation in support groups on survival in breast cancer patients. In 1989 Spiegel and colleagues published data that supported the hypothesis that individuals participating in support groups lived longer than women who did not participate. Several similar studies were published. This research has been surrounded by controversy and criticized harshly (see Coyne, Stefanek, & Palmer, 2007). Spiegel attempted to replicate his findings and was unable to do so in 2007. In addition to attracting vocal critics, this research has attracted many persons who would like to find support for the effects of psychosocial interventions on disease progression, health status, outcomes, and survival. Nausheen, Gidron, Peveler, and Moss-Morris (2009) conducted a systematic review resulting in 26 longitudinal prospective studies (including 31 findings) of social support and cancer progression from 1970 to 2008. Follow-up periods in these studies ranged from 1 to 20 years, and studies included breast cancer, other cancer, and mixed cancer categories. The authors defined 13 of these studies as methodologically sound using criteria to evaluate internal validity.

In this review Nausheen and colleagues distinguished structural support (essentially, the quantity of support) from functional support (the provision of instrumental, emotional, and informational support). In six studies structural support was positively associated with disease progression, whereas in two studies there was a significant negative relationship between social support and disease progression. In only five of 17 studies was there a significant relationship between functional support and disease progression, and in only one of these studies was the relationship positive. Furthermore, there was no evidence that social support was beneficial for any group other than women with breast cancer. However, these authors identify a number of methodological limitations in these studies, including oversimplification of survival outcomes, lack of accounting for differing levels of social support, and lack of control over multiple confounding variables (Nausheen, Gidron, Peveler, & Moss-Morris, 2009). It is clear from this literature that research design must be improved in the area of social support and cancer progression.

For additional review of issues related to social support and adjustment to cancer, see Dunkel-Schetter (1984); Helgeson & Cohen (1996); and Taylor, Falke, Shoptaw, and Lichtman (1986).

Correlates and predictors of social support received by individuals with cancer. In addition to identifying potential consequences of receiving or not receiving social support, several studies have explored antecedents or predictors of social support, though they have defined the term “predictor” differently. In two studies of 50 elderly adults and 71 mothers of young children, Cutrona (1986) examined “objective” characteristics of social networks (e.g., number of individuals providing social support,

frequency of contact, and kin vs. nonkin individuals) to identify determinants of perceived social support. The researchers sought to understand the relationship between network size and frequency of contact and the perceptions of six relational provisions (attachment, social integration, reassurance of worth, reliable alliance, guidance, and opportunity for nurturance). These relational provisions differ from the definitions of social support typically studied. In the study of new mothers, only reliable alliance was predicted by social network variables. Frequency of kin contact predicted attachment, nurturance, and guidance in the sample of elderly adults. This study provides some support for arguments that it is not simply the availability of support that affects the experience of social support.

In a study of 150 community residents (not individuals with cancer), Dunkel-Schetter, Folkman, and Lazarus (1987) interviewed individuals monthly for 6 months about a stressful event in the preceding month to explore psychological correlates of received social support. The authors hypothesized that individual person factors would affect the receipt of social support. In addition, they explored the relationship between coping behaviors or styles and social support receipt. They found that each psychological factor was associated with a specific type of social support (Dunkel-Schetter, Folkman, & Lazarus).

Problem-focused coping, emotion-focused coping, and threat to self-esteem were significantly associated with informational support (Dunkel-Schetter, Folkman, and Lazarus, 1987). Problem-focused coping was associated with more informational support, whereas emotion-focused coping was associated with less informational support. Problem-focused coping was the only factor significantly associated with emotional

support received; the more participants used problem-focused coping, the more emotional support they received. The only significant predictor of instrumental support was perceived threat to one's own health; the more one's health was threatened, the more aid was provided (Dunkel-Schetter, Folkman, & Lazarus, 1987).

Manne and colleagues found that spouse criticism (unsupportive social interactions) were associated with negative mood through avoidant coping (Manne, Paper, Taylor, & Dougherty, 1999). Focusing on the positive was associated with greater perceived support. However, avoidant coping was also increased with focusing on the positive. Some avoidant (or escapist) coping strategies have been associated with poor psychological functioning (Folkman & Moskowitz, 2004).

Moyer and Salovey (1999) also sought to identify predictors of social support in a sample of women with breast cancer. The researchers surveyed 93 women with in situ or early stage breast cancer and a subset of their partners. The goal of this study was to determine if the type of surgical intervention was related to social support or psychological distress and how social support related to psychological distress. There were no differences in levels of social support between women who had breast-conserving surgery and those who had a mastectomy, indicating that surgical treatment was not a significant predictor of social support in this sample. Across the sample, levels of psychological distress and levels of perceived social support decreased over time after surgery. Psychological distress at 3 months post-surgery and physical functioning were significant predictors of changes in levels of support over the period from 3-month to 13-month follow-up. Poor physical functioning at 3 months predicted increased levels of

social support, and increased psychological distress predicted decreases in social support (Moyer & Salovey, 1999).

As described above, relationships among types of coping, social support, and psychological functioning and have been investigated in the existing literature.

However, a review of the coping literature reiterated that coping is a dynamic and multidimensional process and much remains to be learned in this area (Folkman & Moskowitz, 2004). Coping changes over time and depends on the perception of the stressor.

Folkman and Moskowitz discussed the difficulties with nomenclature and measurement in the coping literature. Though multiple studies have used the terms “emotion-focused” and “problem-focused” coping, these terms may be too broad and mask the diversity and impact of specific coping strategies. For example, some avoidant strategies have been associated with negative outcomes (Folkman & Moskowitz).

However, avoidance strategies are also included in the umbrella term of emotion-focused coping, which has been associated with mixed psychological outcomes. Revisions to the two-factor model of emotion-focused and problem-focused coping include a four-factor model: Avoidance, Active, Support, and Positive Cognitive Restructuring (Folkman & Moskowitz). This final factor is consistent with the recent emphasis on the importance of considering positive psychological states in the stress and coping model (Folkman, 1997).

Positive reappraisal (another term for positive cognitive restructuring) was described by Folkman as a meaning-based form of coping. Cognitive strategies for reframing a stressor in a more positive light have been associated with positive affect and other positive psychological outcomes (Sears, Stanton, Danoff-Burg, 2003).

Overall, we have a limited understanding of both the antecedents of social support and the physiological or health outcomes of social support. We have a better sense of the psychosocial consequences or effects of social support. We have mounting evidence that emotional support is perceived as most helpful by individuals with cancer, and emotional support has been associated with higher self-efficacy, improved health-related quality of life, and problem-focused coping (Arora, Rutten, Gustafson, Moser, & Hawkins, 2007; Dunkel-Schetter, Folkman, & Lazarus, 1987; Helgeson & Cohen, 1996). Informational support has been associated with more problem-focused and less emotion-focused coping. These findings are helpful in understanding social support and designing interventions; however, there is much left to be learned about the relationships between social support and psychological variables, the differences between forms and venues of social support, and the effectiveness of social support.

Theories of Traditional Social Support

I have designated the theories described in this section as theories of “traditional social support” because they were developed before virtual support systems had evolved. These theories address proximal support. Of course, they can be expanded to consider online social support, but they do not explicitly incorporate distal support and online experiences, whereas emerging theories (described later) address online social support explicitly.

Lahey and Cohen (2000) summarized the dominant theories of social support in the literature, and Lahey (n.d.) has provided a revised description of traditional theories of social support. Three primary approaches will be discussed here, including the stress and coping perspective, social-cognitive theory, and symbolic interactionism (also known

as a social control perspective). The present study was conducted using the stress and coping perspective, which will be described in more detail than the other theories of social support.

Social-Cognitive Theory. The social-cognitive approach to social support draws upon traditional social-cognitive theories of personality and psychopathology (Lakey & Cohen, 2000). This theoretical approach, as expected, is focused primarily on beliefs about social support, or perceived social support, rather than received social support (Lakey & Cohen, 2000). From this perspective, individuals develop beliefs about social support that become fixed, or at least stable. After these beliefs are established, individuals adjust their perceptions of specific social interactions to fit these beliefs (Lakey & Cohen, 2000). In this model, an individual's global perceptions or impressions of a potentially supportive individual are more important than support received from that person. For example, an individual who perceives her sister to be selfless, always available, and a supportive conversation partner, is more likely to think about these characteristics than any specific interaction or support received from her sister.

In this theoretical approach, social support is related to health through these beliefs or global cognitions. Positive thoughts about social support and social relationships (as in the example above) stimulate positive thoughts about the self and provoke positive emotional states, whereas negative thoughts about social relationships “stimulate negative thoughts about the self, which, in turn, overlap with and stimulate emotional distress” (Lakey & Cohen, 2000, p. 37). Research within this model tends to use measures of perceived social support because this theory emphasizes the importance of global beliefs.

Social Control Theory. The social control perspective draws from symbolic interactionism (Lakey, n.d.). This theory is primarily concerned with social control. According to Lakey and Cohen (2000), from this perspective “our social environments directly promote health and well-being by providing people with a way of making sense of the self and the world” (p. 40). Social support is helpful to the individual because it contributes to the development and sustenance of one’s identity and self-esteem (Lakey & Cohen). Role concepts, or an individual’s beliefs about how persons do or should act in particular roles, are salient in this model, and individuals begin to understand their multiple roles within a social context (or group). As a result of these role concepts, individuals develop expectations about how others in certain roles should act (Lakey & Cohen). Shared role concepts and expectations guide behavior for the individual and for the group who share these concepts and expectations.

In terms of measurement, this approach uses measures that evaluate the extent to which an individual is involved in social networks (Lakey & Cohen, 2000). Other measures inquire about the number of roles an individual occupies.

Stress and Coping. This theory was developed by Lazarus and Folkman (1984) and has been expanded and revised in the past two decades. According to this theory, also known as a transactional theory, social support acts as a buffer and reduces the negative effects of stress through supportive actions by others or through the belief that support is available (Lakey & Cohen, 2000). In this theory an individual experiences stress when he or she appraises a situation negatively. Social support can lead a person to develop more positive or adaptive appraisals (Lakey, n.d.). These terms are further explicated below. The transactional nature of the model refers to the idea that the

individual experiencing stress and the environment have reciprocal influences. The original model focused primarily on coping processes to manage or reduce aversive emotions (Folkman, 1997), whereas the revised model accommodates the role of positive states.

Lazarus and Folkman (1984) described coping as “constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person” (p. 141). As is evident from the language used, this model emphasizes coping as a process rather than a trait. This process includes two key elements (Lazarus & Folkman, 1984): primary appraisal, which is the assessment of the personal significance of an event (or whether the event is a threat); secondary appraisal, which represents a person’s evaluation of the controllability of an event or “what can I do about it” (Lakey & Cohen, 2000, p. 34; Park & Folkman, 1997). Social support may serve as a buffer to stress (or the negative effects of stress) by leading a person to appraise stressful situations less negatively (Lakey & Cohen, 2000). This “buffer hypothesis” complements the “main effects hypothesis” that posits that social support has a direct effect on well-being or health (Cohen & Wills, 1985). The appraisal process, according to Lazarus and Folkman, involves assessing the possibilities for coping. Coping, in turn, represents the actual strategies used to mediate primary and secondary appraisal.

In this model, “supportive actions promote health and well-being by promoting coping” (Lakey & Cohen, 2000, p. 32). Folkman’s (1997) revision of the model describes four types of coping processes associated with positive psychological states related to stress and coping: positive reappraisal, problem-focused coping, spiritual

beliefs and practices, and the infusion of meaning in ordinary events. Positive reappraisal involves reinterpreting an event as positive or nonthreatening. It is similar to finding “a bright side” but differs from the forced optimism described earlier in relation to unsupportive interactions. Problem-focused coping typically entails practical attempts to address the stressful situation. In addition to being practical, problem-focused coping is goal-directed, which allows individuals to feel a sense of control (Folkman, 1997). Under conditions of extreme stress, spirituality and religiosity enhanced the likelihood of positive reappraisal, which then promotes positive affect (Folkman). In a similar vein, in the process of infusing ordinary events with meaning, small and transient events take on positive meaning. In other situations, positive events may happen, but people do not attend to them. The function of this strategy is that it provides a breather from distress and restores resources. This coping process and the use of these four coping strategies are not necessarily linear. The process may be iterative—an individual may use different strategies (e.g., positive reappraisal, problem-focused coping) at different times and repeat these strategies.

This model emphasizes the perceived availability of specific social support and actual received support. The most commonly used measures of support from this perspective are those that evaluate received support. See Figure 1 for a visual depiction of Folkman’s 1997 revision of the model.

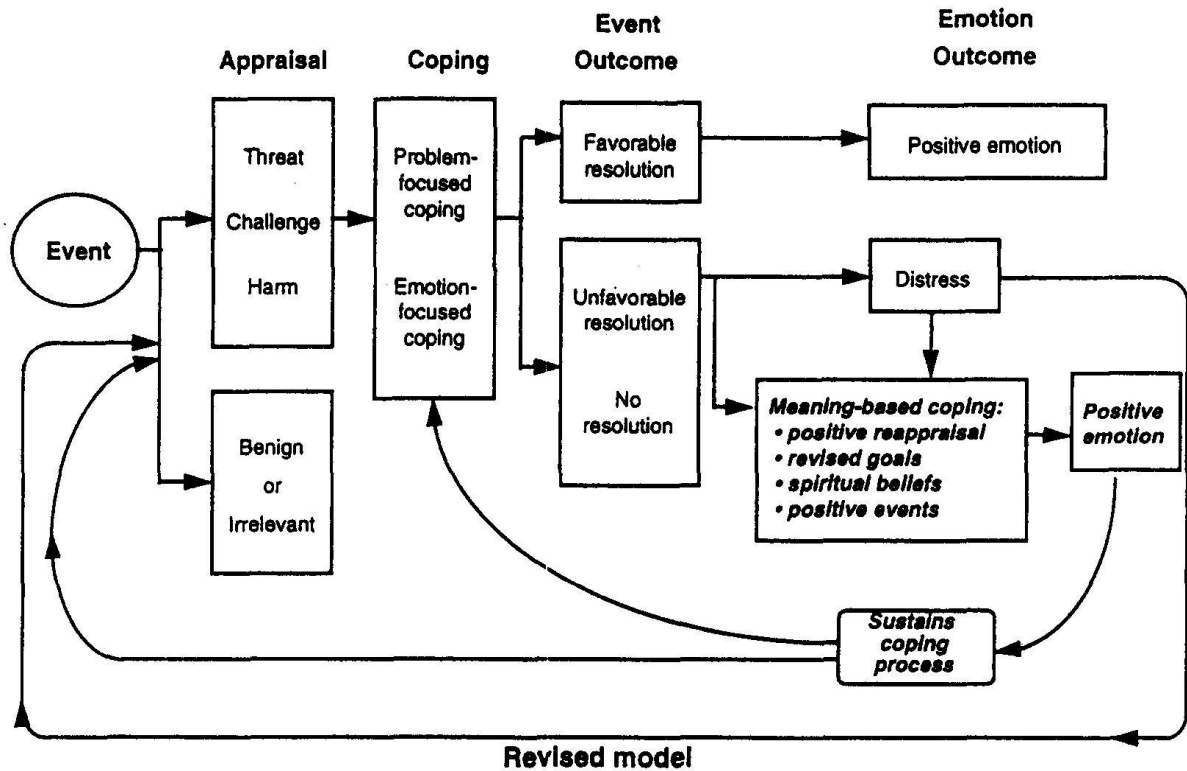


Figure 1. Folkman revised model of coping, which integrates meaning-based coping. The model demonstrates coping responses to events. Problem-focused, emotion-focused, and meaning-based coping are depicted and the relationships between different coping approaches and emotional outcomes are illustrated.

Note. From: Folkman, S. (1997). Positive psychological states and coping with severe stress. *Social Science & Medicine*, 45, 1207-1221. Permission by Elsevier.

Sources of Online Social Support

Multiple sources and sites of online social support will be discussed in this section. Online social support can take a number of different forms, ranging from highly structured formal supports (e.g., scheduled support groups) to informal sources of support (e.g., individual blogs about cancer). Some online cancer-related social interactions are facilitated by professionals, whereas most interactions between individuals are unmoderated. Online social interactions may be scheduled and “closed” (i.e., consisting of a pre-established group of members) or spontaneous and variable in terms of participants. Furthermore, online social interactions can be synchronous or asynchronous. Synchronous online interactions occur when all individuals are present online at the same time (such as a scheduled online support group meeting), whereas asynchronous communication allows individuals to read and respond at different times (e.g., reading blog posts and leaving comments, reading and posting on cancer-related message or discussion boards).

Support groups. Online support groups are defined in a variety of ways, depending on the sponsor. Often support groups are offered via cancer-related organizations. Some support groups are message/discussion forums in which members post concerns, comments, and questions and respond to each other. Other online support groups are synchronous, chat-based forums (e.g., OncoChat at <http://www.oncochat.org/>). Finally, some online support groups are facilitated by professionals (e.g., The Wellness Community’s Group Loop for teens;

<http://www.grouploop.org/content/osg.facilitator.asp>). The content and nature of the group will depend on the specific format and topic of each group.

Blogs. Blogs, or weblogs, have become an increasingly common means for individuals to post personal narratives and communicate with others. Originally more common as a way for individuals to provide information and photos to persons in their intimate circles, blogs have expanded and a culture of blogs has developed. There are now professional bloggers who receive advertising revenue. In addition, one can subscribe to various blogs and blogs are used as organizational and institutional tools. Individuals posting about their individual life experience receive comments and feedback from a broad audience. During the 3 days following a *60 Minutes* interview with Elizabeth Edwards in 2007 about her breast cancer recurrence, more than 1,000 comments were posted on the show's blog (Carr, 2008).

Chung and Kim (2007; 2008) report that of 120 million adults in the United States with Internet access, 7% (8 million) have created blogs. In 2008, the Pew Internet Project reported that 33% of Internet users, or over 50 million Americans, read blogs (Smith, 2008). Blog readership grew from 17 to 27% in 2004.

Heiferty (2009) emphasized the unique aspects of blogs as being unsolicited writing and interactive. Heiferty described the assumption that “writing, reading, and responding to blog entries may serve to diminish suffering, manage the uncertainty inherent in illness, create connections, empower readers, and influence the (re)formulation of identity of those involved” (p. 1542).

Discussion forums. Discussion forums and message boards may serve the function of a support group, as described earlier, or they may be a more casual source of

information exchange. Many discussion forums and message boards are located on the websites of cancer services organizations. Some sites only allow registered users to post and read discussion threads, whereas other sites allow anonymous posts and are publicly available. Some discussion forums are moderated or monitored by health professionals, but the vast majority of forums are patient-led and self-sustaining. Discussion topics range from advice related to treatments to relationship issues to cancer-specific questions. Typically these discussion forums involve asynchronous interactions amidst a group of individuals. Some individuals post regularly, whereas others may post only once to a forum.

Online communities. These communities vary in terms of size, function, and resources. Examples of online communities include PlanetCancer, which is a community of young adults with cancer (www.planetcancer.org), The Wellness Community, which has an online community to complement its physical locations (www.thewellnesscommunity.org), and MyCancerPlace, which provides multiple resources, including free web pages for its members (www.mycancerplace.com). These online communities may provide structured support groups, but they typically offer a combination of resources, including discussion boards, options to create a website, and health information.

Hubs. Cancer-related hubs aim to provide a central location or clearinghouse for information and resources from many sites. These hubs may be organized based on a specific cancer site, geographic region, or demographic characteristic (e.g., women with cancer, adolescents). Often these hubs are organized or managed by a cancer services organization (<http://www.swpho.nhs.uk/skincancerhub/>).

Health information sites. According to the Pew Internet and American Life Project (2003), more than 80% of Internet users in the United States have searched for health information online. Some cancer-related websites have a sole or primary purpose of providing cancer-related health information. These sites are often sponsored by government agencies, non-governmental organizations, or pharmaceutical companies. Examples include www.cancer.gov by the National Cancer Institute and the Cancer Information Network developed by a group of physicians (www.cancerlinksusa.com/). In a cross-sectional survey of 261 Dutch cancer patients' Internet usage, patients reported that they preferred to get reliable information from their oncologists' websites, hospital websites, or the Dutch Cancer Society site. However, they mentioned websites financed and maintained by pharmaceutical companies most frequently as a source of information.

Characteristics of Individuals Using the Internet for Social Support Related to Cancer

Several articles have attempted to describe demographic, personality, and other variables that are associated with Internet use for cancer-related information and communities. Some sites are designed for use by family members, partners, and caregivers of individuals with cancer, but this study and literature review focus primarily on individuals with cancer who use the sites. In a content analysis of posts on a U.S.-hosted breast cancer and a prostate cancer Internet bulletin board, 77% of overall posts were from patients (significantly more patients posted in the breast cancer forum than the prostate cancer forum; Blank & Adams-Blodnieks, 2007). In a sample of British adults who had been diagnosed with prostate, testicular, breast, cervical, or bowel cancer, women with breast cancer were the highest users of the Internet (Ziebland et al., 2004).

In their study of Dutch cancer patients, van de Poll-Franse and van Eenbergen (2008) found that high education, high socioeconomic status, and younger age were all independently associated with Internet use. In their content analysis of postings in an online breast cancer community (location of women unknown), Rodgers and Chen (2006) identified the average user as a married 46-year-old woman with a professional occupation. Other studies found similar demographic profiles (Beaudoin & Tao, 2007; Idriss, Kvedar, & Watson, 2009; Salzer et. al, 2009). In addition, Rodgers and Chen make the point that it is important to compare current users of online cancer communities to each other in addition to comparing current and non-users. They identified significant differences among light, medium, and heavy Internet users, specifically a significant correlation ($r = .212$; $p = .035$) between frequency of posts and improvement in mood over time.

Kim and Chung (2007) used cluster analysis to identify profiles and patterns of U.S. cancer blog users. They identified three clusters of users ($N = 131$): (1) An older group consisting of “new bloggers who were motivated to seek compiled information and were frequent online information seekers” (p. 447); (2) A group divided evenly between individuals with cancer and friends/family members described as “long-time cancer blog users who also use traditional sources for information seeking” (p. 448); (3) A “highly motivated group” seeking medically related information who “made the most frequent behavioral changes while using cancer blogs” (p. 448).

Although there is limited information available about who uses online sources of social support and online communities, there is no consensus about who benefits most from this support. In a study of individuals visiting a site for women (presumed to be in

the U.S.) who had hysterectomies, no demographic variables predicted either general social support or the most helpful type of perceived support (Bunde, Suls, Martin, & Barnett, 2006). Bunde and colleagues (2006) suggested that patients who have low general social support may lack the awareness or access to Internet support; therefore, it is difficult to know who else could benefit from online social support.

Through the limited literature to date on characteristics of individuals with cancer using the Internet for social support, we know that middle-aged Caucasian women with cancer who have higher education and socioeconomic status tend to use the Internet most. Beyond these demographic variables, it appears that specific purposes or functions attract different types of individuals to use the Internet for cancer-related purposes. In addition to knowing more about who uses the Internet for cancer-related support, it would be helpful to understand more about who uses the Internet for specific purposes, what types of support are received online, and who benefits from which forms of support online.

Functions, Benefits, Challenges, and Nascent Theories of Online Cancer

Communities

The existing literature regarding online cancer-related communities describes a variety of benefits, challenges, and functions associated with participation in these communities. Chung and Kim (2008) suggest that individuals have varying reasons for using different types of media, and that different Internet resources may serve different functions for individuals.

Several authors have articulated potential advantages of online support. Rains and Young (2009) emphasized the convenience and accessibility of computer-mediated support groups, stating that they are always available and do not require an individual to

report to a location at a specific time. Sharp (2000) described several unique potential advantages and disadvantages of the Internet as a source of support for individuals with cancer. He suggested that the relative anonymity may allow for less fearful discussion, which was echoed by Rains and Young. In addition, the Internet affords an individual the opportunity for immediate feedback that he or she is not alone. Finally, the Internet allows for the development of alternative communities without geographic restrictions. Sharp described the following disadvantages of Internet use for cancer-related support: (1) Information flows freely and unverified on the Internet, which may contribute to the spread of misleading or inaccurate information; (2) Unsupportive interactions can occur online (though this is not unique to the Internet); and (3) The relative anonymity may also contribute to predatory behavior and lead to some individuals trying to take advantage of individuals with cancer seeking support.

Functions. Among Dutch cancer patients (van de Poll-Franse & van Eenbergen, 2008), the most commonly reported use of the Internet by cancer survivors was to find health-related content. Half of the sample used the Internet for community, but they identified emailing family and friends as the primary community function. Nineteen percent of the sample reported that they would use the Internet in the future to chat with other cancer survivors. In the study by Ziebland and colleagues (2004), the functions of Internet use varied based on the phase of treatment or time since diagnosis. Patients tended to use the Internet for social support immediately after diagnosis and during long-term follow up. At other times (e.g., during treatment and short-term follow up) they tended to use the Internet to seek information. Reported functions of Internet use for social support in this sample were: to tackle isolation, to find alternative treatments, to

access experiential knowledge, to make social connections, and to raise awareness about cancer. Finally, individuals mentioned therapeutic benefits of Internet use (Ziebland et al.).

Chung and Kim (2008) focused on blogging activity of cancer patients and their companions. They identified gratifications and functions of Internet usage from a social-psychological perspective. Participants reported that blogging was most helpful for emotion management and information-seeking. Chung and Kim reported mean gratification scores, and the highest mean gratification scores were for the following functions: help expressing cancer-related frustrations, help coping with cancer, learning new information, and feeling empowered. Bunde and colleagues (2006) reported that 61% of individuals visiting a site for women who had hysterectomies used the site for informational/advice support, and 31% used the site for emotional support.

Høybye, Johansen, and Tjørnhøj-Thomsen (2005) found that their participants used their breast cancer support group for storytelling related to their social isolation and medical treatment, and that these women were searching for versions of their own stories. They recommended that Internet communities “be viewed as complementary to other actions rather than opposing them” (p. 217). Analyses of postings on cancer-related bulletin boards revealed that the most common category of posts were related to support, and the second most common category of posts was comprised of posts related to medical issues and treatment (Blank & Adams-Blodnieks, 2007).

Dickerson, Boehmke, Ogle, and Brown (2006) identified five themes among interviews with individuals with cancer who used the Internet for information and support. These themes reflected different functions of Internet use: (a) retrieving and

filtering information; (b) seeking hope in new treatment options; (c) self-care; (d) empowering patients; and (e) using the Internet for peer support. A woman who started a log of her illness and treatment on the Internet described her motivations for doing so:

I'm giving up my medical privacy...but if it helps one person not to go into a panic when they hear they have cancer, and not to go into a panic when they communicate with their doctor, and have the chutzpah to say, 'This is my life and I'm going to do something about it,' then it's worth it (Landro, 1999, p. 60).

Landro described extensive anecdotal evidence that a primary motivation for patients developing and providing online resources related to cancer is the desire "to light the path for others (p. 60), which is consistent with other findings that individuals seek to give and receive support online (Owen et al., 2005).

Researchers have explored functions of Internet support for other disease groups. A study of users of an online support site for individuals with psoriasis revealed that key factors for individuals were the availability of resources, access to good advice, and the lack of embarrassment when discussing personal issues (Idriss, Kvedar, & Watson, 2009). In a content analysis of posts in a Huntington's disease online support group, 56% of total posts provided informational support, and 52% of posts provided emotional support (Coulson, Buchanan, & Aubeeluck, 2007). Less than 10% of posts provided some form of tangible assistance. These authors also included a category of network support, defined as "communicating belonging to a group of persons with similar concerns or experiences" (p. 175). Forty-eight percent of the posts in the Huntington's group provided network support. Fernsler and Manchester (1997) found similar results in individuals with cancer, who reported seeking contact with others in similar situations.

Benefits. In a study of 175 adults with cancer, Ziebland and colleagues (2004) identified privacy, 24-hour access, and the lack of embarrassment as distinct and appealing characteristics of the Internet. Participants used the Internet strategically to “covertly question their doctors’ advice and to display themselves (to researchers, friends, family, and health professionals) as competent social actors despite serious illness” (Ziebland et al., p. 565). In a study of Dutch cancer patients, individuals who used the Internet to seek information believed they were better informed about cancer (van de Poll-Franse & van Eenbergen, 2008).

Rodgers and Chen (2006) performed a longitudinal content analysis of more than 33,000 postings in an online breast cancer support community. In examining the “life stories” of 100 women, the authors identified a number of psychosocial benefits associated with participation in this community, including optimism related to breast cancer, increased coping skills, improved mood, decreased psychological distress, increase in strategies to manage stress, and receiving/giving social support. Forty-seven percent of individuals benefited from seeking social support, whereas 56% benefited from giving social support. In a concept analysis of illness blogs, Heiferty (2009) identified a number of positive and negative consequences. In addition to those mentioned by other researchers, the positive consequences included enhanced communication and diminished isolation. Fogel and colleagues’ (2002) findings echoed these findings in an interview study of women with breast cancer. After controlling for demographic covariates, they found that women who used the Internet for breast health reported greater overall support than those women using the Internet for general purposes. Women using the Internet for breast health issues also reported a greater sense

of belonging, lower levels of loneliness, and higher appraisal social support than those using the Internet for general purposes.

In a phenomenological study of women with cancer, participants reported that Internet use assisted them in “discovering ways to live with cancer as a chronic illness versus as a death sentence” (Dickerson, Boehmke, Ogle, & Brown, 2006, p. E11). Furthermore, Internet use encouraged patients’ desire for involvement in decisions about their care.

Gender differences have emerged in the benefits and functions of online communities and source of support. Sullivan (2003) reported that women in an online ovarian cancer support group emphasized positive communication and support. Overall, these women described the group as optimistic. Exchanges on a prostate cancer support site consisted mostly of information sharing. In addition, more physicians who were not patients posted in the prostate cancer group.

Rains and Young (2009) conducted a meta-analysis of 28 studies of formal computer-mediated support groups (CMSGs). This paper is not cancer-specific but is focused on health-related outcomes. These CMSGs are formal group programs facilitated by professionals and consist of educational and support components. Rains and Young explored social support, depression, quality of life, and self-efficacy, reporting previous results in these areas as a result of CMSGs. Criteria for inclusion in this meta-analysis required that studies target a health condition, provide computer-mediated interaction, provide education, have closed membership with a fixed start and end date, and meet statistical reporting requirements. Across the studies, CMSG participants demonstrated greater social support, decreased depression, and improved quality of life

after the CMSG intervention than at baseline. These findings are not conclusive, but they do provide support for the benefits of participation in online support groups.

Challenges. Numerous studies have identified concerns or challenges of Internet usage by individuals with cancer. The issue of veracity or the need to “double-check” information received on the Internet has been described (Chung & Kim, 2008; Ziebland et al., 2004). Participants also mentioned that they felt there was too much information to process (Ziebland et al., 2004) and some authors recommend providing training to patients to filter information online (Chung & Kim, 2008). British adults who had been diagnosed with cancer noted in Ziebland and colleagues’ study (2004) that information on the Internet was “too bossy” for the British.

In a study of 15 Scandinavian women participating in an Internet breast cancer support group, Høybye, Johansen, and Tjørnhøj-Thomsen (2005) reported the “absence of a physical dimension to a conversation can lead to misunderstandings and potentially harmful situations” (p. 218). A study of bloggers identified the limited interactivity, or the “interaction at one-remove” provided by blogs (Nardi, Schiano, Gumbrecht, & Swartz, 2004, p. 46). Blogging was perceived as less intrusive and involving “less overhead” than other forms of Internet communication. From this perspective, other forms of Internet communities may be perceived as difficult to maintain or time-consuming. Furthermore, bloggers are “acutely aware of their readers... calibrating what they should and should not reveal (Nardi et al., 43). Whereas this encourages caution, it may be more challenging than less formal social interaction. Negative consequences of blogs identified by Heiferty (2009) included hurt feelings, skewed perceptions, strained relationships, and time away from loved ones.

Owen and colleagues (Owen et al., 2005) evaluated an online intervention targeting support and coping skills. Using a randomized, controlled design, the authors assigned 62 women diagnosed with Stage I or II breast cancer to a self-guided coping skills training and support intervention provided online or a wait-list control group. The online intervention lasted 12 weeks and consisted of self-guided coping skills practice, participation in a discussion board with a small group of other participants, and educational information presented on web pages. There were no specified guidelines for frequency or intensity of participation, but 39 prompts were sent to participants over the course of the 12 weeks as reminders. Outcomes of this study included health-related quality of life, psychological distress, and physical well-being. No significant direct effects were observed for this intervention on the primary outcomes, although the investigators observed “trends toward greater improvement in emotional well-being for treatment relative to control participants” (Owen, p. 61). The investigators also explored quality of participation (as measured by linguistic analyses) and found relationships with psychosocial variables, but those analyses were outside the scope of the intervention. Of note is the fact that the final sample in this study represents less than half of the patients initially contacted for the study, and it is difficult to know to what extent selection bias might have affected this study. This pilot trial did not demonstrate statistically significant results for primary outcomes, but it does provide some information about the feasibility and potential implementation of online support interventions.

In a randomized, controlled study of Internet peer interactions, Salzer and colleagues (Salzer, Palmer, Kaplan, Brusilovsky, Ten Have, & Hampshire, 2009) assigned 78 women recently diagnosed with Stage I or II breast cancer to an unmoderated

Internet peer support group (listserv) or an Internet-based educational control (reviewing information on a cancer-related website). The investigators administered questionnaires at baseline, 4 months, and 12 months. However, they did not report the frequency, consistency, or duration of participation in the peer support group.

In this study, small to moderate (but not statistically significant) effect sizes were found that were contrary to hypotheses (Salzer et al., 2009). Whereas investigators hypothesized that women in the support group would show decreased distress and increased quality of life, women in the intervention tended to do worse on these outcomes. However, despite this increased distress, 60% of women felt supported and satisfied by the group. Furthermore, 16 participants created another group to remain in contact with each other after the conclusion of the study (Salzer et al.). The authors suspected that the lack of long-term survivors in the intervention group may have contributed to the results. They concluded that Internet peer interactions may not be universally beneficial. They suggested that we must understand the relative effectiveness of different types of groups (based on content and structure).

Nascent Theories of Online Social Support

As described in this chapter thus far, a number of studies have attempted to identify and describe the benefits and effects of online interactions, and several studies have explored the effects of online interventions. These results assist us in beginning to understand how online social support may differ from or be similar to traditional social support. However, the theoretical literature on the topic is virtually nonexistent. To date, only one author has attempted to articulate a theory of online social support (LaCoursiere, 2001). This theory will be described later in this section. Calls have been made in the

last decade to link research on online support to broader theoretical frameworks (Wright & Bell, 2003).

There are many possible reasons for the dearth of theoretical writing in this area. First, the nature of the study of online interaction crosses multiple disciplines. Computer science, informatics, sociology, psychology, medicine, and nursing all have an interest in the ways in which people use the Internet for support and interaction. Each of these fields has its own approach to the topic and variables of interest. Currently the empirical work in this area is spread across disciplines, and a body of research has not been amassed yet. It is also possible that the current state of research does not warrant the development of theoretical models, either because there is not enough information or because traditional theories of social support are appropriate to apply to online social support. However, we do not have sufficient information about the mechanisms or effects of online social support to compare it to traditional social support.

Heiferty (2009) began to describe a theory of online communication in illness, but this paper focused more on the narrative process of writing. Heiferty defined theoretical and operational terms and identified motivations, attributes, and consequences of writing illness-related blogs. However, this paper is limited to illness blogs and does not encompass the myriad other interactive online experiences.

LaCoursiere offered her theory of online social support in 2001 from a nursing perspective. It appears that her theory is the only stand-alone theory published to date, and it has not been cited widely. This computer-mediated communication model of online support, the social identity and deindividuation (SIDE) model (LaCoursiere, 2001; Spears & Lea, 1994), attempts to explain online support. This theory proposed that the

context of online communication leads to normative behaviors and egalitarian participation in a setting in which social differences are eliminated (LaCoursiere, 2001). Whereas this model does address online communication and support, it is borne of a very different conceptual and theoretical base from psychological theories of social support.

LaCoursiere (2001) argued for the need for a theory of online social support that was more integrative and comprehensive than the computer-mediated models. She attempted to incorporate psychological, sociological, and anthropological factors in her nursing theory of online social support, and described her model as multidisciplinary. She cited a long list of theorists who influenced her own theoretical development. She also emphasized an open systems perspective, which allows for “the potentiality and integration of current and yet unknown factors, as well as flexibility in current and future interpretive possibilities” (p. 66). Essentially, she designed her theory to be flexible enough to incorporate future findings. LaCoursiere began by defining the two primary concepts of her theory. The first concept is online social support, and the definition offered is:

the cognitive perceptual, and transactional process of initiating, participating in, and developing electronic interactions or means of electronic interactions to seek beneficial outcomes in health care status, perceived health, or psychosocial processing ability. It incorporates all components of traditional social support, with the addition of entities, meanings, and nuances present in a virtual setting, and unique to computer-mediated communication (p. 66).

Online support is further described as a dynamic and fluctuating process. This definition is useful as a global conceptualization, but it is somewhat vague in that it does not define the “entities, meanings and nuances” of virtual settings, nor does it address the unique aspects of online communication. LaCoursiere proceeded to define linking as

“the conscious or unconscious process of relating and weaving emerging awareness to previously learned thoughts or information” (p. 67). She asserted that this process of linking leads to insights about the self in relation to others and the self related to self. She likens the process of linking to the development of a database in which information is stored, linked, understood, and retrieved. The end result is that “individuals form their own personal meaning of the online social support experience” (p. 68).

LaCoursiere (2001) described four sections of her online social support theory. First, initiating events are those events that lead a person to seek support online (e.g., illness). Next, mediating factors affect those initiating events. Mediating factors include health factors (such as diagnosis), demographic factors (such as age or gender), perceived individual factors (such as stress, coping, stigma), and Internet use factors (such as history and pattern of Internet use). These factors are hypothesized to mediate the relationship between the initiating event and support-seeking behavior. The third section of her theory details three filters of online social support: (a) the perceptual filter, or the emotional state of the support-seeking individuals; (b) the cognitive filter, or the intellectual processing of an individual; and (c) the transactional filter, which “represents an evaluation of all information received through electronic support interchanges” (p. 69). The fourth and final section of the theory concerns outcomes of online social support, and LaCoursiere cited three processes that define these outcomes: (a) support mediation, (b) information processing, and (c) evaluative functions. However, she does not describe fully the role of these processes. She attributed quantitative outcomes of online social support (e.g., changes in quality of life, increased hope) to support

mediation and information processing but did not adequately described the qualitative outcomes.

LaCoursiere (2001) proposed ways in which her theory could be implemented and methods of measuring various aspects and processes in the theory. She described her theory as holistic. Unfortunately, this theory is somewhat confusing, and the visual depiction of LaCoursiere's model is multifaceted and difficult to interpret. The theory is a useful model for how to begin to conceptualize the elements of online social support and how it differs or resembles traditional social support, but it is clear that far more work must be done to understand online social support theoretically. In order to articulate a theory of online social support or to understand online social support in the context of traditional social support theories, we must gather more data about these two types of social support. In the absence of a fully articulated psychological theory of online support, Folkman's theory of social support was used as the basis for this study.

Rationale and Purpose of Study

Despite methodological and conceptual issues debated in the literature on social support and cancer, we have learned a great deal about the positive effects of social support on adjustment to and coping with cancer. There is a strong and growing literature on the relationships between socially supportive interactions and other psychosocial variables. Concurrently, there is a rapidly growing body of literature on the use of the internet for health information, health communication, and support as well as an explosion of online resources and communities for individuals with cancer. However, to date there has been little research on how online social support compares to proximal social support. Several online interventions have been evaluated, but the nature and

structure of online social support has not been explored systematically, nor have relationships between online and offline support. We do not know if the same types of social support are sought or are found to be helpful in the same ways online as they are offline. The present study is a preliminary exploration of some of these questions.

The purpose of this study was to examine the differences and similarities between social support received online and social support received offline among people diagnosed with cancer who use the Internet for cancer-related to support. Specifically, the study first compared types of support received online and offline, with specific differences predicted. Second, the study explored the differences between the level/degree of unsupportive social interactions experienced online versus offline. Third, based on the existing literature on social support and drawing upon Folkman's (1997) theory, the present study explored relationships between online social support and other psychological variables, including health-related quality of life, coping, and positive affect. The study explored how relationships between online social support and these psychological variables compare to the relationships reported between traditional social support and psychological well-being. Overall, this study aimed to contribute to the literature on social support received online by individuals with cancer through two primary aims: (1) comparing online (distal) social support to offline (traditional or proximal) social support, and (2) conducting a systematic exploration of the characteristics and potential benefits of online social support.

Research Questions and Hypotheses

Research aim 1. To compare reports of social support received online to social support received offline.

Hypothesis 1. There will be significant differences between the extent and types of social support received online and social support received offline. Predicted differences in types of support and research questions follow.

Hypothesis 1a. Overall, received social support is expected to be higher offline than online.

Hypothesis 1b. Informational support will be higher online than offline.

Research question 1. Are there significant differences between emotional support online and offline?

Research aim 2. To compare reports of unsupportive interactions online to reports of unsupportive social interactions experienced offline.

Hypothesis 2. Participants will report experiencing fewer unsupportive interactions online than offline.

Research aim 3. To compare the relationships between social support received online and psychological variables to those relationships observed between offline social support and psychological variables. The first step was to examine the relationships found between traditional social support and psychological variables in other studies. Associations between traditional social support and indicators of well-being were tested. Associations between these same indicators of well-being and online social support were then tested.

Hypothesis 3a. Offline emotional support will be significantly positively associated with positive affect, health-related quality of life, and focusing on the positive.

Hypothesis 3b. Offline informational support will be significantly positively associated with focusing on the positive and negatively associated with avoidant coping.

Hypothesis 3c. Online emotional support will be significantly positively associated with positive affect, health-related quality of life, and focusing on the positive.

Hypothesis 3d. Online informational support will be significantly positively associated with focusing on the positive and negatively associated with avoidant coping.

Method

Participants

The amount of missing data and the number of incomplete surveys reduced the sample size considerably. One hundred ninety-two individuals completed some of the initial survey items about Internet use, but only 102 individuals actually completed all measures (with some missing items). The issue of missing data will be addressed further in Chapter 5; however, the sample used for analyses were the 102 individuals who completed the survey.

See Tables 1 and 2 for full information on the demographic and illness characteristics of the sample. The final sample consisted of 102 adult men and women who had been diagnosed with any type of cancer not included in the following statements about specific exclusions. Individuals with non-melanoma skin cancer were excluded because it was expected that the issues faced by individuals with these forms of very treatable cancer would be quite different from the rest of the population. Participants had to be at least 21 years of age, able to read English, and able to give informed consent. Participants must have participated in online cancer-related communities. Participation was defined specifically to allow for the whole range of participation. A time limit was

not established because individuals vary widely in how much time they spend online, how many tasks they undertake simultaneously, and how quickly they accomplish their goals online.

The mean age of the sample was 42.63 years ($SD = 13.71$), ranging from 21 to 69 years old. There were eight males and 92 females (two participants did not indicate gender). Most of the participants identified as Caucasian ($n = 86$; 84%). Four participants identified as African American (4%). Two participants identified as Asian/Pacific Islander (2%), three participants (3%) identified as American Indian, and one participant identified as “other.” Four participants (4%) did not indicate their racial/ethnic background. Sixty-six participants (65%) reported their relationship status as married or partnered, 18 participants reported being single (18%), 10 participants described their relationship status as dating (10%), five participants indicated they were divorced or separated (5%), one participant disclosed they were widowed (1%), and two participants did not indicate relationship status. In terms of living arrangements, 49 participants (48%) reported that they lived with a spouse or partner only, 17 participants (17%) reported living alone, 16 participants (16%) lived with a spouse/partner and children, five participants (5%) lived with other family, four participants (4%) lived with non-family, three participants (3%) lived with children only, and five participants reported living in other configurations (e.g., spouse and other family, spouse and non-family). Three participants did not provide information about living arrangements.

Participants identified with a variety of religious backgrounds and affiliations. Twenty-six participants (26%) identified as Catholic, 25 participants identified as Protestant/Other Christian (25%), 16 participants (16%) identified as atheist or agnostic,

seven participants (7%) identified as Jewish, four participants identified as Unitarian specifically, and nine participants defined their religious affiliation as Other (including pagan, Church of Latter Day Saints, and not specified). Five participants did not provide a religious affiliation. Forty-seven participants had a college degree (46%), 28 participants had earned a graduate or professional degree (28%), 16 participants had attended some college (16%), six participants had earned a high school diploma or a GED (6%), one participant had attended a trade/business school, and four participants did not provide their educational background. Forty-two participants (41%) indicated that they were employed full-time at the time they completed the survey, 21 participants (21%) were employed part-time, 30 participants (29%) were unemployed, and seven participants (7%) indicated they were retired.

Participants were diverse in terms of their type of cancer. The most common cancer sites were breast ($n = 36$; 35%), gynecologic ($n = 14$; 14%), and non-Hodgkin Lymphoma ($n = 10$; 10%). Six participants (6%) reported being diagnosed with Hodgkin Lymphoma, six (6%) indicated they were diagnosed with thyroid cancer, five (5%) were diagnosed with bone cancer, five (5%) reported being diagnosed with leukemia, three (3%) indicated they were diagnosed with brain cancer, and three (3%) were diagnosed with colorectal cancer. The remaining diagnoses included lung cancer ($n = 2$; 2%), head and neck cancer ($n = 2$; 2%), prostate cancer ($n = 2$; 2%), melanoma, appendix cancer, bile duct cancer, and testicular cancer (one participant, or 1%, each).

Eighty-four participants (82%) indicated that this was their first diagnosis of cancer, and 16 participants (16%) reported that it was not their first diagnosis of cancer. Two participants did not respond to this question. The most common combination of

treatment among the study's participants was a combination of surgery, chemotherapy, and radiation ($n = 34$; 33%). Twenty-one participants reported receiving undergoing surgery and chemotherapy (21%), 13 participants (13%) underwent surgery and radiation, and 13 participants (13%) reported undergoing surgery only. The number of months since diagnosis ranged from 1 month to 252 (21 years), and mean time since diagnosis was 38.81 months ($SD = 41.10$). Many participants reported that their spouse or partner served as their main support person ($n = 62$; 61%), 17% ($n = 17$) indicated the most important support came from a friend, 10% ($n = 10$) reported that their main support person was a parent, 5% ($n = 5$) noted that their main support person was a sibling, and 4% ($n = 4$) reported that their main support came from a child. Four participants (4%) indicated that their main support came from someone else (not specified).

Table 1

Demographic Characteristics of Participants

Variable	<i>N</i>	<i>n</i>	%	<i>M</i>	<i>SD</i>	Sample Range
Age	97			42.63	13.71	21-69
Months since diagnosis	98			38.81	41.10	1-252
Days per week visiting cancer-related websites	89			3.12	2.02	1-7
Gender	102					
Male		8	8			
Female		92	90			
Missing		2	2			
Racial/ethnic background	100					
African American		4	4			
White/Caucasian		86	84			
Asian American/Pacific Islander		2	2			
American Indian		3	3			
Other		1	1			
Missing		4	4			
Religious background/affiliation	92					
Catholic		26	26			
Protestant/Christian		25	25			
Atheist/Agnostic		16	16			
Jewish		7	7			
Unitarian		4	4			
Other (including Pagan, Latter Day Saints, not specified)		9	9			
Missing		5	5			
Relationship Status	102					
Married/Partnered		66	65			
Single		18	18			
Dating		10	10			
Divorced/Separated		5	5			
		50				

Table 1(continued)

Variable	<i>N</i>	<i>n</i>	%	<i>M</i>	<i>SD</i>	Sample Range
Widowed		1	1			
Missing		2	2			
Education completed	102					
High school/GED		6	6			
Trade/business school		1	1			
Some college		16	16			
College degree or higher						
College degree		47	46			
Graduate degree		28	28			
Missing		4	4			
Employment	102					
Employed full-time		42	41			
Employed part-time		21	21			
Unemployed		30	29			
Retired		7	7			
Missing		2	2			
Living Arrangements	102					
Live with spouse/partner only		49	48			
Live alone		17	17			
Live with spouse/partner and children		16	16			
Live with other family		5	5			
Live with non-family		4	4			
Live with children only		3	3			
Other (including spouse and other family, spouse and non-family)		5	5			
Missing		3	3			
Hours spent online per day	102					
Less than 30 minutes		5	5			
30-60 minutes		17	17			
1-2 hours		30	29			
2-3 hours		18	18			
3-4 hours		11	11			
4-5 hours		6	6			
5-6 hours		6	6			
More than 6 hours		9	9			

Table 2

Illness Characteristics of Participants

Variable	<i>N</i>	<i>n</i>	%
Type of Cancer	100		
Breast		36	35
Gynecologic		14	14
Non-Hodgkins Lymphoma		10	10
Hodgkins Lymphoma		6	6
Thyroid		6	6
Bone		5	5
Leukemia		5	5
Brain		3	3
Colon/Rectal		3	3
Lung		2	2
Head and Neck		2	2
Prostate		2	2
Melanoma		1	1
Appendix		1	1
Bile duct		1	1
Testicular		1	1
Missing		2	2
First Diagnosis of Cancer	102		
Yes		84	82
No		16	16
Missing		2	2
Type of Treatment	102		
Surgery only		13	13
Chemotherapy only		7	7
Radiation only		1	1
Biotherapy only		1	1
Surgery and radiation		13	13
Surgery and chemotherapy		21	21
Radiation and chemotherapy		3	3
Surgery, radiation, and chemotherapy		34	33
None		1	1
Other combination treatment		5	5
Missing		3	3

(continued)

Table 2 (continued)

Variable	<i>N</i>	<i>n</i>	%
Main Support Person	102		
Spouse/Partner		62	61
Father/Mother		10	10
Friend		17	17
Son/Daughter		4	4
Brother/Sister		5	5
Other		4	4

For this study, when conducting hierarchical regression equations that had one covariate and four predictor variables, with 97 participants and alpha set at .01, power was calculated to be .72 to detect an effect size of .15 (medium effect size; Cohen, Cohen, Aiken, & West, 2003). For the hierarchical regression equations that had one covariate and one predictor variable, 80 participants and alpha set at .01, power was calculated to be .78 to detect an effect size of .15.

Procedure

Approval was obtained from the Massey Cancer Center Protocol Review and Monitoring System (PRMS) and the Virginia Commonwealth University Institutional Review Board to recruit individuals with cancer in the following ways. Participants were recruited primarily through online contact. The investigator contacted cancer centers, cancer blog authors, cancer networks, cancer resource websites, online cancer support groups, and cancer-related organizations to request assistance with recruitment. In addition, Facebook was used to advertise and recruit for this study. To minimize the selection bias in this study, which is unavoidable in Internet research (Eysenbach & Wyatt, 2002), the investigator attempted to recruit from a diverse set of websites in terms of potential participants.

The investigator provided an e-flyer and email text to representatives of these groups to distribute to their members. This e-flyer described the study briefly and provided the hyperlink to the survey. Invitation letters were sent via email by representatives of the groups to potential participants, who could go to the website link to find out more information and enroll if desired. This email invitation also described

briefly the ways in which the investigator obtained email addresses for recruitment (i.e., the mailing list or organization used).

The survey was developed using the *Inquisite* 9.5 software and was hosted on VCU's survey server (<https://survey.vcu.edu>). The website was open only during the period of active recruitment. The initial screen of the website consisted of the following three elements: (a) a letter describing the study in greater detail, (b) an informed consent document, and (c) contact information for the investigator. The informed consent contained the following necessary elements of consent: (a) the purpose of the research; (b) risks, discomforts, and benefits of participation; (c) activities required to participate in the research; (d) description of participation as voluntary; (e) confidentiality of responses. After reading the consent document, participants were able to indicate consent and their voluntary participation in the study by selecting an opt-in radio button after the following statement: "By clicking the following button to enter the survey, you are agreeing to participate in this research."

Individuals who were contacted by e-mail were able to opt out of any further contact by contacting the study email address and requesting they not receive any further direct emails. The survey was designed so that individuals could skip questions they do not wish to answer and can stop participation at any time. As email invitations were mailed by organizations and participants were anonymous, it was difficult to ensure that participants did not receive multiple invitations via email. However, all efforts were made to avoid contacting individuals who had opted out. Individuals who consented to participate were eligible for a drawing of four \$25 gift cards.

Internet recruitment was most appropriate for this study, as the subject is Internet use and online experiences. Previous research suggests that the validity and reliability of web-based surveys is comparable to that of studies conducted offline (Eysenbach & Wyatt, 2002).

Recruiting participants online is very convenient but also poses potential human subjects risks. In Internet recruitment, the researcher may have minimal or no direct contact with participants. Furthermore, the process of obtaining consent is different in online data collection than in face-to-face recruitment. Often it is not feasible to obtain signed consent from the participant. The design of this study aimed to reduce some of these risks. Names were not collected as part of the survey study. Each participant's survey was assigned an identification number. There were two conditions under which participants were asked to provide their names or email addresses: (1) If participants wanted to receive information about the results of the study; (2) If participants were interested in entered into the drawing for gift cards. Beyond these two situations, participation in this study was anonymous. However, participants were informed that confidentiality and anonymity could not be guaranteed in Internet communication.

The safeguards and procedures outlined in this section were designed to address ethical issues raised and guidelines offered by previous publications on Internet survey research (Eysenbach & Wyatt, 2002; Wright, 2005) and a presentation to the VCU Institutional Review Board (Shickle, 2009).

Measures

Background questionnaire. This questionnaire gathered general demographic and background information about participants related to ethnicity, race, gender, age,

household composition, participation in offline support groups or other organized social outlets, employment status, relationship status, and cancer-specific information. See Appendix A for a copy of this measure.

Online Behaviors Questionnaire. This measure queried the extent of and time spent in the following online behaviors: (a) writing a blog or online journal about cancer, (b) reading blogs about cancer, (c) Participating in chat rooms/real-time support groups, (d) posting on cancer-related discussion boards, (e) seeking health information online, (f) spending time on social networking sites unrelated to cancer; (g) using the Internet for other purposes (e.g., entertainment, news, personal correspondence). The questionnaire also gathered information about total time spent online, reasons for Internet use, and technology used. See Appendix B for a copy of this questionnaire.

Center for Epidemiologic Studies Depression Scale. The Center for Epidemiologic Studies Depression Scale (CES-D, Radloff, 1977) has been widely used in clinical and community samples as a measure of depressive symptomatology. The CES-D is a 20-item self-report scale measuring symptoms such as loss of appetite, sleep disturbance, psychomotor retardation, and hopelessness. Instructions ask individuals to rate how frequently they have felt certain ways in the past week. Respondents must rate frequency on the following scale: scale of 1 = *rarely or none of the time*, 2 = *some or a little of the time*, 3 = *occasionally or a moderate amount of the time*, and 4 = *most or all of the time*. An example of an item on this scale is “I felt that I could not shake off the blues even with help from my family or friends.” The scoring of four positive items is reversed. The possible range of scores on the CES-D is 0 to 60, with higher scores indicating the presence of more depressive symptoms. Generally, scores above 16 are accepted as

indicating probable depression (Barnes & Prosen, 1984; Weissman, Sholomskas, Pottenger, Prusoff & Locke, 1977). Researchers have also identified a Positive Affect subscale of the CES-D (the four positively worded items that are typically reverse-scored for depressive symptoms; Sheehan, Fiefield, Reisine, & Tennen, 1995), which was used as the measure of positive affect in this study. Previous studies have used the reverse-scored values, so that lower scores indicate higher positive affect (Schroevvers, Sandermann, van Sonderen, & Ranchor). However, this researcher found that scoring to be potentially confusing. Therefore, the four items are scored in a positive direction and result in a possible range of 0-12, with high scores indicating higher levels of positive affect.

Radloff (1977) reported the CES-D yields scores that are internally consistent (Cronbach's alpha = .85). The CES-D also discriminates effectively between depressed and non-depressed individuals (e.g., Radloff, 1977) and exhibits convergent validity with other measures of depression. See Appendix C for a copy of the CES-D.

Ways of Coping—Cancer. The Ways of Coping—Cancer (WOC-CA, Dunkel-Schetter, Feinstein, Taylor, & Falke, 1992) is a 52-item questionnaire adapted from the Ways of Coping Inventory (Folkman & Lazarus, 1980; Lazarus & Folkman, 1984). The measure traditionally queries coping over the past 6 months. This time frame was retained, as the present study explored recent coping behaviors. The questionnaire first prompts respondents to select the cancer-related problem that has been most difficult or troubling in the past 6 months and to rate how troubling it has been. The respondent then answers a series of questions with the stem, "How often have you tried this in the past 6 months to manage the problem circled above?" Individuals must respond on a scale from 0 to 4, with 0 = *Does not apply/Never* and 4 = *Very often*. A sample item is "Went on as

if nothing were happening.” The original study revealed the following five factors: seek and use social support, focus on the positive, distancing, cognitive escape-avoidance, and behavioral escape-avoidance. Other studies have created emotion-focused and problem-focused coping composites from the original Ways of Coping (Folkman & Lazarus, 1985; Lilly & Graham-Bermann); however, these composites have not been evaluated in the WOC-CA. Furthermore, the lack of specificity about the problem-focused and emotion-focused coping renders these composites less useful. Manne and her colleagues (Manne, Paper, Taylor, & Dougherty, 1999) selected the Cognitive Escape/Avoidance and Behavioral Escape/Avoidance coping subscales to describe avoidant coping and used the Focus on the Positive subscale to describe positive reappraisal/creating positive meaning. They selected these subscales because of their relationships with psychological outcomes for cancer patients in a previous study (Manne, Sabbioni, Bovbjerg, Jacobsen, Taylor, & Redd, 1994). These scales correspond with the Avoidant and Positive Cognitive Restructuring factors of the four-factor model described in the literature review. These subscales were used in hypothesis testing in the present study.

In a study with women with breast or gynecologic cancer and their partners using the WOC-CA at four time points, internal consistency coefficients ranged from .87 to .96 (Scott, Halford, & Ward, 2004). Specific validity data have not been located. See Appendix D for a copy of the WOC-CA.

Functional Assessment of Cancer Therapy—General (FACT-G; Cella et al., 1993; see Appendix E). This measure assessed health-related quality of life. The FACT-G is a 27-item self-administered measure that uses a 5-point Likert rating scale ranging from 0 (*not at all*) to 4 (*very much*). The FACT-G and related subscales are reported to be

written at the 4th grade-reading level (Cella et al., 1993). The following subscales comprise the FACT-G: Physical Well-Being (PWB; 7 items); Social/Family Well-Being (SWB; 7 items); Emotional Well-Being (EWB; 6 items); and Functional Well-Being (FWB; 7 items). In the initial validation study, the internal consistency reliability estimate for the total scale score was .89, and subscale alphas ranged from .69 to .82. Temporal stability over 3-7 days for total score and subscale scores ranged from .82 to .92, and the measure demonstrated strong discriminant and construct validity (Cella et al., 1993). The measure correlated highly with other measures of functional quality of life, whereas correlations with measures of social desirability were low.

Inventory of Socially Supportive Behaviors (ISSB; see Appendix F). Social support received from others was assessed by the 28 items of the 40-item ISSB (Barrera, Sandler, & Ramsey, 1981). This scale is a measure of received support on which individuals rate how frequently they have experienced each of the supportive actions on this measure on a scale from 1 (*not at all*) to 5 (*about every day*). Several studies examined the dimensionality of the ISSB, and some authors have reported four factors or subscales (Stokes and Wilson, 1984), whereas others have reported a three-factor structure (Barrera, 2000; Haber, Cohen, Lucas, & Baldes, 2007). The three components were described as (a) emotional support (e.g., “Told you she/he feels close to you”); (b) tangible assistance and material aid (e.g., “Loaned you over \$25”); and (c) cognitive information, feedback, and clarification (e.g., “Told you what to expect in a situation that was about to happen. The instrumental support items were not included in this study as it was expected that few instances of instrumentally supportive behaviors would occur online. The other two subscales were kept intact. This measure was completed three

times: for online experiences, for offline experiences with the main support person, and for offline experiences with other friends and family.

Internal consistency coefficients ranged from .93-.94 in the development study (Barrera, Sandler, & Ramsay, 1981). In the same study, 2-day temporal stability was .88. ISSB total scores were significantly correlated with measures of other dimensions of social support (Barrera, Sandler, & Ramsay).

Unsupportive Social Interactions Inventory (USII; see Appendix G). The USII (Ingram et al., 2001) is a 24-item, self-report measure that asks participants how often they have received unsupportive behaviors from others regarding a specific stressor. To minimize participant confusion, a revised version of the scale modifies the wording of the response scale and asks participants to rate the items on a 4-point scale ranging from 0 (*never responds this way*) to 4 (*often responds this way*). The USII yields four subscale scores as well as a total unsupportive social interactions score. The four subscales are: (1) Distancing (e.g., “Did not seem to want to hear about my experience with cancer”); (2) Bumbling (e.g., “Seemed to be telling me what he or she thought I wanted to hear.”); (3) Minimizing (e.g., “Told me to be strong, to keep my chin up, or that I should not let it bother me”); and (4) Blaming (e.g., “In responding to me about my experience with cancer, this person seemed disappointed in me”). The total score is calculated by taking the mean of the individual’s responses across the 24 items. Responses for the total scale score can range from 0 – 4 with higher scores indicating more received unsupportive responses.

The measure was normed on an undergraduate college population, and in the initial study, the internal consistency reliability estimate for the total scale score was .86

(Ingram et al., 2001). A Cronbach's alpha of .89 was found in a study of women with cancer (Figueiredo et al., 2004). Ingram and colleagues reported that the USII scales were not associated with received social support scales, indicating that unsupportive interactions and social support are distinct constructs. This measure was completed three times: for online experiences, for offline experiences with the main support person, and for offline experiences with other friends and family.

After the survey was created and posted to the online server, it was piloted with several individuals ages 26 to 69. The initial round of pilot-testing included a measure of social support effectiveness. However, feedback from these individuals confirmed that it was a very confusing measure and extended the length of the survey significantly. Therefore, this measure was removed from the survey. The final version of the survey was piloted, and these individuals reported completing the survey in 27 to 37 minutes. Therefore, the introductory material for the survey estimated that it would take approximately 30 minutes to complete. Once the survey was launched for participants, several respondents provided feedback about completion time, which ranged from 15 minutes to an hour. One participant wrote to the investigator to complain about the length of the survey.

Results

This chapter presents the study findings in eight sections. First, the strategy for data analysis is described. The second section describes data entry, cleaning, and screening. Third, descriptive univariate statistics for the demographic and disease characteristics of the sample are presented. The fourth section provides descriptive statistics regarding the online behaviors and characteristics of the sample. The fifth

section provides descriptive analyses about the measures used in the study, including measures of central tendency, distributions, and internal consistency reliability. The sixth section describes results of bivariate analyses of relationships among the independent and dependent variables. The seventh section presents univariate and multivariate analyses corresponding to the research questions and hypotheses described in Chapter Three. In the final section exploratory analyses will be presented. All analyses were conducted using the IBM Statistical Package for the Social Sciences (SPSS) version 18.0 (SPSS, Inc., 2009, Chicago, IL).

Data Entry and Cleaning

Participants completed the survey online and data were stored by Inquisite Survey software. Therefore, no manual data entry was required and no errors in data entry were expected. Recoding of variables and preparation of scale score syntax was performed by the researcher. Scoring statements were reviewed and confirmed through spot-checking manual scale scores.

Missing Data and Errors

Before conducting analyses, the collected data set was inspected for errors. Missing item-level data were examined. As described in Chapter 3, there was a high level of missing data in the database, much of which was addressed by removing sparse surveys.

The investigator attempted to compare those who completed the survey with those who did not complete the survey. Unfortunately, most demographic information was missing for the non-completers because the demographic questions were located at the end of the survey per suggestions from other researchers. Therefore, completers and non-

completers could not be compared on age, gender, ethnicity, employment, or disease characteristics. Most non-completers responded to questions about Internet use and then did not respond to the structured questionnaires. Completers and non-completers were compared on the available Internet characteristics. There were significant differences between completers and non-completers on average hours per day of Internet use $\chi^2(2, n = 182) = 7.96, p = .019$. For these analyses, the categories for daily internet use were collapsed to create three categories: 1 (low Internet use: ≤ 2 hours per day, excluding email); 2 (medium Internet use: 2-4 hours per day, excluding email); and 3 (high Internet use: more than 4 hours per day, excluding email). More completers than non-completers were low Internet users. Completers ($M = 2.99$) and non-completers ($M = 3.00$) did not differ in terms of the number of days they used the Internet per week, $t(156) = -.031, p = .975$.

The final data set consisted of 102 participants. Missing data remained in the final database, particularly in measures of online support. It is suspected that some participants did not find these measures relevant or applicable to their experiences. However, there was no place in the survey to indicate why they did not complete these measures. A series of bivariate correlations were analyzed to explore whether there were patterns to the missing data in the final sample. Results of these analyses suggested that data were likely missing at random.

During data screening, items that had missing values were identified. Cases with more than 20% of data missing on a particular scale or subscale were excluded from analyses using that scale. If fewer than 20% of items were missing, the missing data were imputed using mean substitution based on the participant's scores on other items in

that particular scale. For 15 participants scores could not be imputed on the USII and subscales due to excessive missing data on this measure.

Pre-Screening

Prior to analysis, data were screened and the assumptions underlying multiple regression were explored. First, frequencies were inspected for the categorical variables to ensure that the minimum and maximum values for each item were within the range of potential responses. Descriptive statistics were run on the continuous variables to inspect the minimum, maximum, and mean values. All values were found to be within the range of possible responses.

Multivariate analyses, including multiple regression, rely on the following important assumptions: exploration of influential cases (outliers), normality, absence of perfect multicollinearity, homoscedasticity, and normally distributed residual error (Tabachnick & Fidell, 2007).

Outliers

Outliers are cases that have scores outside the normal range. A conservative approach is to define outliers as those with scores two standard deviations from the mean, but a common approach is to use standardized scores in excess of 3.29, which is between three and four standard deviations (Tabachnick & Fidell, 2007). Univariate outliers have extreme scores on single variables, whereas multivariate outliers have unexpected combinations of scores on multiple variables. The presence of outliers can contribute to Type I and Type II errors in a study and should be detected (Tabachnick & Fidell). In the present study preliminary analyses were run to test for univariate and multivariate outliers. Tabachnick and Fidell suggest four possible reasons that outliers may exist.

First, data entry errors may result in outliers. In this study data entry occurred at the participant level and cannot be verified. All research-initiated scoring and entry was checked thoroughly to avoid errors. The second possible reason is the mis-coding of missing value codes. In this study missing-value codes were assigned by SPSS. The third reason for outliers results from cases being sampled outside the population of interest. The fourth reason is that the case is drawn from the intended population but the values on variables measured do not fit a normal distribution. Under this circumstance one can retain the outliers but may consider how to lessen the impact of those cases (Tabachnick and Fidell, 2007). Procedures for identifying outliers and addressing the third and fourth reasons are addressed in the next paragraph.

Univariate outliers were identified by examining the descriptive statistics for variables, visually inspecting histograms, box plots, stem-and-leaf plots, and executing the extreme values command in SPSS (5 highest and 5 lowest extreme values). It was discovered that instead of a few discrete cases with extreme scores, each scale had approximately 10-12 cases with very low or very high scores, which relates more to non-normal distribution of the variables (discussed in the next section) than to outliers. Nevertheless, after identifying cases with extreme scores, the individual case-level data were examined for possible restricted responses, fit within intended population, or possible error. These cases were deemed to be part of the intended population, and there were no patterns or indicators suggesting error. There was no evidence of restricted response patterns (there was some variation of values within each scale for each participant). Therefore, these cases were not removed from analyses at this point.

Multivariate outliers were identified using Cook's distance (Cook's D). Cook's D

identifies outliers and provides an estimate of their influence. Cook's D was calculated in SPSS. The conventional cut-off for Cook's D is $4/n$. However, in the current study a more conservative cut-off of $4/(n-k-1)$ was used, where k is the number of independent variables. Given the potential impact of outliers, a more conservative approach was selected to ensure that the maximum number of outliers would be identified. Using this cutoff when examining the independent variables, four multivariate outliers were identified. Data entry error and measurement error had been ruled out previously. The cases did appear to be part of the intended population. Therefore, the researcher considered how to handle these outliers. Upon reviewing the individual cases, it appeared that these cases represented legitimate members of the sample and could be considered interesting cases. Therefore, they were retained and their scores were not altered.

Normality

Multivariate normality, another assumption of regression, refers to the normal distribution of all variables and combinations of variables (Tabachnick & Fidell, 2007). Initially, normality of the distribution of each variable was examined using visual inspection of histograms, normal probability plots, and probability plots. Multivariate normality was evaluated using an SPSS macro developed by DeCarlo (1997), which incorporates several tests of multivariate skew, multivariate kurtosis, and an omnibus test of multivariate normality. These tests are reported in Table 3 (for additional information, see DeCarlo, 1997). Most tests were significant at $p = .01$ (used to correct for the number of tests conducted), indicating that the data do not conform to the assumption of normality. However, the macro also produces a plot of the squared Mahalanobis

distances, which allows one to inspect the multivariate distribution visually and identify multivariate outliers. The plot is included as Figure 2, with a 45 degree angle line (normal distribution) imposed upon the distribution in the current study. The sampling distribution deviates moderately from the assumption of multivariate normality. Finally, one would not expect some of these variables to be distributed normally. For example, the USII queries unsupportive interactions with people close to the participant. Individuals generally report low levels of unsupportive interactions, so one could expect the USII total score to be positively skewed, with few high values. This variable was indeed positively skewed. USII subscales were the most skewed variables in this study. More information about the distribution of scale scores will be addressed in sections on specific scales.

Transformations of skewed variables were considered. However, they were not utilized for several reasons. First, the Central Limit Theorem applies to large sample sizes and therefore it is acceptable to assume a normal distribution regardless of variable distribution (Tabachnick & Fidell, 2007). Definitions for large sample sizes vary, but Healey (2005) recommended 100 observations as a large sample. Second, square root and log transformations were run on the skewed and kurtotic variables to determine if these transformations would result in more normally distributed variables. Whereas the skew and kurtosis were reduced, neither transformation resulted in non-significantly skewed data. Given this fact and the additional knowledge that the nonnormal distributions of some variables could be expected, untransformed variables were used in this study.

Multicollinearity and Singularity

Multicollinearity refers to very high correlation between variables included in analyses. Multicollinearity occurs when two instruments measure the same construct. Singularity occurs when two variables are completely redundant (one is a composite of the other or two identical sets of questions are used in a different order), resulting in a perfect correlation (Tabachnick & Fidell, 2007). To explore the possibility of multicollinearity in this study, bivariate correlations among the independent variables were examined. Multicollinearity is suspected when correlations between variables exceed .80, and correlations above .90 are considered evidence of problematic multicollinearity (Tabachnick & Fidell). Except for two variables, no bivariate correlation exceeded .80 among the independent variables, suggesting the absence of multicollinearity (those correlations approaching .80 were between subscale scores and their corresponding total scale scores). The exception was the correlation between online emotional support and online informational support ($r = .90$). The high correlation suggested multicollinearity between these two variables; therefore, they were not entered together as independent variables in any analysis.

Homoscedasticity is the assumption that the standard deviation of errors are approximately the same for all predicted dependent variable scores, meaning that the band encompassing the residuals is approximately the same width for all values of the predicted dependent variable (Tabachnick & Fidell, 2007). Homoscedasticity can be considered the multivariate version of homogeneity of variance. Heteroscedasticity (the violation of the assumption of homoscedasticity) can occur when some variables are skewed but others are not skewed (Tabachnick & Fidell). It can weaken multivariate

analyses but does not render the analysis invalid. Homoscedasticity was evaluated in this study through examination of residuals versus predicted value. The residuals appeared to be randomly scattered and no curve or pattern was evident in these plots; therefore, the assumption of homoscedasticity appeared to be met.

Table 3

Tests of Multivariate Normality

Tests of multivariate skew:		
	Value	<i>p</i>
Small's Test (χ^2)	48.81	0.000
Srivastava's test	10.35	0.410
Tests of multivariate kurtosis:		
	Value	<i>p</i>
A variant of Small's test (χ^2)	27.16	0.000
Srivastava's test	3.12	0.003
Mardia's test	123.74	0.289
Omnibus test of multivariate normality:		
	Value	<i>p</i>
	75.97	0.000

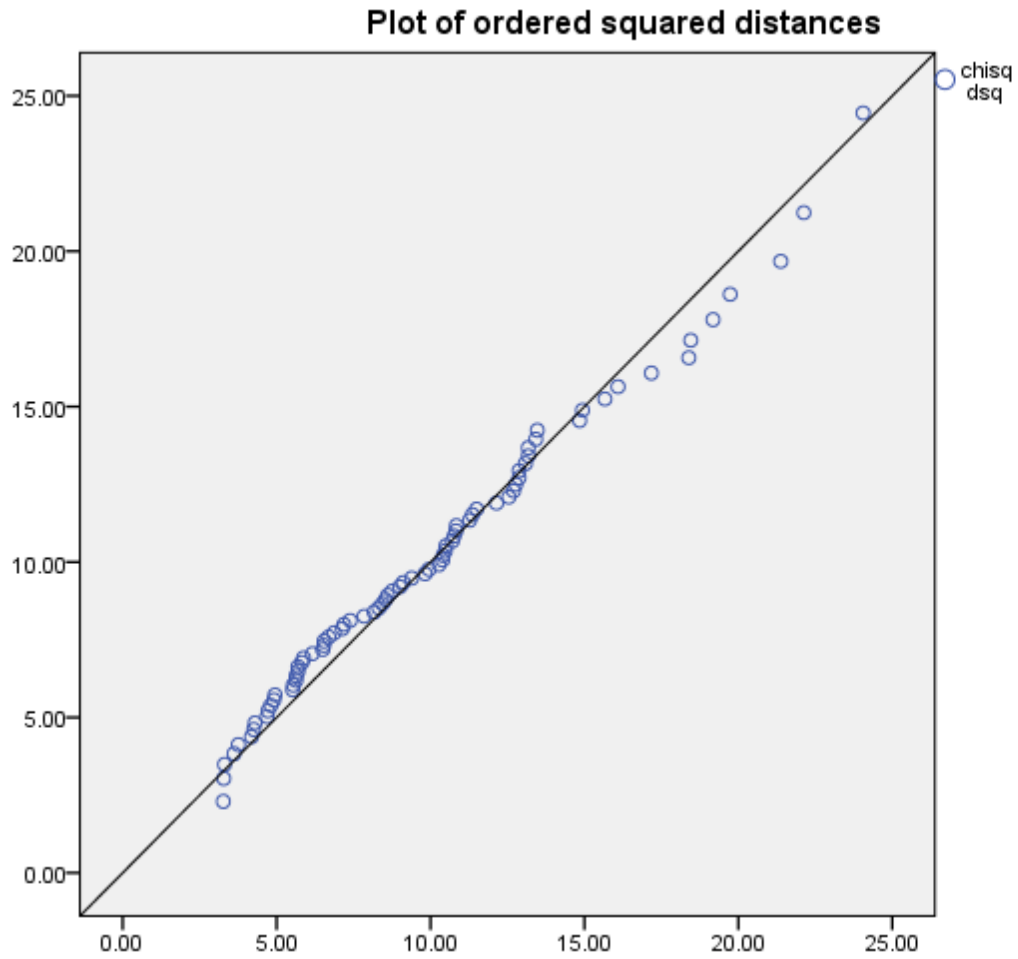


Figure 2. *Plot of squared Mahalanobis distances*

Internal Consistency Reliability

Internal consistency values (Cronbach's alpha) were calculated to determine internal consistency reliability for measures of received social support (online, offline—main and offline—other), unsupportive social interactions (online, offline—main, and offline—other), health-related quality of life, and coping (and the subscales; see Table 4). Values for total scale scores and subscales demonstrated high internal consistency (most above .75), with the exception of the Bumbling subscale of the USII for the main support person, which demonstrated lower internal consistency among the subscale items ($\alpha = .60$), and the Emotional Well-Being subscale of the FACT-G ($\alpha = .45$). Most of these values are consistent with those reported in previous studies.

Table 4

Internal Consistency Reliability Estimates for Scales and Subscales

Instrument	Alpha
Center for Epidemiological Studies Depression scale (CES-D)	
Total	.93
Positive Affect	.82
Inventory of Socially Supportive Behaviors	
Total—MAIN	.95
Emotional Support—MAIN	.93
Guidance/Information—MAIN	.92
Inventory of Socially Supportive Behaviors	
Total—OTHER	.97
Emotional Support—OTHER	.94
Guidance/Information—OTHER	.94
Inventory of Socially Supportive Behaviors	
Total—ONLINE	.98
Emotional Support—ONLINE	.97
Guidance/Information—ONLINE	.97
Unsupportive Social Interactions Inventory (USII)	
Total—MAIN	.93
Distancing—MAIN	.93
Bumblng—MAIN	.60
Minimizing—MAIN	.84
Blaming—MAIN	.77
Unsupportive Social Interactions Inventory (USII)	
Total—OTHER	.94
Distancing—OTHER	.89
Bumblng—OTHER	.75
Minimizing—OTHER	.85
Blaming—OTHER	.83

(continued)

Table 4 (continued)

Instrument	Alpha
Unsupportive Social Interactions Inventory (USII)	
Total—ONLINE	.96
Distancing—ONLINE	.91
Bumblng—ONLINE	.82
Minimizing—ONLINE	.86
Blaming—ONLINE	.93
Ways of Coping—Cancer	
Total	.94
Seek/Use Social Support	.86
Focus on Positive	.84
Distancing	.85
Cognitive Escape/Avoidance	.76
Behavioral Escape/Avoidance	.78
Avoidance Coping composite	.86
Functional Assessment of Cancer Therapy—General (FACT-G)	
Total	.77
Physical Well-Being	.70
Emotional Well-Being	.45
Functional Well-Being	.85

Note. $N = 101$. However, the sample size for some of the variables is smaller due to missing data (lowest $N = 77$ for several USII—Online subscales).

Descriptive Analyses

Means, standard deviations, and frequencies were computed for all variables included in the current study (see Table 5). For ratings of support received by the main support person, the mean score for the total modified Inventory of Socially Supportive Behaviors (ISSB) scale was 87.65 ($SD = 24.21$; possible range = 28-140). The emotional support subscale mean for the main support person was 41.88 ($SD = 11.09$; possible range = 11-55), and the guidance/informational support subscale mean was 34.29 ($SD = 13.50$; possible range = 14-70).

For support received by other friends and family (offline), the mean score for the total modified ISSB scale was 71.96 ($SD = 23.87$; possible range = 28-140). The emotional support subscale mean for other support persons was 33.09 ($SD = 11.09$; possible range = 11-55), and the guidance/informational support subscale mean was 29.50 ($SD = 11.67$; possible range = 14-70).

For support received online, the total modified ISSB scale mean score was 57.00 ($SD = 29.02$; possible range 28-140). The emotional support subscale mean for online support was 24.07 ($SD = 12.99$; possible range = 11-55), and the guidance/informational support subscale mean was 27.10 ($SD = 13.63$; possible range = 14-70).

The received support variable scores in this study tended to be relatively high for total score and emotional support, with informational support scores closer to the middle of the possible range. The author is not aware of previous studies using this same modification of the ISSB, nor have any known studies used any version of the ISSB to measure online social support. Therefore it is difficult to compare the means obtained in

this study to previous results. However, previous studies of individuals with cancer have found that participants reported high levels of received support using similar measures (Balliet, 2010; Manne, Taylor, Dougherty, & Kemeny, 1997). Higher emotional support scores and lower guidance/informational support scale scores for the main support person and other support persons are also consistent with a previous study with a similar sample (Balliet).

The Unsupportive Social Interactions Inventory (USII) was also completed for the main support person, other friends and family (offline), and online support persons. Total scale scores will be described here. For subscale scores, please refer to Table 5. In this study a 4-point scale was used: 1 = *never responds this way* and 4 = *often responds this way*. The original USII used a 5-point scale (0 = *none* to 4 = *a lot*; Ingram, Betz, Mindes, Schmitt, & Smith, 2001). A recent study (Balliet, 2010) used the 4-point scale to enhance readability and make the response scale consistent with the social support measure (a modified ISSB). The mean USII total score for main support person was 1.54 ($SD = 0.53$; possible range 1-4). The mean USII total score for other friends and family (offline) was 1.61 ($SD = 0.56$; possible range 1-4), and the mean USII total score for online support persons was 1.27 ($SD = 0.44$; possible range 1-4).

Overall, participants reported relatively low levels of unsupportive interactions (below mid-range for every scale and subscale score). Due to the different scale, these scores cannot be compared to some of the previous studies. However, Balliet (2010) reported very similar total scale and subscale averages using the same 4-point scale. The findings of low unsupportive interactions are consistent with previous research exploring unsupportive interactions reported by individuals with cancer using the original USII

(Figueiredo, Fries, & Ingram, 2004) and a different measure of unsupportive interactions (Manne, Ostroff, Winkel, & Grana, 2005; Manne, Taylor, Dougherty, & Kemeny, 1997). Given these results, it is not surprising that several subscales of the USII were positively skewed. Generally one would not expect variables measuring negative or unsupportive interactions to be normally distributed.

The Center for Epidemiological Studies Depression scale (CES-D) was normed on a general, or non-clinical population (Radloff, 1977) and has since been used in a variety of populations, including a number of medical populations. The measure has been used primarily to assess symptoms of depression; however, it also contains a four-item scale measuring positive affect, which has been used in previous studies of individuals with cancer (e.g., Schroevers, Sandermann, van Sonderen, & Ranchor, 2000). The mean score on the CES-D in this study was 15.85 ($SD = 11.38$). Scores of 16 or higher indicate possible depression and the overall mean score was just under that threshold in this study. Whereas previous studies reported lower scores in breast cancer patients (Hann, Winter, & Jacobsen, 1999; Schroevers, Sandermann, van Sonderen, & Ranchor, 2000), Balliet (2010) found slightly higher scores in her sample, which is fairly similar to the sample in the present study.

The mean Positive Affect scale score in the present study was 9.01 ($SD = 2.84$; median = 2.00; possible range = 0-12). Higher scores indicate a higher level of positive affect. It is difficult to compare this score with previous research because few studies have reported results using this subscale and the available research used reverse-scored item means to measure positive affect (Schroevers, Sandermann, van Sonderen, & Ranchor).

The Ways of Coping-Cancer (WOC-CA) is a cancer-specific adaptation by Dunkel-Schetter and colleagues (1992) of the original Ways of Coping Inventory (Folkman & Lazarus, 1980; Lazarus & Folkman, 1984). The measure queries coping strategies over the past 6 months. All of the subscale scores are included in Table 5, but only the subscales used in the analyses of the present study will be addressed here. In this study, the researcher combined the Cognitive Escape/Avoidance and Behavioral Escape/Avoidance subscales, both representing avoidant coping, to create an Avoidant Coping composite. The mean score for the Cognitive Escape/ Avoidance subscale in the present study was 16.82 ($SD = 7.04$; possible range = 0-34). The mean for the Behavioral Escape/Avoidance subscale was 12.14 ($SD = 6.12$; possible range = 0-36), and the mean for the combined Avoidant Coping composite was 29.02 ($SD = 12.08$; possible range = 0-72). The mean score for the Focus on the Positive subscale was 15.02 ($SD = 6.77$; possible range = 0-32). Manne and colleagues used the same subscales of the WOC-CA to represent avoidant coping; however, they removed three items and subjected the items to a factor analysis after collecting data (Manne, Paper, Taylor, & Dougherty, 1999). As a result, they used a different scoring metric, and direct comparisons cannot be made to the scores in the current study. The original scale development article does not report means and standard deviations for the subscales, and it has been difficult to locate publications using this measure. However, in a previous small study by this investigator of individuals recently treated for cancer ($n = 9$), very similar mean scores were observed (Cohen, 2009). In that study, the Cognitive Escape mean was 17.11 ($SD = 4.99$), the Behavioral Escape mean was 13.33 ($SD = 4.61$), and the Focus on the Positive mean was 14.67 ($SD = 6.98$).

The Functional Assessment of Cancer Therapy—General (FACT-G) was normed on a heterogeneous sample of cancer patients (Cella et al., 1993). The mean for the total scale score in this study was 59.43 ($SD = 12.55$; possible range = 0-108). The mean Physical Well-Being (PWB) scale score was 12.69 ($SD = 4.53$; possible range = 0-28). The mean Social Well-Being (SWB) scale score was 18.39 ($SD = 6.39$; possible range = 0-28). The mean Emotional Well-Being (EWB) scale score was 10.68 ($SD = 3.54$; possible range = 0-24). The mean Functional Well-Being (FWB) scale score was 17.79 ($SD = 6.24$; possible range = 0-28).

In a study of 308 diverse individuals with cancer and a relatively recent normative study of the FACT-G, researchers found higher mean scores on all subscales (Brucker, Yost, Cashy, Webster, & Cella, 2005; Cella, Hann, & Dineen, 2002). In the latter study, means were as follows: PWB = 21.3; SWB = 22.1; EWB = 18.7; FWB = 18.9; and FACT-G total = 80. In the present study descriptive statistics, box plots, and stem-and-leaf plots were reviewed to ensure that these lower scores were not a result of several discrete outliers. Whereas there were a few outliers on specific subscales, they were not consistent across the subscales. Overall, participants in this study reported lower health-related quality of life overall and on several subscales than in previous research.

Table 5

Means, Standard Deviations, and Ranges of Scales and Subscales

Instrument	Mean	SD	Sample Range	Possible Range
Center for Epidemiological Studies Depression scale (CES-D)				
Total	15.85	11.38	0-46	0-60
Positive Affect	9.01	2.84	1-12	0-12
Inventory of Socially Supportive Behaviors				
Total—MAIN	87.65	24.21	28-135	28-140
Emotional Support—MAIN	41.88	11.09	11-55	11-55
Guidance/Information—MAIN	34.29	13.50	14-67	14-70
Inventory of Socially Supportive Behaviors				
Total—OTHER	71.96	23.87	29-135	28-140
Emotional Support—OTHER	33.09	11.09	11-53	11-55
Guidance/Information—OTHER	29.50	11.67	14-69	14-70
Inventory of Socially Supportive Behaviors				
Total—ONLINE	57.00	29.02	28-140	28-140
Emotional Support—ONLINE	24.07	12.99	11-55	11-55
Guidance/Information—ONLINE	27.10	13.63	14-70	14-70
Unsupportive Social Interactions Inventory (USII)				
Total—MAIN	1.54	.53	1-3.48	1-4
Distancing—MAIN	1.45	.77	1-4	1-4
Bumblng—MAIN	1.72	.55	1-3.33	1-4
Minimizing—MAIN	1.77	.75	1-4	1-4
Blaming—MAIN	1.22	.40	1-3.33	1-4

(continued)

Table 4 (continued)

Instrument	Mean	<i>SD</i>	Sample Range	Possible Range
Unsupportive Social Interactions Inventory (USII)				
Total—OTHER	1.61	.56	1-3.74	1-4
Distancing—OTHER	1.58	.76	1-4	1-4
Bumblng—OTHER	1.90	.68	1-3.67	1-4
Minimizing—OTHER	1.74	.70	1-3.67	1-4
Blaming—OTHER	1.25	.45	1-3.67	1-4
Unsupportive Social Interactions Inventory (USII)				
Total—ONLINE	1.27	.44	1-3.67	1-4
Distancing—ONLINE	1.21	.48	1-3.50	1-4
Bumblng—ONLINE	1.28	.48	1-3.83	1-4
Minimizing—ONLINE	1.46	.59	1-3.67	1-4
Blaming—ONLINE	1.12	.40	1-3.67	1-4
Ways of Coping—Cancer				
Seek/Use Social Support	23.00	8.57	0-41	0-44
Focus on Positive	15.02	6.77	0-30	0-32
Distancing	26.31	8.98	0-47	0-48
Cognitive Escape/Avoidance	16.82	7.04	0-34	0-36
Behavioral Escape/Avoidance	12.14	6.12	0-31	0-36
Avoidance Coping composite	29.02	12.08	0-65	0-72
Functional Assessment of Cancer Therapy—General (FACT-G)				
Total	59.43	12.55	24.92-89	0-108
Physical Well-Being	12.69	4.53	3-28	0-28
Social Well-Being	18.39	6.39	0-28	0-28
Emotional Well-Being	10.68	3.54	3-21	0-24
Functional Well-Being	17.79	6.24	0-28	0-28

Online Behaviors and Characteristics of Sample

Complete details about specific reasons for using the internet and frequency and time spent on various online behaviors are provided in Tables 6 and 7. Participants visited cancer-related websites an average of 3 days per week ($SD = 2.02$), with a range of 1 to 7 days per week (see Table 1). Forty-seven percent ($n = 48$) spent between 1 and 3 hours on the Internet daily (for any reason). Eleven percent ($n = 11$) spent between 3 and 4 hours online daily. Twenty-one percent ($n = 21$) reported spending more than 4 hours per day online, and 22% ($n = 22$) reported spending up to an hour online each day.

Participants described engaging in a number of cancer-related activities online. Thirty-nine percent ($n = 40$) reported writing a blog or online journal at least once during the week. Seventy-eight percent ($n = 79$) indicated that they read a blog about cancer for some time during the week. Thirty-six percent ($n = 37$) participated in a chat room or a real-time support group related to cancer each week. Fifty-two percent ($n = 53$) posted on cancer-related discussion boards weekly. Ninety-six percent ($n = 98$) reported seeking health information for some period of time each week.

Participants described a number of reasons for using the Internet in general. Eighty-six percent ($n = 88$) reported that email was a primary reason for using the Internet, 81% ($n = 83$) reported using the Internet to stay in touch with friends, and 73% ($n = 74$) described using it to stay in touch with family. Seventy-two percent ($n = 73$) reported that a primary reason for using the Internet was to get information. Thirty-six percent ($n = 37$) reported that reading blogs was a primary reason for Internet use, and 21% ($n = 21$) included blog writing as one of the primary reasons. Twenty-three percent ($n = 23$) reported that seeking support was a primary reason for general Internet use.

Other primary reasons for using the Internet included entertainment (39%; $n = 40$), playing games (18%; $n = 18$), news and current events (66%; $n = 67$), work (47%; $n = 48$), social networking (59%; $n = 60$), online banking (49%; $n = 50$), and downloading files (15%; $n = 15$).

Participants also endorsed a variety of reasons for using cancer-related websites and communities. Seventy-five percent of participants ($n = 76$) reported that they used cancer-related websites get health-related information from professionals, and 65% ($n = 66$) reported using cancer-related sites to get health-related information from other patients. Sixty-three percent ($n = 64$) used cancer-related sites to do research about their diagnoses, 52% ($n = 53$) reported using these sites to explore treatment recommendations and options, and 28% ($n = 28$) sought information about clinical trials. Seventy-one percent ($n = 72$) reported that finding resources was a primary reason for using cancer-related sites. In terms of seeking support and connecting with others, 21% ($n = 21$) sought friends, 53% ($n = 54$) were looking for people to understand what they were going through, 34% ($n = 35$) wanted to share their stories. Twenty-four percent ($n = 24$) wanted to vent, 7% ($n = 7$) used cancer-related sites to ask for help, and 42% ($n = 43$) reported that a primary reason for using cancer-related websites was to help others.

Table 6

Online Characteristics of Participants

Variable	Frequency					
	Never done this	≤ 1 time/ month	2-3 times/ month	Once/ week	2-3 times/ week	Nearly every day/ every day
	<i>n (%)</i>	<i>n (%)</i>	<i>n (%)</i>	<i>n (%)</i>	<i>n (%)</i>	<i>n (%)</i>
Writing a blog or online journal about cancer	52 (51)	20 (20)	8 (8)	6 (6)	6 (6)	10 (10)
Reading blogs about cancer	17 (17)	33 (33)	16 (16)	8 (8)	9 (9)	19 (19)
Participating in chat rooms/real-time support groups	59 (58)	26 (26)	4 (4)	7 (7)	4 (4)	2 (2)
Posting on cancer-related discussion boards	46 (45)	28 (27)	7 (7)	7 (7)	7 (7)	7 (7)
Seeking health information online	3 (3)	27 (27)	18 (18)	16 (16)	16 (16)	22 (22)
Spending time on social networking sites unrelated to cancer	14 (14)	9 (9)	2 (2)	3 (3)	9 (9)	64 (64)
Using the Internet for other purposes	2 (2)	1 (1)	0	1 (1)	1 (1)	98 (96)

Variable	Time spent per week					
	N/A	< 30 minutes	30-60 minutes	1-2 hours	2-4 hours	More than 4 hours
	<i>n (%)</i>	<i>n (%)</i>	<i>n (%)</i>	<i>n (%)</i>	<i>n (%)</i>	<i>n (%)</i>
Writing a blog or online journal about cancer	62 (61)	13 (13)	9 (9)	7 (7)	5 (5)	6 (6)
Reading blogs about cancer	22 (22)	39 (38)	15 (15)	9 (9)	9 (9)	7 (7)
Participating in chat rooms/real-time support groups	65 (64)	23 (23)	4 (4)	5 (5)	4(4)	1 (1)
Posting on cancer-related discussion boards	48 (48)	28 (28)	10 (10)	5 (5)	6 (6)	4 (4)
Seeking health information online	4 (4)	42 (41)	18 (18)	15 (15)	14 (14)	9 (9)
Spending time on social networking sites unrelated to cancer	15 (15)	11 (11)	10 (10)	14 (14)	14 (14)	38 (37)

Note. Percentages may not add to 100 due to rounding.

Table 7

Primary Reasons for Using the Internet

Variable	N	%
What are your primary reasons for using the Internet?		
Email	88	86
Staying in touch with friends	83	81
Staying in touch with family	74	73
Get information	73	72
News and current events	67	66
Social networking	60	59
Online banking	50	49
Work	48	47
Entertainment	40	39
Reading blogs	37	36
Seeking support	23	23
Writing blog	21	21
Play games	18	18
Download files	15	15
Instant messaging	14	14
Online education	11	11
Meeting new people	8	8
Marketing	5	5
Variable	N	%
What are your primary reasons for using cancer-related websites and communities?		
Get health-related information from professionals	76	75
Find resources	72	71
Get health-related information from other patients	66	65
Do research on my diagnosis	64	63
Find people who understand what I am going through	54	53
Explore treatment recommendations and options	53	52
Help others	43	42
Share my story	35	34
Look for information about clinical trials	28	28
Vent	24	24
Make friends	21	21
Ask for help	7	7

Correlations Among Variables Tested in Hypotheses

Pearson correlations were computed to examine the relationships among variables used in hypothesis testing (see Table 8). Correlations among the variables associated with offline support will be discussed first. The scales measuring support received from the main support person were kept separate from the offline support received from other friends and family. As expected, informational support received from the main support person was significantly positively correlated with the Focus on the Positive subscale of the Ways of Coping—Cancer ($r = .21; p = .039$). However, informational support received from the main support person was also positively correlated with the Avoidant Coping composite ($r = .22; p = .034$), which was in the opposite direction from what was expected. In addition, there was no significant correlation between informational support received from the main support person and positive affect, which had been expected. Though it was not predicted, there was a significant correlation between informational support received from the main support person and FACT-G total ($r = .29; p = .003$). Emotional support received from the main support person was significantly positively associated with positive affect ($r = .28; p = .005$), Focus on the Positive ($r = .24; p = .017$), and health-related quality of life as measured by the FACT-G total ($r = .44; p < .001$). All of these associations were consistent with the hypotheses except for the last finding. The relationship between emotional support received from the main support person and positive affect was in the opposite direction from what was expected.

As expected, informational support received from other support persons (offline) was significantly positively correlated with the Focus on the Positive subscale of the Ways of Coping—Cancer ($r = .21; p = .042$). However, there was no significant

association between informational support received from other support persons (offline) and positive affect (positive correlation predicted) or avoidant coping (negative correlation expected). Though not predicted, there was a significant positive correlation between informational support received from other support persons and FACT-G total scores ($r = .28; p = .005$). Emotional support received from the other support persons (offline) was significantly associated with positive affect ($r = .25; p = .012$), Focus on the Positive ($r = .26; p = .009$), and health-related quality of life as measured by the FACT-G total ($r = .36; p < .001$). All of these associations were consistent with the hypotheses.

As expected, informational support received online was significantly positively correlated with the Focus on the Positive subscale of the Ways of Coping—Cancer ($r = .34; p = .002$). However, informational support received online was also positively correlated with the Avoidant Coping composite ($r = .37; p = .001$), which was in the opposite direction from what was expected. In addition, there was no significant correlation between informational support received online and positive affect, which had been expected. As expected, emotional support received online was significantly associated with Focus on the Positive ($r = .33; p = .003$). However, emotional support received online was not significantly associated with positive affect or health-related quality of life. Emotional support received online was positively associated with avoidant coping ($r = .32; p = .004$), which was unexpected.

Table 8

Correlations Among Variables Tested in Regression Hypotheses

	1	2	3	4	5	6	7	8	9	10
1. Emotional Support—MAIN	---									
2. Emotional Support—OTHER	.55**	---								
3. Emotional Support—ONLINE	.01	.05	---							
4. Informational Support—MAIN	.58**	.36**	.06	---						
5. Informational Support—OTHER	.44**	.74**	.13	.68**	---					
6. Informational Support—ONLINE	.02	.01	.90**	.16	.20	---				
7. FACT-G Total	.44**	.36**	.11	.29**	.28**	.07	---			
8. CES-D Positive Affect	.28**	.25**	.06	.10	-.14	.05	.56**	---		
9. Avoidant Coping	-.08	-.10	.32**	.22*	.11	.37**	-.19	.42***	---	
10. Focus on the Positive	.24*	.26**	.33**	.21*	.21*	.34**	.26*	-.20*	.62**	---

Note. * $p < .05$. ** $p < .001$.

Potential Covariates

Tests were conducted to determine if specific demographic or disease variables were associated with any of the dependent variables in the regression equations. To adjust for the high number of analyses being conducted, a modified Bonferroni correction procedure was used, and the familywise error rate was set at .01.

To determine whether there were differences in any of the dependent variables by gender, *t* tests were conducted. The researcher recognized that any comparison between the two groups would be affected by the small sample of male participants in the study. Nevertheless, independent-samples *t* tests were conducted to compare the scores for males and females on outcome variables. There was no significant difference on the CES-D Positive Affect subscale for males ($M = 8.50$) and females ($M = 9.02$) in scores, $t(97) = -0.50, p = .622$; FACT-G total score (mean for males = 58.50; mean for females = 59.57), $t(98) = -0.23, p = .820$; Avoidant Coping (mean for males = 35.50; mean for females = 28.52), $t(98) = 1.57, p = .121$; or Focus on the Positive (mean for males = 15.13; mean for females = 14.99), $t(97) = .05, p = .957$. Therefore, gender was not included as a potential covariate in hypothesis testing.

Pearson correlations were conducted to determine whether age or time spent online were significantly associated with the dependent variables. Age was not significantly correlated with participants' scores on the CES-D Positive Affect subscale ($r = -.16, p = .125$), FACT-G total ($r = -.01, p = .962$), Avoidant Coping ($r = -.19, p = .068$), or Focus on the Positive ($r = -.02, p = .860$). Therefore, age was not included as a potential covariate in hypothesis testing.

For time spent online, two variables were used due to the difficulty obtaining a precise measure of time spent online and time spent on cancer-related sites. First, participants reported how many hours per day they spent online (excluding email). The numbers of hours online per day was a categorical variable, but it was entered as a continuous variable for these correlations. Second, participants reported how many days per week they visit cancer-related sites on the Internet (also measured as a categorical variable but used as a continuous variable in these analyses). The number of hours online per day was not significantly correlated with participants' scores on the CES-D Positive Affect subscale ($r = -.17, p = .094$), FACT-G total ($r = -.14, p = .158$), or Focus on the Positive ($r = -.02, p = .851$). However, the number of hours online per day was significantly associated with Avoidant Coping ($r = .25, p = .012$), suggesting a positive relationship between hours online and avoidant coping. Therefore, the number of hours spent online per day was considered as a covariate and controlled for in the regression equations. The number of days per week visiting cancer-related Internet sites was not significantly correlated with participants' scores on the CES-D Positive Affect subscale ($r = -.05, p = .656$), FACT-G total ($r = .09, p = .389$), Avoidant Coping ($r = -.16, p = .139$), or Focus on the Positive ($r = .06, p = .566$). Therefore, the number of days per week visiting cancer-related websites was not considered a covariate in the analyses.

ANOVAs were conducted to determine whether significant differences exist between groups by ethnicity on any of the dependent variables. The groups used for this analysis were Caucasian, African-American, Asian/Pacific-Islander, Hispanic/Latino, American Indian, and Other. Unequal sample sizes affect the power of these tests, but results of these analyses showed that ethnicity was not significantly related to the

outcome variables: CES-D Positive Affect, $F(5, 91) = 0.98, p = .435$; FACT-G total, $F(5, 92) = 0.57, p = .727$; Avoidant Coping, $F(5, 92) = 1.37, p = .243$, or Focus on the Positive, $F(5, 92) = 1.14, p = .344$. Ethnicity was not used as a covariate in hypothesis testing.

In addition to the analyses planned to explore potential covariates, Pearson correlations were conducted to determine if number of months since diagnosis was significantly associated with the dependent variables. This analysis was added due to the very wide range of months since diagnosis in the sample and the possibility that this variable would have an effect on outcome variables. Time since diagnosis was not significantly associated with CES-D Positive Affect subscale ($r = .19, p = .060$), FACT-G total ($r = .06, p = .584$), Avoidant Coping ($r = -.15, p = .155$), or Focus on the Positive ($r = -.17, p = .103$). Therefore, time since diagnosis was not used as a covariate in hypothesis testing.

Testing of Hypotheses

Hypotheses were tested using t tests, bivariate correlations, and hierarchical multiple linear regression analyses.

Hypothesis 1. There will be significant differences between social support received online and social support received offline. Predicted differences in types of support follow.

Hypothesis 1a. Overall, received social support was expected to be higher offline than online.

Analysis of Hypothesis 1a. Mean overall received support scores were compared using paired samples t tests. Two paired samples t tests were conducted to test this

hypothesis. First, overall social support received from the main support person was compared to overall support received online. Overall support received from the main support person ($M = 86.40$) was higher than overall support received online ($M = 56.11$); $t(79) = 7.45, p < .001$. Next, overall social support received from other support persons was compared to overall support received online. Overall support received from other persons ($M = 70.02$) was higher than overall support received online ($M = 27.10$); $t(80) = 3.23, p = .002$. Therefore, hypothesis 1a was supported.

Hypothesis 1b. Informational support will be higher online than offline.

Analysis of Hypothesis 1b. Means on the online and offline informational support subscales were compared using paired samples t tests. Two paired samples t tests were conducted to test this hypothesis. First, informational social support received from the main support person was compared to informational social support received online. Informational support received from the main support person ($M = 34.24$) was higher than informational support received online ($M = 26.77$); $t(78) = 3.83, p < .001$, which was the opposite of the expected result. Next, informational social support received from other support persons was compared to informational support received online. Informational support received from other persons ($M = 28.97$) was not significantly different from informational support received online ($M = 27.15$); $t(79) = 1.02, p = .313$. Therefore, hypothesis 1b was not supported.

Research question 1. Are there significant differences between emotional support offline and online?

Analysis of research question 1. Means on the online and offline emotional support subscales were compared using paired samples t tests. Two paired samples t tests

were conducted to test this hypothesis. First, emotional social support received from the main support person was compared to emotional social support received online.

Emotional support received from the main support person ($M = 41.40$) was significantly higher than emotional support received online ($M = 23.76$); $t(79) = 9.28, p < .001$. Next, emotional social support received from other support persons was compared to emotional support received online. Emotional support received from other persons ($M = 32.20$) was significantly higher than emotional support received online ($M = 24.07$); $t(80) = 4.33, p < .001$. Therefore, in this study there was a significant difference between emotional support received offline from the main support person and emotional support received online and between emotional support received from other support persons and emotional support received online.

Hypothesis 2. Participants will report experiencing fewer unsupportive interactions online than offline.

Analysis of Hypothesis 2. Means on the online and offline USII total and subscale scores were compared using paired samples t tests. Two paired samples t tests were conducted to test this hypothesis. First, overall unsupportive social interactions with the main support person were compared to overall support received online. Overall unsupportive social interactions with the main support person ($M = 1.55$) was higher than overall unsupportive social interactions online ($M = 1.27$); $t(78) = 5.80, p < .001$. Next, overall unsupportive social interactions with other support persons were compared to overall support received online. Overall unsupportive social interactions with other persons ($M = 1.62$) was higher than overall unsupportive social interactions online ($M = 1.27$); $t(77) = 7.94, p < .001$. Therefore, hypothesis 2 was supported.

Hypothesis 3

Hypothesis 3a. Emotional support received offline will be significantly positively associated with positive affect, health-related quality of life, and focusing on the positive.

Hypothesis 3b. Informational support received offline will be significantly positively associated with focusing on the positive and positive affect, and negatively associated with avoidant coping.

Hypothesis 3c. Online emotional support will be significantly positively associated with health-related quality of life, focusing on the positive, and positive affect.

Hypothesis 3d. Online informational support will be significantly positively associated with positive affect and focusing on the positive, and negatively associated with avoidant coping.

Analysis of Hypotheses 3a - 3d. To test the associations hypothesized in 3a-3d, hierarchical multiple linear regression analyses were conducted (see Tables 9 and 10). Two decisions should be noted here. Received offline social support was measured separately for the main support person and other support persons. Therefore, they were kept separate during the regression analyses and entered in separate steps. Support from the main person was entered first, and then support from other persons was entered next to determine its unique contribution. Second, due to the extremely high correlation between emotional support received online and informational support received online ($r = .90, p < .001$), only one scale was used per regression analysis involving online support variables. The researcher determined which scale to use based on the original hypotheses. For example, online informational support was hypothesized to be negatively associated with avoidant coping. There was no hypothesized relationship

between online emotional support and avoidant coping; therefore, online emotional support was excluded for that particular regression analysis.

Positive Affect. Two separate hierarchical multiple linear regression analyses were conducted to test the associations hypothesized between received social support and positive affect. In the first equation, scores on the positive affect subscale of the CES-D were the dependent variable. The covariate, hours spent online per day, was entered first. Next, emotional support received by the main support person and informational support received by the main support person were entered. In the third block, emotional support received by other support persons and informational support received by other support persons were entered.

The overall model was significant, $F(5, 90) = 2.73, p = .024$. However, the model was stronger at Step 2, $F(3, 92) = 4.42, p = .006$, without the addition of emotional support and informational support received by other support persons. Step 1 indicated there was a marginally significant association between hours spent online and positive affect, $\Delta F(1, 94) = 3.41, p = .068$. Step 2 of the model shows that emotional support received by the main support person and informational support received by the main support person significantly predicted 9.1% of unique variance in positive affect, above and beyond that which is accounted for by the demographic variable (hours spent online per day), $\Delta F(2, 92) = 4.78, p = .011$. More emotional support from the main support person ($\beta = .35, p < .001$) predicted higher positive affect. Informational support received from the main support person did not contribute significantly to the prediction of positive affect. In Step 3, the addition of emotional and informational support received from other support persons contributed only 0.6% of variance in positive affect above and

beyond support received from the main support person, and neither emotional support nor information support contributed significantly. Therefore, this hypothesis was supported for the main support person but not for other support persons. Of note is the fact that more emotional support from the main person contributed to higher levels of positive affect after controlling for hours spent online; however, in earlier correlational analysis, these two variables were inversely related.

In the second equation, scores on the positive affect subscale of the CES-D were the dependent variable. The covariate, hours spent online per day, was entered first. Next, emotional support received online was entered. The overall model was not significant $F(2, 77) = 1.76, p = .179$. The number of hours spent online in Step 1 was not statistically significant, meaning hours spent online did not predict positive affect. Step 2 of the model shows that the addition of emotional support received online did not contribute significantly to the model. Therefore, this hypothesis was not supported for online support.

Health Related Quality of Life. Two separate hierarchical multiple linear regression analyses were conducted to test the associations hypothesized between social support and health related quality of life.

In the first equation, total scores on the FACT-G were the dependent variable. The covariate, hours spent online per day, was entered first. Next, emotional support received by the main support person and informational support received by the main support person were entered. In the third block, emotional support received by other support persons and informational support received by other support persons were entered.

The overall model was significant, $F(5, 91) = 6.09, p < .001$. Again, the model was stronger at Step 2, $F(3, 93) = 9.45, p < .001$, without the addition of emotional support and informational support received by other support persons. Step 1 indicated there was no significant association between hours spent online and health related quality of life, $F(1, 95) = 2.52, p = .116$. Step 2 of the model shows that emotional support received by the main support person and informational support received by the main support person significantly predicted 20.8% of unique variance in FACT-G scores, above and beyond that which is accounted for by the demographic variable (hours spent online per day), $\Delta F(2, 93) = 12.61, p < 0.001$. More emotional support from the main support person ($\beta = .43, p < .001$) predicted higher health related quality of life. Informational support received from the main support person did not contribute significantly to the prediction of health related quality of life. In Step 3, the addition of emotional and informational support received from other support persons contributed only 1.7% of variance in FACT-G scores above and beyond support received from the main support person, and neither emotional support nor information support contributed significantly. Therefore, this hypothesis was supported for the main support person but not for other support persons.

In the second equation, total scores on the FACT-G were the dependent variable. The covariate, hours spent online per day, was entered first. Next, emotional support received online was entered. The overall model was not significant $F(2,78) = 2.08, p = .132$. Step 1 indicated there was no significant association between hours spent online and FACT-G total score. Step 2 of the model shows that emotional support received

online did not significantly predict FACT-G total scores. Therefore, this hypothesis was not supported for online support.

Focus on the Positive Coping. Two separate hierarchical multiple linear regression analyses were conducted to test the associations hypothesized between social support and focusing on the positive.

In the first equation, scores for the Focus on the Positive subscale of the WOC-CA were the dependent variable. The covariate, hours spent online per day, was entered first. Next, emotional support received by the main support person and informational support received by the main support person were entered. In the third block, emotional support received by other support persons and informational support received by other support persons were entered.

The overall model was not significant, $F(5, 90) = 1.85, p = .112$. Again, the model was stronger at Step 2, $F(3, 92) = 2.51, p = .063$, without the addition of emotional support and informational support received by other support persons but was not significant. Step 1 indicated there was no significant association between hours spent online and focusing on the positive, $F(1, 94) = 0.13, p = .722$. Whereas the overall model was not significant, Step 2 of the model shows that emotional support received by the main support person and informational support received by the main support person did significantly contribute to the prediction of Focus on the Positive scores, $\Delta F(2, 92) = 3.70, p = .028$. However, neither emotional support from the main person nor informational support from the main person emerged as a significant predictor. In Step 3, the addition of emotional and informational support received from other support persons did not contribute significantly to the prediction of Focus on the Positive scores.

Therefore, this hypothesis was not supported for the main support person or for other support persons.

In the second equation, scores for the Focus on the Positive subscale of the WOC-CA were the dependent variable. The covariate, hours spent online per day, was entered first. Next, emotional support received online was entered.

The overall model was significant $F(2, 77) = 6.66, p = .002$. Step 1 indicated there was no significant association between hours spent online and Focus on the Positive scores. Step 2 of the model shows that the addition of emotional support received online contributed significantly to predicting Focus on the Positive total scores, $\Delta F(1, 77) = 13.31, p < 0.001$. Emotional support received online accounted for 14.7% of unique variance in Focus on the Positive scores ($\beta = .44, p < .001$), with higher emotional support received online predicting higher focusing on the positive. Therefore, the hypothesis was supported for support received online.

Avoidant coping. Two separate hierarchical multiple linear regression analyses were conducted to test the associations hypothesized between social support and avoidant coping.

In the first equation, scores for the Avoidant Coping composite of the WOC-CA were the dependent variable. The covariate, hours spent online per day, was entered first. Next, emotional support received by the main support person and informational support received by the main support person were entered. Finally, emotional support and informational support received by other support persons was entered in Step 3.

The overall model was significant, $F(5, 91) = 3.46, p = .007$. Again, the model was strongest at Step 2 without support from other persons. Step 1 indicated there was a

significant association between hours spent online and avoidant coping, $F(1, 95) = 5.80$, $p = .018$. Hours spent online accounted for 5.8% of the variance in avoidant coping, $\Delta F(1, 95) = 5.80$, $p = 0.018$. More hours spent online predicted higher avoidant coping ($\beta = .24$, $p = .018$). Step 2 of the model shows that emotional support received by the main support person and informational support received by the main support person significantly predicted 9.7% of unique variance in positive affect, above and beyond that which is accounted for by the demographic variable (hours spent online per day), $\Delta F(2, 93) = 5.36$, $p = 0.006$. More emotional support from the main support person ($\beta = -.28$, $p = .019$) predicted less avoidant coping. Informational support received from the main support person also contributed significantly to the prediction of avoidant coping; however, more informational support received from the main person ($\beta = .38$, $p = .002$) contributed significantly to higher avoidant coping. In Step 3, the addition of emotional and informational support received from other support persons contributed only 0.5% of variance in avoidant coping above and beyond support received from the main support person, and neither emotional support nor information support contributed significantly. This hypothesis was not supported. No relationship was hypothesized between emotional support received from the main person. The association between informational support received by the main person and avoidant coping was in an unexpected direction. No significant association emerged between informational support received from other support persons and avoidant coping.

In the second equation, scores for the Avoidant Coping composite of the WOC-CA were the dependent variable. The covariate, hours spent online per day, was entered first. Next, informational support received online was entered.

The overall model was significant $F(2, 78) = 6.69, p = .002$. Step 1 indicated there was a significant association between hours spent online and Avoidant coping scores. $F\Delta(1, 79) = 5.10, p = .027$. However, the number of hours spent online was not a significant predictor in the final model. Step 2 of the model shows that the addition of informational support received online contributed significantly to predicting avoidant coping scores, $\Delta F(1, 78) = 7.85, p = .006$. Informational support received online accounted for 8.5% of unique variance, above and beyond the influence of hours spent online. More informational support ($\beta = .33, p = .006$) predicted more avoidant coping. Therefore, this hypothesis was not supported because the association between informational support received online and avoidant coping was in the opposite direction from what was expected.

Table 9

Summary of Hierarchical Regression Analysis for Variables of Emotional Support and Informational Support Received Offline by Main Support Person and Other Support Persons Predicting Positive Affect, Health Related Quality of Life, Focus on The Positive Coping and Avoidant Coping (N = 95)

Variable	df	R ²	ΔR ²	ΔF	B	SE B	β	t
Equation 1: Predicting Positive Affect								
Step 1 Hours online	1, 94	.04	.04	3.41				
					-.28	.15	-.19	-1.85
Step 2	2, 92	.13	.09	4.78*				
Emotional support—Main					.09	.03	.35	2.92**
Informational support—Main					-.02	.03	-.10	-0.86
Step 3	2, 90	.13	.01	.32				
Emotional support—Other					.02	.05	.07	0.38
Informational support—Other					.01	.05	.03	0.16
Equation 2: Predicting Health Related Quality of Life (FACT-G)								
Step 1 Hours online	1, 95	.03	.03	2.52				
					-1.06	.67	-.16	-1.59
Step 2	2, 93	.23	.21	12.61***				
Emotional support—Main					.50	.13	.43	3.83***
Informational support—Main					.04	.11	.05	0.41
Step 3	2, 91	.25	.02	1.03				
Emotional support—Other					.24	.20	.21	1.19
Informational support—Other					-.08	.21	-.08	-0.39

(continued)

Table 9 (continued)

<i>Variable</i>	<i>df</i>	<i>R</i> ²	ΔR^2	ΔF	<i>B</i>	<i>SE B</i>	β	<i>t</i>
Equation 3: Predicting Focus on the Positive Coping scores								
Step 1	1, 94	.00	.00	.13				
Hours online					-.13	.37	-.04	-0.36
Step 2	2, 92	.08	.07	3.70*				
Emotional support—Main					.13	.08	.22	1.72
Informational support—Main					.04	.06	.09	0.69
Step 3	2, 90	.09	.02	.86				
Emotional support—Other					.13	.12	.21	1.09
Informational support—Other					-.05	.13	-.08	-0.38
Equation 4: Predicting Avoidant Coping								
Step 1	1, 95	.06	.06	5.80*				
Hours online					1.54	.64	.24	2.41*
Step 2	2, 93	.16	.10	5.36**				
Emotional support—Main					-.32	.13	-.28	-2.39*
Informational support—Main					.34	.11	.38	3.21**
Step 3	2, 91	.16	.01	.26				
Emotional support—Other					-.15	.20	-.13	-0.72
Informational support—Other					.11	.22	.10	0.50

Note. Beta weights are reported for each separate step of the regression equation.
* $p < .05$. ** $p < .01$. *** $p < .001$.

Table 10

Summary of Hierarchical Regression Analysis for Variables of Emotional Support and Informational Support Received Online Predicting Positive Affect, Health Related Quality of Life, Focus on The Positive Coping and Avoidant Coping (N = 80)

<i>Variable</i>	<i>df</i>	<i>R²</i>	<i>ΔR²</i>	<i>ΔF</i>	<i>B</i>	<i>SE B</i>	<i>β</i>	<i>t</i>
Equation 1: Predicting Positive Affect								
Step 1 Hours online	1,78	.04	.04	3.36				
					-.29	.16	-.20	-1.83
Step 2 Emotional support online	1,77	.04	.00	.19				
					.01	.03	.06	.44
Equation 2: Predicting Health Related Quality of Life (FACT-G)								
Step 1 Hours online	1,79	.02	.02	1.20				
					-.85	.78	-.12	-1.10
Step 2 Emotional support online	1,78	.05	.04	2.93				
					.22	.13	.22	1.71
Equation 3: Predicting Focus on the Positive Coping scores								
Step 1 Hours online	1,78	.00	.00	.00				
					-.02	.40	-.01	-.06
Step 2 Emotional support online	1,77	.15	.15	13.31***				
					.23	.06	.44	3.65***
Equation 4: Predicting Avoidant Coping								
Step 1 Hours online	1,79	.06	.06	5.10*				
					1.60	.71	.25	2.26*
Step 2 Informational support online	1,78	.15	.09	7.85**				
					.30	.11	.33	2.80**

Note. Beta weights are reported for each separate step of the regression equation.

* $p < .05$. ** $p < .01$. *** $p < .001$.

Cluster Analysis

A cluster analysis was proposed initially to identify clusters or profiles of respondents participating in online cancer communities regarding social support and psychological well-being. The function of the analysis would have been to identify profiles of participants who may benefit from online support and from online interventions. There are no specific recommendations for sample size when conducting a cluster analysis; however, it is recommended that the ratio of participants to variables be considered (Dolnicar, 2002), and a rule of thumb is that a sample size of 200 is expected. Due to the smaller sample size in this study, the cluster analysis could not be conducted.

Exploratory Analyses

Several exploratory analyses were conducted in an effort to enhance understanding the results previously described. There were two goals for these analyses. The first goal was to explore the relationship between social interactions online and depressive symptoms, an important area that was not addressed in the original hypotheses. The second goal was to delve further into the findings related to unsupportive social interactions. Both sets of analyses were intended to contribute to an understanding of the findings in the present study.

None of the hypotheses addressed the relationships between social support and depressive symptoms. It was believed that depressive symptoms could contribute to the larger picture of this study. Therefore, bivariate correlations were run to examine the relationship between depressive symptoms and other variables of interest. Then, possible covariates were explored. Finally, a hierarchical multiple linear regression analysis was

conducted to determine if online social support variables were significantly associated with depressive symptoms.

To determine possible covariates, several analyses were conducted. A *t* test was used to compare means on the CES-D. There was no significant difference on the CES-D total scores for males ($M = 22.25$) and females ($M = 15.33$) in scores, $t(98) = 1.65, p = .103$. Therefore, gender was not included as a covariate. Age was not significantly correlated with participants' scores on CES-D total scores ($r = -.14, p = .183$).

Therefore, age was not included as a potential covariate in hypothesis testing. An ANOVA was conducted to determine whether significant differences exist between groups by ethnicity on depressive symptoms. Results of these analyses showed that ethnicity was not significantly related to CES-D scores, $F(5, 92) = 1.30, p = .269$.

Ethnicity was not used as a covariate in hypothesis testing.

Pearson correlations were conducted to determine if number of hours online per day or number of months since diagnosis were significantly associated with the dependent variables. The number of hours online per day was significantly correlated with participants' scores on the CES-D ($r = .30, p = .002$). Therefore, hours online was used as a covariate in this analysis. Time since diagnosis was also significantly associated with CES-D scores ($r = -.20, p = .048$). Therefore, number of hours online per day and time since diagnosis were used as covariates in exploratory analyses.

In the hierarchical multiple linear regression equation, total CES-D scores were the dependent variable. The covariates, hours spent online per day and months since diagnosis, were entered first. Next, emotional support received online was entered. In the final step, online unsupportive interactions were entered.

The overall model was significant, $F(4, 71) = 3.48, p = .012$. Step 1 indicated there was a significant association between the two covariates, hours spent online and time since diagnosis, and CES-D scores, $F\Delta(2, 73) = 5.92, p = .004$. These covariates predicted 13.9% of unique variance in CES-D scores. Hours spent online contributed significantly to CES-D scores, whereas the relationship between months since diagnosis was marginally significant. More hours spent online ($\beta = .25, p = .033$) predicted higher depressive symptoms (CES-D scores). More time since diagnosis ($\beta = -.22, p = .058$) predicted lower CES-D scores. Step 2 of the model shows that the addition of emotional support received online did not contribute significantly to predicting CES-D scores, $\Delta F(1, 72) = .53, p = .471$. Step 3 of the model indicated that the addition of unsupportive social interactions also did not contribute significantly to predicting CES-D scores $\Delta F(1, 71) = 1.56, p = .216$. Therefore, it was concluded that there was no significant association between emotional support received online and depressive symptoms. In addition, there was no significant relationship between online unsupportive interactions and depressive symptoms.

Table 11

Correlations Among Variables Tested in Exploratory Analyses

	1	2	3	4
1. Total Online Support	---			
2. Emotional Support Received Online	.98**	---		
3. Unsupportive Interactions Online	.29*	.25*	---	
4. CES-D	.21	.18	.33	---

* $p < .05$. ** $p < .01$.

Table 12

Summary of Hierarchical Regression Analysis for Variables of Emotional Support and Unsupportive Social Interactions Received Online Predicting Depressive Symptoms (N = 78)

Variable	df	R ²	ΔR ²	ΔF	B	SE B	β	t
Equation 1: Predicting Positive Affect								
Step 1	2,73	.14	.14	5.92**				
Hours online					1.49	.68	.25	2.18*
Months since diagnosis					-.06	.03	-.22	-1.93
Step 2	1,72	.15	.01	.53				
Emotional support online					-.08	.12	-.09	-0.73
Step 3	1,71	.16	.02	1.56				
Unsupportive social interactions online					4.66	3.73	.14	1.25

* $p < .05$.

The second set of exploratory analyses pertained to the unsupportive social interactions reported by participants. Hypothesis 2, which was supported, predicted lower overall levels of unsupportive social interactions would be received online than offline. However, the Unsupportive Social Interactions Inventory (USII) provides a greater understanding of the types of unsupportive social interactions through its subscale scores. Therefore, the subscale scores on the USII were compared for online and offline support. For a visual summary of the scale descriptive statistics, see Table 5.

Two paired samples *t* tests were conducted to compare scores on each USII subscale. First, Distancing subscale scores were compared. Both distancing interactions with the main support person and other support persons were compared to distancing experienced online. Distancing responses from the main support person ($M = 1.50$) were significantly higher than distancing unsupportive interactions online ($M = 1.22$); $t(77) = 3.58, p = .001$. Distancing unsupportive social interactions with other support persons ($M = 1.60$) were also higher than online unsupportive social interactions, $t(75) = 5.25, p < .001$.

In the second set of paired samples *t* tests, bumbling responses received in the various contexts were compared. Bumbling responses from the main support person ($M = 1.72$) were significantly higher than bumbling responses received online ($M = 1.28$); $t(78) = 7.66, p < .001$, as were bumbling responses received from the other support person ($M = 1.88$); $t(77) = 9.86, p < .001$.

Next, minimizing interactions offline by the main support person and by other support persons were compared to minimizing received online. Minimizing responses from the main support person ($M = 1.76$) were significantly higher than minimizing

unsupportive interactions online ($M = 1.47$); $t(78) = 3.97, p < .001$. Minimizing unsupportive social interactions with other support persons ($M = 1.77$) were also higher than online minimizing interactions, $t(75) = 5.04, p < .001$.

Finally, blaming responses offline by the main support person and by other support persons were compared to blaming responses online. Blaming responses from the main support person ($M = 1.22$) were significantly higher than blaming unsupportive interactions online ($M = 1.12$); $t(77) = 2.44, p = .017$. Blaming unsupportive social interactions with other support persons ($M = 1.26$) were also higher than online blaming interactions, $t(76) = 4.32, p < .001$. Consistent with the total USII scale score comparisons, mean scores for all USII subscales were higher for offline interactions than for online interactions.

Discussion

This chapter has been organized in five sections. First, the purpose of the present study will be reviewed. Next, the findings of the present study are summarized and are integrated with the literature. Next, strengths and limitations of the present study are addressed. Following the strengths and limitations is a discussion about the implications of the findings for psychological research, including suggestions for future research. Last, the implications for psychological practice are discussed.

Purpose of Study

This study was conceptualized as an early exploration of the relationships between traditional social support and social support received on the Internet by persons diagnosed with cancer. A limited body of research has emerged regarding participation in online support groups and other formal experiences online; however, there is little

research available that explores the mechanisms or structures of online social support, particularly the less formal support individuals find on their own.

The purpose of this study was to examine the differences and similarities between social support received online and social support received offline among people diagnosed with cancer who use the Internet for cancer-related support. Specifically, the study first compared types of support received online and offline, with specific differences predicted. Second, the study explored the differences between the level/degree of unsupportive social interactions experienced online versus offline. Third, based on the existing literature on social support and drawing upon Folkman's (1997) theory, the present study explored relationships between online social support and psychological outcomes including health-related quality of life, coping, and positive affect. The study explored how relationships between online social support and these psychological variables compare to the relationships reported between traditional social support and psychological well-being.

Summary of Findings

Hypothesis testing. The current study was built around three main hypotheses and one research question. The findings for each hypothesis, sub-hypothesis, and research question will be reviewed. Based on the limited available literature, the first hypothesis posited that there will be significant differences between social support received online and social support received offline. Specifically, two predictions regarding differences were posited. First, overall received social support was expected to be higher offline than online. Results of analysis comparing mean scores offline and online did support this hypothesis for both the main support person and other support

persons (i.e., overall received support was higher for both of these groups than for online experiences). Second, informational support was expected to be higher online than offline. Two analyses were conducted to test this hypothesis. First, informational social support received from the main support person was compared to informational social support received online. Informational support received from the main support person was higher than informational support received online, which was opposite the expected result. When comparing informational support received from other support persons to online informational support, no significant difference was found. Therefore, this hypothesis was not supported. This result will be discussed following the next paragraph.

There was no research basis for predicting differences in emotional support so the following research question was posed regarding emotional support: Are there significant differences between emotional support offline and online? Analyses revealed that more emotional support was received from the main support person and from other support persons than was received online.

Overall, participants reported receiving lower levels of support online than offline. Overall support, informational support, and emotional support received from the main support person were significantly higher than overall support, informational support, and emotional support received online. Overall support, informational support, and emotional support received from other support persons were also higher than those same types of support received online, but differences were not always significant. It is important to consider at least two possible explanations for these findings. First, it is possible that individuals generally receive less support (or less intense support) online than they do offline or in person. Certainly one would expect that individuals would

receive the most support from their main support persons. However, it is also possible that the existing measures of received social support do not capture the nature of online support completely. From a psychometric perspective, these measures perform adequately. However, with a larger sample size, factor analyses could be conducted and the structure of these measures could be compared for offline and online support. Measurement issues will be discussed later in this chapter.

Hypothesis 2 predicted that participants would report experiencing fewer unsupportive interactions online than offline. Mean scores on the USII were compared to detect differences. First, overall unsupportive social interactions with the main support person were compared to overall support received online. Next, overall unsupportive social interactions with other support persons were compared to overall support received online. Overall unsupportive social interactions with the main support person and other support persons were higher than overall unsupportive social interactions online; therefore, this hypothesis was supported. Exploratory analyses also revealed that the levels of distancing, bumblng, minimizing and blaming interactions were all significantly higher offline (with both the main support person and other support persons) than the level of these interactions experienced online.

It is possible that individuals simply have less contact with persons online, resulting in lower levels of negative interactions. Despite the possibility of having negative interactions online, it was expected that interactions and relationships online would perhaps be less intense and less emotionally fraught than those with persons offline. However, the investigator has recently observed a series of discussions occurring across cancer-related blogs about breast cancer identity that have resulted in very

personal dialogues with vitriolic remarks and personal attacks. A growing body of literature has emerged discussing “flaming,” or hostile expressions including insults, profanity, or obscenity in electronic communication (Alonzo & Aiken, 2004).

Furthermore, participants in the present study commented on negative interactions online in their responses to open-ended questions. These findings warrant additional research on the nature, intensity, and impact of unsupportive social interactions. In particular, it is would be helpful to understand the differential impact of unsupportive interactions in different contexts. For example, how does the impact of a “flame” from an anonymous blog commenter differ from the impact of a disagreement via email with an online friend whom the person met in a cancer support group? Finally, how do these unsupportive interactions differ in impact from a face-to-face interaction with a friend?

The third hypothesis tested relationships between subtypes of social support and psychological outcome variables. This hypothesis was based on evidence in the existing literature for certain relationships between traditional social support and psychological variables. In the present study these documented relationships were tested for offline, or traditional, social support to determine if they were replicated in this sample. Next, these same relationships were tested using the online social support variables. The findings will be reviewed first, and discussion about the findings will follow.

As a reminder, hours spent online per day emerged as having significant relationships with some of the outcome variables; therefore the number of hours spent online daily was used as a covariate for all regression analyses. Also, informational support received online was highly correlated with emotional support received online.

As a result, they were not both used in a single analysis due to concerns about

multicollinearity.

The first psychological variable addressed was positive affect. The hypotheses regarding positive affect predicted that emotional support would be significantly associated with positive affect. There were two sets of analyses conducted—one for support received offline and one for support received online. Hierarchical multiple linear regression analyses were conducted to test the associations hypothesized between received social support and positive affect. In the first regression analysis, emotional support and informational support received offline from the main support person and other support persons were entered with the covariate to determine if they predicted positive affect (using the subscale of the CES-D). Results of this analysis supported the hypothesis that emotional support from the main support person was a significant predictor of positive affect. Informational support from the main support person, emotional support from other support persons, and informational support from other support persons did not contribute to the prediction of positive affect. Therefore, the hypothesis was not supported for other support persons. In the second regression analysis, the relationship between emotional support received online and positive affect was tested. No significant relationship emerged and this hypothesis was not supported for online emotional support.

This hypothesis was based in the existing literature on social support; therefore, it was expected that emotional support received from the main support person would be related to positive affect. However, this relationship was not replicated for emotional support received online. Once again, it is possible that the lack of significant relationship can be explained by the lower overall support received online. It is also possible that

there is a less direct impact made by support online on affect. Additional research on the relationship between online support and affect should be explored.

The next hypothesis posited that emotional support would be positively associated with health related quality of life. Again, separate analyses were run for online and offline support. Hierarchical multiple linear regression analyses were conducted to test the associations hypothesized between received social support and health related quality of life. In the first regression analysis, emotional support and informational support received offline were entered with the covariate to determine if they predicted health related quality of life. Results of this analysis supported the hypothesis that emotional support from the main support person was a significant predictor of health related quality of life. Informational support from the main support person, emotional support from other support persons, and informational support from other support persons did not contribute to the prediction of health related quality of life. Therefore, the hypothesis was not supported for other support persons. In the second regression analysis, the relationship between emotional support received online and health related quality of life was tested. No significant relationship emerged; therefore, this hypothesis was not supported for online emotional support.

The next hypothesis predicted that both emotional support and informational support would be significantly associated with positive reappraisal coping (Focus on the Positive). Again, in the first regression analysis, informational and emotional support from the main support person was entered followed by informational and emotional support received by other persons. In this case, none of these types of support was a significant predictor of Focus on the Positive coping. Therefore, this hypothesis was not

supported for the main support person or for other support persons. In the second regression analysis the relationship between emotional support online and Focus on the Positive coping was evaluated. Emotional support received online contributed significantly to predicting Focus on the Positive total scores, thereby supporting this hypothesis for online support.

This is the only set of analyses in which the hypothesis was supported for online support but not for offline support. Reasons for the discrepancy and the lack of support for offline support will be described briefly. First, the conceptualization of positive reappraisal, positive reframing, or focusing on the positive varies. Folkman (1997) defined positive reappraisal as a form of meaning-based coping, which has been associated with positive psychological outcomes. However, other researchers have defined positive reappraisal as an emotion-focused coping strategy. As discussed in Chapter 2 and observed in the results in this study, emotion-focused coping has been associated with mixed psychological outcomes.

One possible explanation for the discrepant findings related to offline and online support may be found in the differences in support providers. Presumably, many of the main support persons and other support persons in an individual's life are not currently living with a cancer diagnosis (there will be exceptions, of course). In contrast, most support provided on cancer-related websites and communities comes from individuals who have been diagnosed with cancer. Therefore, the nature of the emotional support is likely to be different. A recurrent theme in the narrative responses in this study and previous research on online cancer experiences is that of individuals with cancer seeking persons who have had similar experiences. They are eager to connect with others with

similar diagnoses and treatments. Whereas seeking information is one component of this search, individuals are also looking for emotional connections with persons with shared experiences. One participant reported that his/her initial reason for seeking support online was that he/she “wanted to find someone in my area who was in the same trial as I was in, taking the same meds. [I] wanted to find someone with good outcomes.” Another participant reported that the best part of using the Internet for cancer support was, “I have met a wonderful, life-long friend with my same cancer and have met a few other promising friends. Also, [I] have heard stories about people with my type of cancer who have positive, acceptable outcomes.” These quotes speak to the importance of commonality in these online experiences.

Despite the anecdotal reports in this study of positive outcomes of Internet use for cancer-related support, social support received online was positively associated only with focusing on the positive, or positive reappraisal coping. Online social support was not associated with health related quality of life or positive affect. No clear explanation for these results has emerged; however, there are several possible explanations. First, it is possible that emotional support online has a more distal effect on affect and quality of life. Emotional support (solace and comfort) may lead more directly to positive cognition (which is not necessarily related to affect). Second, coping behavior can be modeled online and be imitated (or possibly learned), whereas quality of life and affect cannot be truly modeled or imitated. These psychological outcomes may depend on multiple (and different) factors. Longitudinal relationships between emotional support online and psychological outcomes should be explored. In addition, future research should investigate the importance of context and source of emotional support.

Given the difference between offline and online support and the importance of contact with others with similar experiences, at least two possible reasons for the pattern of findings for Focus on the Positive coping should be considered. First, it is possible that emotional support (expressions of concern and caring) is interpreted or received differently when received by others diagnosed with cancer. Previous research has demonstrated that emotional support is perceived as the most helpful type of support (Helgeson & Cohen, 1996). Perhaps in this context emotional support leads to more positive reappraisal. For example, a woman diagnosed recently with breast cancer might seek support on a breast cancer discussion board. If she receives comfort and encouragement from other women with breast cancer, she may respond with increased optimism or focusing on positive aspects.

Another possible explanation for the different relationship between emotional support online and focusing on the positive pertains to social norms and models established online in these communities encountered. An example of an item comprising the Focusing on the Positive scale is “[I] looked for the silver lining, so to speak; tried to look on the bright side of things.” This item is an example of positive reframing. It is also likely a very common refrain on cancer-related websites and communities. As one participant stated when describing the best thing about her experiences online, “I am not alone. There are others who have gone—and are going through the same disease(s)—who are healthy and whole because of their knowledge and attitude.” This issue of attitude as it relates to cancer outcomes is controversial among professionals and individuals with cancer; however, it is a clear message conveyed on many cancer-related websites that a positive attitude is important.

Social cognitive theory (Bandura, 1986) provides a useful perspective on this phenomenon. Social cognitive theorists sought to explain the ways in which people adopt behavior patterns. From this perspective, there is constant interaction between the person, his or her environment, and behaviors (Bandura). Bandura described observational learning, in which individuals learn from watching others model behaviors and then adopt/enact certain behaviors. Models tend to be imitated when the observer perceives the model as similar to herself (Bandura; Glanz, Rimer, & Lewis, 2002). One of the determinants of whether a person enacts a behavior is motivation. This motivation depends on the perceived costs and benefits of the observed behavior. In the case of positive reframing and the emphasis on a positive attitude, it is quite likely that individuals witness the reinforcement of positive self-talk, positive-reframing, and focusing on the positive in cancer-related websites and communities. Interactions with (and receiving support from) other persons who are reinforced for positive reappraisal could very well lead a person to engage more in this type of coping.

The final hypothesis regarding psychological variables predicted that informational support would be negatively associated with avoidant coping. Once again, two regression analyses were conducted. In the first equation, informational support and emotional support received by the main support person was tested as a predictor followed by support received from other support persons. Analyses revealed that informational support and emotional support from the main support person both contributed significantly to the prediction of avoidant coping. More emotional support predicted less avoidant coping. However, the relationship between informational support received from the main support person contradicted the hypothesis—more informational support

received from the main support person predicted more avoidant coping. When the relationship between support from other persons and avoidant coping was tested, neither informational nor emotional support emerged as a significant predictor. Thus, the hypothesis was not supported for other support persons. In the second regression analysis, online information support received online was evaluated as a predictor of avoidant coping. Again, informational support and avoidant coping were positively associated, which contradicted the hypothesis. Therefore, this hypothesis was not supported for informational support received online.

Avoidant coping has been classified by many as a form of emotion-focused coping (Austenfeld & Stanton, 2004). Emotion-focused coping strategies include efforts to regulate or reduce emotions associated with a stressor (Austenfeld & Stanton, 2004). Whereas it may seem counterintuitive that informational support (i.e., advice, guidance, or resources) is positively associated with avoidant coping, there are several possible explanations for this finding. It is possible that guidance and information contribute to an individual's heightened awareness about the stressor (in this case, cancer). Benefits of informational/guidance support include enhanced sense of control, reduced confusion, and movement towards action (Helgeson & Cohen, 1996). However, informational support may also lead to intense emotions resulting from (a) increased awareness of illness or (b) being overwhelmed by information or advice. Some participants reported that they used the Internet primarily to obtain information about their diagnoses.

One participant gave the following response to the question "*In your own words, what are your primary reasons for using the Internet for cancer-related issues?*"

Ovarian cancer is a killer disease and while my doctors told me it was a deadly

cancer, they would not give me any idea just how deadly it was. On the internet I was able to get statistics that my doctor wouldn't give me because they are so bleak. But it was information that I felt I needed to prepare both for the fight and for whatever might come next. I have a young son and I needed to know how soon the worst might come and what that 'worst' might look like. I guess my doctors thought that in order to keep hope alive, they had to keep the worst news from me, but that just made it harder for me to understand my situation.

In this case, the participant sought information actively that her doctors withheld. She made the choice that she would rather know the “worst” than to be ignorant. Other participants reported that their experiences with cancer-related websites were depressing and scary. It is possible that both offline and online, receiving more information, or different information than one would like, might lead to avoidant coping to manage the subsequent emotions.

Another possible explanation for the unexpected positive relationship between informational support and avoidant coping could relate to the advice element of informational support. Advice may vary widely in its intent, delivery, tone, and receipt. For example, the following two items are included in the ISSB Guidance/Informational Support subscale: “Suggested some action you should take” and “Helped you understand why you didn't do something well.” These forms of informational support could have a wide range of results depending on the recipient's mood, willingness to accept advice, or relationship with the person. Interpersonal factors shape the outcome, and it is quite possible that such advice might result in a negative emotional state, thereby leading the recipient to use emotion-focused strategies to manage distress. The two subscales of the Ways of Coping—Cancer that comprise the avoidant coping composite were Behavioral Escape/Avoidance and Cognitive Escape/Avoidance. These subscales included items such as “prepared for the worst,” “avoided being with people” and “tried to keep my

feelings from interfering.” It appears evident how receiving information could lead to preparing for the worst. The interplay between feelings and information could also contribute to avoidant coping. Information overload could lead to active attempts to manage the emotions that arise.

Another issue to consider is the significant positive association between hours spent online per day and avoidant coping. This study did not query online behaviors, goals, or the breakdown of time spent online sufficiently to speculate about the nature or patterns of Internet use by participants. However, it is possible that the Internet is used as a form of avoidant coping. Individuals may use the Internet for a variety of reasons, some of which could be attempts to manage distress. In fact, even online interactions could represent a distraction from or avoidance of a person’s offline support persons.

Each of these possible scenarios reinforces the importance of considering social support matching (i.e., measuring whether the type of support matches the individual’s need at that time). In addition, the effectiveness of social support must be addressed in future research.

Other Notable Findings

Several interesting findings emerged that were not hypothesized a priori. First, emotional support received online and informational support received online were very highly correlated ($r = .90$; $p < .001$), a phenomenon that was not observed regarding offline support. It is possible that this relationship is related to a measurement issue. As described elsewhere in this chapter, the measures of support (in this case the ISSB) have not been used to measure online support, and more psychometric data are needed to evaluate the application of this measure to online support. Another possibility is that

participants did not distinguish clearly between informational support and emotional support received online. Online communication of support may be perceived or received as less nuanced absent tone of voice, facial expressions, and other visual cues. More research is needed to explore this relationship further.

Next, there was a significant positive bivariate correlation between positive affect and avoidant coping ($r = .42; p < .001$), indicating that positive affect increased as avoidant coping increased. This association does not take into consideration any other variables; however, it was unexpected. One possible explanation for this finding relates to the fact that avoidant coping is used to avoid distress. Whereas avoidant coping is often considered maladaptive, the possibility exists that avoidant coping is sometimes effective. Therefore, it makes sense that avoidant coping strategies could result in decreased distress or an increase in positive affect. Again it is unknown whether this relationship would persist over time or in the presence of other factors.

Despite a significant positive relationship between emotional support from the main person and positive affect in the hierarchical multiple linear regression analyses, the raw bivariate correlation between emotional support from the main person and positive affect was negative ($r = -.28, p = .02$), suggesting that as emotional support increased, positive affect decreased. This result was unexpected and did reverse when the number of hours online was entered as a covariate. Again, it is unclear why the number of hours online would influence the relationship between offline emotional support and positive affect. In terms of the negative relationship, there are several possible explanations. Previous research has indicated that individuals with cancer may experience a sense of guilt or feeling like they are a burden to their loved ones and that support groups and

other interventions can alleviate this guilt (Fobair, 1998). It is possible that emotional support received from the main support person (most often a spouse or partner) can lead to an increase in distress or a decrease in positive affect. The provision of comfort and consolation may enhance the sense of guilt or being a burden in an individual with cancer. Another possibility is that emotional support related to cancer serves as a reminder of the illness and thereby affects positive affect. Finally, emotional support has been described as the most helpful form of support (Helgeson & Cohen, 1996); however, the importance of matching support to the needs of the individual must be considered. For instance, a person who is in need of health information or instrumental support (e.g., help with chores or financial support) but receives emotional support may be discouraged or disappointed. Under these circumstances, the emotional support may not be effective or well-received, which could result in lower positive affect. It may also be useful to consider a different form of this association. For example, experiencing low positive affect could elicit more emotional support from others. Individuals may seek emotional support when feeling low positive affect or higher distress.

Exploratory analyses investigated two areas. First, depressive affect was explored in relation to online interactions. Whereas depressive affect was not a focus of the study, the investigator wished to see if depressive affect was associated with online emotional support or unsupportive social interactions experienced online. Hours spent online and months since diagnosis were significantly associated with depressive affect, so they were entered as covariates for this analysis. The results of these analyses confirmed significant relationships between the covariates but no significant relationship between online emotional support and depressive symptoms or between total unsupportive interactions

and depressive symptoms. However, these relationships are worth exploring longitudinally and with more detail in future research.

The emergence of these two covariates deserves some attention. The number of hours online per day was significantly positively correlated with participants' scores on the CES-D ($r = .30, p = .002$), indicating that increased number of hours online was associated with higher levels of depressive symptoms. Time since diagnosis was significantly negatively associated with CES-D scores ($r = -.20, p = .048$), indicating that more time since diagnosis was associated with lower levels of depressive symptoms. Given the correlational nature of these analyses, they should be interpreted with caution. The association between hours online and depressive symptoms at first could substantiate claims that heavy Internet use leads to depression and isolation; however, this is likely an oversimplification. Depressed affect could lead individuals to use the Internet (as distraction, support, connection, etc.). Also, as will be discussed later, it is most important to know how these relationships depend on person-level characteristics, including personality, other supports, and demographics. The relationship between time since diagnosis and lower depressive symptoms makes intuitive sense, though these results would need to be explored further, given that the depressive symptoms were reported for the previous 7 days and the range of time since diagnosis was very wide.

Strengths and Limitations

The present study demonstrates several strengths and limitations, all of which will be relevant to the design of future research. Based on the transactional stress and coping theory proposed by Lazarus and Folkman (1984), this study was situated in a strong theoretical framework of social support. Given the lack of existing theory related to

online social support, this framework offered a strong basis for the current study. There was consistency across the theoretical framework, the measures selected, and the interpretation of findings. Despite the fact that not all tenets of this theory could be tested or supported in the present study, it provides us with a general framework to interpret the results and consider future research directions.

Another strength of the current study is its novel contribution to the literature on social support received online. This study is the first known to use validated measures of social support to explore support received online. These measures performed well in terms of reliability, which provides some information about their usefulness in evaluating online support. Comparing support received offline to support received online by the same persons allowed for exploration of this new area while maintaining a feasible recruitment timeline. There has been an explosion of cancer-related activity on the Internet, as well as controversy surrounding the outcomes and value of this activity. Anecdotally, participants and those individuals who assisted in recruitment were excited about this research and thanked the investigator for focusing on this area.

The diversity of the sample (on some dimensions) is another asset of the present study. Whereas the sample was limited in terms of race and ethnicity and gender, a broad range of cancer types, ages, time since diagnosis, and extent and intensity of cancer-related Internet use was represented. The ability to generalize the results of this study is restricted by limitations that will be discussed in the next section; however, the diversity of the sample enhances the likelihood that these results can be applied to the larger population.

Finally, this study reinforces the importance of studying social support, generally, and more specifically, the structure, nature, and sub-types of social support. Some significant relationships between traditional support and psychological variables were confirmed (e.g., between emotional support and positive affect), whereas others were contradicted (e.g., informational support and avoidant coping). These relationships were not consistent for support received online, but this finding further reinforces the notion that we must continue to explore social support and unsupportive social interactions online, as well as the relationships between social support and psychological functioning. More studies have focused on perceived support than received support, but the findings of the present study affirm that received support should be considered, as well.

In addition to demonstrating a number of strengths, the current study has several limitations. These limitations restrict the utility of the current study, but they provide valuable information for investigators wishing to conduct research related to online social support. First, the study is cross-sectional and affords no ability to know how associations might change over time. For example, consider the positive association between emotional support received online and focusing on the positive. There are at least three possible explanations for this association. First, it is possible that receiving more emotional support online leads to higher levels of focusing on the positive. Second, it is possible that focusing on the positive leads individuals to seek or receive more emotional support online. Finally, there could be a bidirectional relationship in which emotional support online and focusing on the positive reinforce each other. In addition, the cross-sectional, non-experimental nature of the study prevents one from making causal interpretations. Next, recruitment for this study was challenging. This barrier led

to another limitation, which was the slight under-powering of the regression analyses and the inability to conduct the cluster analysis planned. Recruitment was difficult primarily because no cancer organization was willing to assist in recruitment for the study; therefore, whole segments of the population were not reached by this study. In the future, the investigator would solicit support from specific organizations before finalizing the study. Facebook and contact with individual bloggers were the most fruitful sources of recruitment, but these channels led to a restricted sample and may have over-sampled individuals from certain groups. On a related note, the survey failed to ask participants to state how they had heard about the study or where they were located geographically. Though this information was not essential for data analysis, it would have been helpful for context and to inform the design of future studies.

The lack of diversity in some respects also limits the generalizability of the results of the current study. The sample was overwhelmingly White and female. As a result, the perspectives of males and ethnic minority groups are not represented. Ironically, diversity of the sample also served as a possible limitation. The wide range of months since diagnosis and frequency or intensity of use of cancer-related websites and communities may have affected the results. In fact, a number of individuals reported minimal to no use of cancer-related websites or communities. As mentioned in Chapter 3, the decision to not impose a cut-off for quantity or frequency of Internet use was intentional and reflected the goal of recruiting a diverse set of participants. However, a sample must be sufficiently homogeneous to be able to describe the experiences of a set of individuals.

In terms of time since diagnosis, the investigator received a number of emails,

comments, and responses to survey items indicating that some participants felt the questions did not apply to them at this point. One woman who started the survey wrote, “And some, like me, lost their ‘cancer identity’ fairly quickly. Two years post cancer was about when I lost the idea of cancer being part of my life...” It would have been difficult to pre-screen for this issue, as there is no clear linear relationship between time since diagnosis and “cancer identity”; however, it would make sense to adjust the questions for this reason in the future. Adding a “not applicable” response option is one possibility, as is allowing individuals to respond retrospectively to support received when they were closer to the time of diagnosis. Each of these options would alter the results and data but could be considered.

Related to the issue of individuals who felt that questions were not relevant to their experiences is the issue of missing data. This study was limited by a high level of missing data. The investigator made the decision not to require responses to individual questions because it was important to her to allow participants to skip questions that made them uncomfortable or that they did not wish to answer. However, this decision probably affected the data quality. Some of this missing data can be explained by the fact that some participants did not complete items or measures that they did not find relevant to their current situations. Nearly 200 participants ($n = 192$) consented and began the study. As reported, the final sample consisted of 102 participants, and the data set still reflected a high level of missing data on some scales. The investigator pilot-tested the survey for length so that she could provide an estimated completion time; however, it is likely that some participants found that the survey took too long to complete. It is also possible that other reasons contributed to the missing data. Many of the participants

responded to the questions about Internet use and online behaviors but stopped once they reached the first structured measure. Boredom, mistrust, and frustration are all possible explanations for early termination.

These limitations provide important information that can be used to improve future research designs. For example, the investigator could query participants who terminated early about their reasons for discontinuing the survey. Next, it would be very easy to obtain information about geographic region and where participants heard about the study. In the future it will be important to offer guidance to those individuals who find questions do not apply to their situations. It is also critical that the directions for measures are clear and that the selected measures and their respective time frames are relevant to the broadest possible range of participants. Finally, study and survey design should be altered to maximize survey completion and minimize missing data. This goal may require shortening surveys, providing more information about the expected length of time required for the survey, and enhancing instructions to participants.

Implications for Psychological Research and Future Directions

The psychological literature on Internet activity for individuals diagnosed with cancer has focused on two areas primarily: (a) outcomes of structured interventions (e.g., facilitated support groups) and (b) the dissemination and consumption of health information on the Internet. In the related area of cancer prevention, many online behavior change interventions have been evaluated. The evaluation of structured interventions is extremely important and informs intervention development. However, it is also important to evaluate interactions and support occurring naturally on the Internet through blogs, discussion boards, patient-initiated groups, social network sites, and other

mechanisms. Participants in the present study reported using a variety of sites to seek support and information. Thirty-nine percent ($n = 40$) reported having participated in an online cancer-related support group, and 51% of these groups were peer support groups with no facilitator. The majority of participants were receiving support through other channels.

To date psychological studies related to online social support have been largely descriptive, focusing on participants' narrative descriptions of received support and have included a number of qualitative studies related to participation in cancer-related groups online. This qualitative research is very important in beginning to understand the functions, benefits, and challenges of online interactions. It is also important to understand the structure of this support and these interactions. One way to advance our understanding is to use psychometrically sound measures to evaluate the nature and structure of social support received online. This study was a first step in implementing such measures to evaluate online social support and relate it to other psychological constructs. In considering the results of this study, it is evident that more attention should be paid to the measures used.

Several suggestions are offered here regarding the measurement of social support online. First, as described earlier, these measures demonstrated strong internal consistency; however, little else is known about their psychometric properties when they are used to measure online support. Furthermore, at least one extremely high correlation was identified in the subscales of the Inventory of Socially Supportive Behaviors (ISSB)—between emotional support received online and informational support received online. This high correlation suggests that these subscales are not measuring separate

constructs and are redundant, a relationship that has not been found when evaluating offline social support. One simple future study that would allow us to evaluate the utility of these measures would be an analysis of the measure properties. For example, an investigator could administer the ISSB (or the modified version used in the present study), the Unsupportive Social Interactions Inventory, and other social support measures to individuals who use online communities and website for support. With a large enough sample (200-300), the researcher could conduct a factor analysis to examine the factor structures of the instruments when used to measure online support. In addition, construct and criterion validity could be evaluated. After evaluating the use of existing measures, it may be evident that there is a need for new Internet-specific social support measures or modifications to existing measures, and scale development studies could follow.

Recent developments in technology have introduced the concept of automated data analysis. Essentially, this technology allows an investigator to use machine learning techniques to “train” computer software to retrieve and classify pieces of text (Huang, Nambisan, & Uzuner, 2010). Very recently the first known paper using this technology to identify types of expressions of social support on Internet message boards was presented at a conference (Huang, Nambisan, & Uzuner). Coincidentally, the study pertained to informational and emotional support communicated in online breast cancer and prostate cancer message boards. This type of analysis is intended to reduce the burden of qualitative content analysis, especially when analyzing narrative data spanning years. Huang and colleagues analyzed 10,000 messages using this approach. The first step in the process is to code or classify a subset of messages manually (for complete information on this process and the background of automated content analysis, see

Huang, Nambisan, & Uzuner). The next step is to clean or pre-process the sentences. The next step involves training the machine to classify the subset of messages in a manner similar to the manual classification. Finally, the products of the classification are examined, and the machine is now used to classify a larger set of messages with the “trained classifier” (Huang, Nambisan, & Uzuner, 2010, p. 7).

In the study described by the authors, this system was used to classify messages from the cancer-related boards in two groups, informational support and emotional support. They concluded based on their preliminary results that the automated classification process had an accuracy rate of 87.5%. Certainly there are limitations and risks involved in using this approach, but it reveals possibilities for widespread data aggregation, analysis, and interpretation that were unimaginable until very recently. Qualitative research on online support continues to be important, as does quantitative research using valid and reliable messages. This automated analysis approach, however, offers the potential to analyze vast amounts of data to better understand the structure and nature of social support offered and received online.

Additional research is needed regarding the relationships between social support received online and psychological well-being. It may be useful to continue to test the relationships found between traditional (offline) social support and measures of psychological functioning; however, exploratory research identifying unique and new relationships between online support and well-being is also warranted. In addition, longitudinal research should be conducted to examine these relationships over time, as the cross-sectional design of the present study describes only associations at one time point.

An initial goal of this study was to conduct a cluster analysis to identify clusters or profiles of respondents participating in online cancer communities regarding social support and psychological well-being. The function of the analysis would have been to identify profiles of participants who may benefit from online support and from online interventions. Unfortunately, the sample size was too small in the present study to conduct these analyses. This line of research is still worthwhile; however, as is suggested in the following paragraphs, the approach proposed in the current study may have been overly simplistic. In all likelihood, the process of identifying those persons who benefit most from online support will involve consideration of offline support networks, personality factors, and other variables not included in the proposed approach.

As a discipline, psychology has been somewhat slower to explore both the potential and nuanced nature of Internet communities and relationships than fields such as sociology, education, public health, and information science. Understandably, there exists some skepticism and uncertainty regarding the use and value of new media and technology. Also logical is the concern that Internet use may result in isolation rather than connection and the worry that online interactions may replace face-to-face relationships. In fact, an early study of heavy Internet use demonstrated negative effects on psychological well-being (e.g., increased depression and loneliness) in 169 persons in their first 1-2 years online (Kraut, Patterson, Lundmark, Kiesler, Mukophadhyay, & Scherlis, 1998). However, several years later these same researchers found that these negative effects dissipated over time and participants experienced improvements in communication and well-being (Kraut, Kiesler, Boneva, Cummings, Helgeson, & Crawford, 2002). Interestingly, this follow-up study also discovered that those who were

extroverted and already had strong support benefited, whereas introverted individuals and those with less support had poorer outcomes. These findings support arguments for considering benefits and disadvantages of Internet use in the context of personality, other support, and current stressors.

Viewed in conjunction with Kraut et al.'s findings (2002), the results of the current study suggest that perhaps some of the critics and advocates of Internet use for support have oversimplified the issues involved. The current study resulted in some counterintuitive findings, as well as some differences between online and offline support. However, it is possible that these results are not accurate, or are at least complicated by other factors. Haythornthwaite (2007) suggested that part of what leads to such strong contrasting opinions about online groups is the reliance on oversimplified dichotomies. She proposed that this same tendency is used to oversimplify the notion of community and the nature of communication, both of which are quite relevant to the present study. Haythornthwaite and others have suggested that a more nuanced view can reveal "how online and offline interaction are synergistic in maintaining relations and thus of communities" (Haythornthwaite, 2007, p. 130). Her suggested approach will be discussed in the next several paragraphs.

The present study relied on the online/offline dichotomy in its design. However, the results and research from other fields confirm that this division may not be accurate or helpful. For example, it was known before the study that individuals with cancer correspond and interact with their offline friends and family via the Internet. However, it became clear in the results that the crossing of the offline/online divide can happen the other way, as well. Forty-six percent ($n = 47$) of participants in the current study reported

that they had met someone online who became a friend in person. It is impossible to know how these friends were categorized when participants responded to the survey. This finding supports the notion that we must consider support received from all sources in context. Given that the goal of the present study was to learn more about the experiences of individuals diagnosed with cancer, a more nuanced perspective would be helpful. In fact many of the narrative responses challenged quantitative study findings, leading the investigator to think that a more holistic approach should be taken. In all likelihood, online and offline social support are more complementary and connected than distinct. Future psychological research in this area can be informed by theoretical work in other fields. The next paragraphs will discuss one possible approach.

Sociologists have studied online communication and relationships for over two decades. One theoretical approach used to study online relationships has been social network analysis. This approach

focuses on what is happening between people, within collectives and across boundaries, in order to find what kind of collective exists. Geography, co-location, face-to-face meetings, and home bases can be unbundled from communication, information exchange, knowledge sharing and provision of advice, social support, goods and services. Interpersonal interactions and relationships can be examined for the way they build network level characteristics... This opens up the possibility of finding community among co-located or distributed participants, maintained solely offline or online, or maintained through combinations of computer-media and face-to-face communication.

(Haythornthwaite, 2007, p. 125)

The language of social network analysis is dense and complex, but the core concepts are fairly simple to understand. The previous quote illustrates how this approach is contextual and does not rely on simple definitions of community. Instead of

separating settings and focusing online on person-computer interaction, dyads interacting online, or even the functioning of small groups online, social network analysis emphasizes computer-supported social networks that develop and thrive in multiple contexts (Garton, Haythornthwaite, & Wellman, 1997). Before delving into the terminology and concepts of social network analysis, it is important to consider the notion of community.

First, there are researchers and theorists who reject the notion of a virtual community, believing that online interactions are superficial and devoid of true connection. In fact, the term *pseudocommunity* has been used to describe the current state of perceived disconnectedness (Haythornthwaite, 2007). Haythornthwaite described the perspective of those writers who concentrate on alienation and loneliness associated with mass-media communication and the lack of strong local communities. However, there is a more optimistic view of online communities that includes evidence of people connecting despite geographic distance, feeling part of a group, and engagement with other people (Haythornthwaite). This perspective argues that online communities do exist and can enhance and complement existing support. Furthermore, it underscores the notion that we are all part of multiple communities, many of which are defined personally rather than dictated externally. The present study may have relied too heavily on external definitions of community (e.g., a single support group, a message board). Future research could benefit from a network perspective.

A social network approach shifts from a focus on the individual to a focus on relations and interactions among social actors (Garton, Haythornthwaite, & Wellman, 1997). The unit of analysis is not a single person but the relation. Individuals are

considered social *actors*. Social actors are connected or *tied* to each other through the maintenance of *relations*, are “characterized by content, direction and strength” (Garton, Haythornthwaite, & Wellman, p. 4). Relations may consist of the exchange of information, social support or more tangible items like money or services (Haythornthwaite, 2007). When such an exchange is maintained by two actors, they have a tie. Ties can be strong (when actors maintain multiple relations, especially those relations are intimate or socially supportive) or weak, when contact is infrequent and there is low intimacy (Haythornthwaite). Patterns of ties comprise social networks, and social network analysts consider where resources are combined and distributed, all of which can lead to network-level effects in which all members of a network may benefit beyond a person-to-person reciprocity (Haythornthwaite). This added value or benefit is referred to as *social capital*, which is a characteristic of stable networks. From a social network perspective, communities that combine face-to-face and computer-mediated communication can be more effective than communities that rely on one mode (Haythornthwaite).

This social network perspective highlights potential limitations of the present study and provides exciting directions for future research. The results of the current study suggest that support from a main support person has a more direct or stronger effect on psychological outcomes than support from other persons. However, beyond measuring received support separately for the main support person and other support persons, the current study did not consider the nature or strength of connection between the participants and other persons. Participants reported information about specific dyadic interactions and general impressions of their experiences with social support, but

there was no exploration of ties or the context of support. Future research should examine the relations maintained in various contexts and the strength of ties in these contexts. A multidimensional approach should be used, and possible interactions between the nature of relations, the strength of ties, and the effectiveness of support exchanges should be considered. Finally, future research should explore how online communities and offline communities may enhance each other, and the nature of communities that rely on both online and offline connections. This research is likely to entail more complicated methodologies and study designs, but it is likely to provide a much more useful perspective on social networks.

Implications for Psychological Practice

In addition to the research implications, the present study offers important information for psychological professionals. The quantitative data are enlightening, and the narrative, qualitative data (which will be analyzed formally later) provide a rich perspective on the benefits and challenges of online social support. The initial set of survey items about Internet use and behaviors emphasizes the diversity of experiences, as well as the prominence of these activities in the lives of some participants. The results of this study echoed reasons for Internet use by individuals diagnosed with cancer provided in other studies, including the five themes identified by Dickerson and colleagues (Dickerson, Boehmke, Ogle, and Brown, 2006): (a) retrieving and filtering information; (b) seeking hope in new treatment options; (c) self-care; (d) empowering patients; and (e) using the Internet for peer support. Psychological professionals working with individuals diagnosed with cancer can utilize this information to provide clients with a sense of what individuals have found online and how they have used Internet resources. In addition,

psychologists can direct clients to a variety of resources, depending on the needs of the client.

The descriptive information about the risks and benefits can better equip psychological professionals to discuss the possibilities of social support online. One participant in the study reported, “One time, I went to a blog, and the statements that people were making were idiotic and misinformed. I spent about 3 minutes and took my doctors' advice not to even go onto these sights [*sic*]”. Clearly this participant had a negative experience visiting this blog; however, the comment reflects a general mistrust or apprehension about online resources that may characterize many health-related professionals. It is important that professionals and patients approach these resources with a critical perspective. Patients must be educated about how to evaluate health information online and how to determine whether a particular Internet resource may be helpful or harmful. However, these resources should be presented in a balanced manner and the choice should be that of the individual patient. It is easy to accept or reject online support completely, but these extremes are unlikely to benefit clients. With the advent of new technology and information, Internet interventions and resources are quite prevalent. Advice like that issued by the oncologists referenced above will not help patients become critical consumers of these resources.

This study also reinforces the notion of online support as an adjunctive or alternative for individuals. Online resources and support offer alternatives to face-to-face contact for individuals diagnosed with cancer. For reasons described previously (e.g., the anonymity of online communities, ease of access, and freedom from the constraints of face-to-face contact), cancer-related groups and websites may be a viable and preferable

option for some patients. Major systems of care like the Veterans Administration are implementing telehealth or telemedicine interventions in which medical (and psychosocial) care is delivered through the use of audiovisual equipment (webcams, telephone, and instant messaging programs). These interventions allow practitioners to reach individuals in rural communities or those who are unable to travel. One participant in the present study reported, “I still feel alone. I live in a rural area, and most of my friends and family live far away. I sought online communities to find people whose experiences were similar to mine, and am still searching. . .” Whereas this person has not found what he/she is seeking, other participants describe being able to connect with others through the Internet in a way that was not available otherwise. Psychological professionals can explore these options with clients and may be able to recommend online resources as an adjunct to psychotherapy.

Given the inconsistent (and sometimes absent) links between social support received online and psychological variables, more information is needed to determine the interventions that may have the most beneficial effects. For example, there was a significant positive association between emotional support received online and focusing on the positive. However, as mentioned earlier, these results were cross-sectional and limited by the measures used. The time frame for received emotional support was not specified and the time frame for focusing on the positive was the past six months. It will be important to explore this relationship longitudinally and with more specificity. However, it is clear that social support continues to merit attention from psychological professionals designing interventions for individuals diagnosed with cancer.

Psychologists can explore the dimensions and effectiveness of social support received by

their patients. In terms of intervention designs, the primary interventions implemented and studied by psychologists online have been online support groups. There are many options for alternative interventions to enhance social support, both online and offline.

Imerman Angels (<http://www.imermanangels.org>) is an example of a not-for-profit organization designed to enhance support for individuals diagnosed with cancer. The organization matches individuals with cancer (“support seekers”) with a “mentor angel,” who is a person who “has been there.” Typically individuals are matched with a person who has been diagnosed with the same type of cancer for whom more time has elapsed since diagnosis. The website states clearly that mentors are not supposed to offer medical advice. Rather, the relationship is described as natural and friendly. Resources are offered to both support seekers and mentors, and the organization offers a number of suggestions of ways for mentor-mentee pairs to be in contact, including telephone, Skype, email, instant messaging, and face-to-face meetings. These matches are made regardless of geographic location, and the organization guarantees that a support seeker will be matched within one business day of contacting the organization. It is unclear whether any formal program evaluation has been conducted, but such programs provide additional resources and potential opportunities to explore the characteristics of online social support.

Finally, mental health professionals will benefit from continued research in the area of social support, unsupportive interactions, the process of seeking support and the effectiveness of support.

Conclusion

The current study explored a recent trend for individuals diagnosed with cancer: the use of Internet resources for online support. The purpose of this study was to compare social support received online and social support received offline among people diagnosed with cancer who use the Internet for cancer-related support. Specifically, the study first compared types of support received online and offline. Based on the existing literature, the study then explored relationships between offline and online social support and other psychological variables, including health-related quality of life, coping, and positive affect. Participants reported a variety of reasons for using cancer-related websites and online communities and provided information regarding types, frequency, and intensity of online activities.

Most hypotheses were supported for traditional social support but were not supported for online support. Consistent with hypotheses, total social support received offline was higher than support received online. Emotional support and informational support were significantly higher offline than online. As predicted, participants experienced fewer unsupportive interactions online than offline. Also consistent with the hypotheses, emotional support received from the main support person was positively associated with positive affect and health related quality of life, whereas online emotional support was only positively associated with Focus on the Positive coping. Contrary to the hypotheses, hierarchical regression equations indicated that received informational support was positively associated with avoidant coping. This study contributes to the literature as one of the first studies to explore in a systematic manner social support received online. The results have important research and clinical implications for

understanding the distinct and overlapping elements of social support received online and offline by individuals with cancer.

The complexity of the questions and the findings in this study suggest that new directions for future research may be warranted. In addition to providing new information about social support received online, the results suggest new questions to explore in future research. The addition of theory that includes a view of networks as multidimensional and personal may enhance our understanding of received social support. Findings from the current study reinforce the need for additional research on social support received online and the use of online cancer-related websites and communities.

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APPENDIX A
BACKGROUND QUESTIONNAIRE

Please provide the following background information about yourself.

1. Today's Date _____Month _____Day _____ Year

2. Date of Birth: _____

3. What is your race? _____

3. What is your racial/ethnic background? (Check all that apply)

- African American (Black)
- Caucasian (White)
- Asian/Pacific Islander
- Hispanic/Latino/Latina
- American Indian
- Other (specify) _____

4. What is your gender? _____

5. What is your religious background/affiliation?

- Catholic
- Protestant
- Jewish
- Muslim
- Hindu
- Buddhist
- Other(specify) _____
- Prefer not to answer

6. When were you first diagnosed with cancer? _____
(Month and Year)

7. With which type of cancer were you diagnosed?

- | | |
|---|--|
| <input type="checkbox"/> Bladder | <input type="checkbox"/> Melanoma |
| <input type="checkbox"/> Breast | <input type="checkbox"/> Non-Hodgkin Lymphoma |
| <input type="checkbox"/> Cervical Cancer | <input type="checkbox"/> Ovarian |
| <input type="checkbox"/> Colon or Rectal | <input type="checkbox"/> Pancreatic |
| <input type="checkbox"/> Endometrial | <input type="checkbox"/> Prostate |
| <input type="checkbox"/> Head and Neck Cancer | <input type="checkbox"/> Thyroid |
| <input type="checkbox"/> Kidney (Renal Cell) Cancer | <input type="checkbox"/> Uterine |
| <input type="checkbox"/> Leukemia | <input type="checkbox"/> Other (specify) _____ |
| <input type="checkbox"/> Lung (Including Bronchus) | |

8. Is this your first diagnosis of cancer?

- Yes
 No

9. Have you experienced any other major medical/health conditions before?

- Yes
 No

If so, what type? _____

10. What type(s) of medical treatment did you undergo for your cancer? Please check any that apply.

- Surgery
 Radiation
 Chemotherapy
 Biotherapy (or immune therapy)
 Other: _____

11. What is your current relationship status?

- | | |
|---|------------------------------------|
| <input type="checkbox"/> Single | <input type="checkbox"/> Separated |
| <input type="checkbox"/> Dating | <input type="checkbox"/> Widowed |
| <input type="checkbox"/> Married or partnered | |
| <input type="checkbox"/> Divorced | |

12. What are your current living arrangements? (Check all that apply)

- Live alone
- Live with spouse/partner
- Live with my children
- Live with other family members
- Live with non-family members

13. How much formal education have you had?

- 8th Grade or less
- some high school/trade school
- high school graduate/GED
- trade/business school
- some college
- college graduate
- post-graduate degree

Are you currently employed?

- Yes, full-time
- Yes, part-time
- Retired
- Not employed, but not retired.

If no, when were you last employed? _____ - _____

APPENDIX B
ONLINE BEHAVIORS QUESTIONNAIRE

Approximately how often do you do the following activities?

	Every day	Nearly every day	2-3 times per week	Once per week	2-3 times per month	Once a month	Less than once a month	N/A I have never done this
Writing a blog or online journal about cancer								
Reading blogs about cancer								
Participating in chat rooms/real-time support groups								
Posting on cancer-related discussion boards								
Seeking health information online								
Spending time on social networking sites unrelated to cancer								
Using the Internet for other purposes (e.g., news, entertainment, personal correspondence).								

Approximately how much time do you spend time doing the following activities **each week**?

	Less than 30 minutes	30-60 minutes	1-2 hours	2-4 hours	4-6 hours	More than 6 hours	N/A I do not do this activity
Writing a blog or online journal about cancer							
Reading blogs about cancer							
Participating in chat rooms/real-time support groups							
Posting on cancer-related discussion boards							
Seeking health information online							
Spending time on social networking sites unrelated to cancer							
Using the Internet for other purposes (e.g., news, entertainment, personal correspondence).							

Have you ever met someone online who became a personal friend?

- Yes
- No

How many hours **per day** do you use the Internet?

- Less than 30 minutes
- 30-60 minutes
- 1-2 hours
- 2-3 hours
- 3-4 hours
- 4-5 hours
- 5-6 hours
- More than 6 hours

How many days **per week** do you use the Internet to visit cancer-related sites?

- 1
- 2
- 3
- 4
- 5
- 6
- 7

What are your primary reasons for using the Internet? (Check all that apply):

- News & Current events
- Get Information
- Play Games
- Email
- Staying in touch with friends
- Staying in touch with family

- Meeting new people
- Work
- Instant messaging
- Reading Blogs
- Writing Blog
- Seeking Support
- Social Networking
- Entertainment
- Download Files
- Marketing
- Online Banking
- Online Education
- Other (specify): _____

What are your primary reasons for using cancer-related websites and communities?
(Check all that apply):

- Get health-related information from professionals
- Get health-related information from other patients
- Make friends
- Find people who understand what I am going through
- Share my story
- Help others
- Find resources
- Explore treatment recommendations and options
- Do research on my diagnosis
- Look for information about clinical trials
- Vent
- Ask for help
- Other (please specify): _____

What type of Internet access do you have at home?

- No home access
- Dial-up
- High-speed DSL
- High speed broadband, satellite, or cable Internet
- I have access but I do not know what type

Have you participated in an online support group related to cancer?

- Yes
- No

If yes, who facilitated the group?

- There was no facilitator—it was peer support
- A patient facilitated

- A psychological professional (social worker, psychologist, etc.) facilitated the group
- A medical professional (physician, nurse, etc) facilitated the group
- A member of a religious or spiritual organization facilitated the group
- A non-professional person (who was not a patient) facilitated the group

If you participated in an online support group, please tell us a bit about your experience:

Have you participated in an offline or in-person support group related to cancer?

- Yes
- No

For all:

What were the initial reasons that led you to seek support or information online?

What has been the best or most satisfying part of your experiences online?

What has been the worst or least satisfying part of your experiences online?

In your own words, what are your primary reasons for using the Internet? _____

APPENDIX C

CENTER FOR EPIDEMIOLOGIC STUDIES DEPRESSION SCALE (CES-D)

For each of the following statements, please circle the number that best describes how often you felt or behaved this way **during the past week**.

	0 Rarely or None of the Time (Less than 1 Day)	1 Some or a Little of the Time (1-2 Days)	2 Occasionally or a Moderate Amount of Time (3-4 Days)	3 Most or All of the Time (5-7 Days)
DURING THE PAST WEEK				
I was bothered by things that usually don't bother me.	0	1	2	3
I did not feel like eating; my appetite was poor. .	0	1	2	3
I felt that I could not shake off the blues even with help from my family or friends.	0	1	2	3
I felt that I was just as good as other people.	0	1	2	3
I had trouble keeping my mind on what I was doing.	0	1	2	3
I felt depressed.	0	1	2	3
I felt that everything I did was an effort. . . .	0	1	2	3
I felt hopeful about the future.	0	1	2	3
I thought my life had been a failure.	0	1	2	3
I felt fearful.	0	1	2	3
My sleep was restless.	0	1	2	3
I was happy.	0	1	2	3

	0 Rarely or None of the Time (Less than 1 Day)	1 Some or a Little of the Time (1-2 Days)	2 Occasionally or a Moderate Amount of Time (3-4 Days)	3 Most or All of the Time (5-7 Days)
DURING THE PAST WEEK				
I talked less than usual.	0	1	2	3
I felt lonely.	0	1	2	3
People were unfriendly.	0	1	2	3
I enjoyed life.	0	1	2	3
I had crying spells. . .	0	1	2	3
I felt sad.	0	1	2	3
I felt that people disliked me.	0	1	2	3
I could not get "going". .	0	1	2	3

APPENDIX D
WAYS OF COPING-CANCER

Cancer is generally a difficult or troubling experience for those who have it. The following are some possible problems associated with cancer. Please indicate which one has been the most difficult or troubling for you in the **past six months** by circling the appropriate number.

1. Fear and uncertainty about the future due to cancer
2. Limitations in physical abilities, appearance, or lifestyle due to cancer
3. Pain, symptoms, or discomfort from illness or treatment
4. Problems with family or friends related to cancer
5. Other (please specify _____)

How stressful has this problem been for you in the **past six months**?

1. EXTREMELY STRESSFUL
2. STRESSFUL
3. SOMEWHAT STRESSFUL
4. SLIGHTLY STRESSFUL
5. NOT STRESSFUL

When we experience stress in our lives, we usually try to manage it by trying out different ways of thinking or behaving. These can be called ways of “coping”. Sometimes our attempts are successful in helping us solve a problem or feel better and other times they are not. The next set of items is on the ways of coping you may have used in trying to manage the most stressful part of your cancer. Please read each item below and indicate **how often you have tried this in the past six months** in attempting to cope with the specific problem circled above. It is important that you answer every item as best you can.

How often have you tried this <u>in the past 6 months</u> to manage the specific problem circled above?					
	DOES NOT APPLY/ NEVER	RARELY	SOMETIMES	OFTEN	VERY OFTEN
1. Concentrated on what I had to do next—the next step.	0	1	2	3	4
2. Felt that time would make a difference—the only thing to do was to wait.	0	1	2	3	4
3. Did something which I didn't think would work, but at least I was doing something.	0	1	2	3	4
4. Talked to someone to find out more about the situation.	0	1	2	3	4
5. Criticized or lectured myself.	0	1	2	3	4
6. Tried not to close off my options but leave things open somewhat.	0	1	2	3	4

How often have you tried this **in the past 6 months** to manage the specific problem circled above?

	DOES NOT APPLY/ NEVER	RARELY	SOMETIMES	OFTEN	VERY OFTEN
7. Hoped a miracle would happen.	0	1	2	3	4
8. Went along with fate; sometimes I just have bad luck.	0	1	2	3	4
9. Went on as if nothing were happening.	0	1	2	3	4
10. Tried to keep my feelings to myself.	0	1	2	3	4
11. Looked for the silver lining, so to speak; tried to look on the bright side of things.	0	1	2	3	4
12. Slept more than usual	0	1	2	3	4
13. Looked for sympathy and understanding from someone.	0	1	2	3	4
14. Was inspired to do something creative.	0	1	2	3	4
15. Tried to forget the whole thing.	0	1	2	3	4
16. Tried to get professional help.	0	1	2	3	4
17. Changed or grew as a person in a good way.	0	1	2	3	4
18. Waited to see what happen before doing anything.	0	1	2	3	4
19. Made a plan of action and followed it.	0	1	2	3	4
20. Let my feelings out somehow.	0	1	2	3	4
21. Came out of the experience better than when I went in.	0	1	2	3	4
22. Talked to someone who could do something concrete about the problem.	0	1	2	3	4
23. Tried to make myself feel better by eating, drinking, smoking, or using drugs.	0	1	2	3	4
24. Took a big chance or did something risky.	0	1	2	3	4
25. Tried not to act too hastily or follow my first hunch.	0	1	2	3	4
26. Found new faith.	0	1	2	3	4
27. Rediscovered what is important in life.	0	1	2	3	4
28. Changed something so things would turn out all right.	0	1	2	3	4

How often have you tried this in the past 6 months to manage the specific problem circled above?					
	DOES NOT APPLY/ NEVER	RARELY	SOMETIMES	OFTEN	VERY OFTEN
29. Avoided being with people in general.	0	1	2	3	4
30. Didn't let it get to me; refused to think about it too much.	0	1	2	3	4
31. Asked a relative or friend I respect for advice.	0	1	2	3	4
32. Kept others from knowing how bad things are.	0	1	2	3	4
33. Made light of the situation; refused to get too serious about it.	0	1	2	3	4
34. Talked to someone about how I was feeling.	0	1	2	3	4
35. Took it out on other people.	0	1	2	3	4
36. Drew on my past experiences; I was in a similar experience before.	0	1	2	3	4
37. Knew what had to be done, so redoubled my efforts to make things work.	0	1	2	3	4
38. Refused to believe it would happen.	0	1	2	3	4
39. Came up with a couple of different solutions to the problem.	0	1	2	3	4
40. Tried to keep my feelings from interfering with other things too much.	0	1	2	3	4
41. Changed something about myself.	0	1	2	3	4
42. Wished that the situation would go away or somehow be over with.	0	1	2	3	4
43. Had fantasies or wishes about how things might turn out.	0	1	2	3	4
44. Prayed.	0	1	2	3	4
45. Prepared myself for the worst.	0	1	2	3	4
46. Went over in my mind what I would say or do.	0	1	2	3	4
47. Thought of how a person I admire would handle this situation and used that as a model.	0	1	2	3	4
48. Reminded myself how much worse things could be.	0	1	2	3	4
49. Tried to find out as much as I could about cancer and my own case.	0	1	2	3	4
50. Treated the illness as a challenge or battle to be won.	0	1	2	3	4

51. Depended mostly on others to handle things or tell me what to do.	0	1	2	3	4
52. Lived one day at a time or took one step at a time.	0	1	2	3	4

53. Tried something entirely different from any of the above. Please describe _____

APPENDIX E

FUNCTIONAL ASSESSMENT OF CANCER THERAPY—GENERAL (FACT-G)

Below is a list of statements that other people with your illness have said are important. Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

<u>PHYSICAL WELL-BEING</u>		Not at all	A little bit	Some-what	Quite a bit	Very much
GP1	I have a lack of energy	0	1	2	3	4
GP2	I have nausea	0	1	2	3	4
GP3	Because of my physical condition, I have trouble meeting the needs of my family	0	1	2	3	4
GP4	I have pain	0	1	2	3	4
GP5	I am bothered by side effects of treatment	0	1	2	3	4
GP6	I feel ill	0	1	2	3	4
GP7	I am forced to spend time in bed	0	1	2	3	4

<u>SOCIAL/FAMILY WELL-BEING</u>		Not at all	A little bit	Some-what	Quite a bit	Very much
GS1	I feel close to my friends	0	1	2	3	4
GS2	I get emotional support from my family	0	1	2	3	4
GS3	I get support from my friends	0	1	2	3	4
GS4	My family has accepted my illness	0	1	2	3	4
GS5	I am satisfied with family communication about my illness..	0	1	2	3	4
GS6	I feel close to my partner (or the person who is my main support).....	0	1	2	3	4

Q1	Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please mark this box <input type="checkbox"/> and go to the next section.					
GS7	I am satisfied with my sex life.....	0	1	2	3	4

Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

<u>EMOTIONAL WELL-BEING</u>		Not at all	A little bit	Some-what	Quite a bit	Very much
GE1	I feel sad	0	1	2	3	4
GE2	I am satisfied with how I am coping with my illness.....	0	1	2	3	4
GE3	I am losing hope in the fight against my illness	0	1	2	3	4
GE4	I feel nervous.....	0	1	2	3	4
GE5	I worry about dying.....	0	1	2	3	4
GE6	I worry that my condition will get worse	0	1	2	3	4

<u>FUNCTIONAL WELL-BEING</u>		Not at all	A little bit	Some-what	Quite a bit	Very much
GF1	I am able to work (include work at home)	0	1	2	3	4
GF2	My work (include work at home) is fulfilling.....	0	1	2	3	4
GF3	I am able to enjoy life.....	0	1	2	3	4
GF4	I have accepted my illness.....	0	1	2	3	4
GF5	I am sleeping well	0	1	2	3	4
GF6	I am enjoying the things I usually do for fun	0	1	2	3	4
GF7	I am content with the quality of my life right now.....	0	1	2	3	4

APPENDIX F

INVENTORY OF SOCIALLY SUPPORTIVE BEHAVIORS (ISSB)

Please think about your main support person (the person you count on the most).

What is your main support person's relationship to you? (Check one only)

- My spouse/partner
- My son/daughter
- My brother/sister
- My father/mother
- Other family member
- Friend
- Other (please specify) _____

For each statement, please indicate: How often has your **MAIN SUPPORT PERSON** responded this way in helping you deal with your experience with cancer?

1 Not at all	2 Once or twice	3 About once a week	4 Several times a week	5 About every day
-----------------	--------------------	------------------------	---------------------------	----------------------

1.	Looked after a family member when you were away.	1	2	3	4	5
2.	Was right there with you (physically) in a stressful situation.	1	2	3	4	5
3.	Provided you with a place where you could get away for awhile.	1	2	3	4	5
4.	Watched after your possessions when you were away (pets, plants, home, apartment, etc.).	1	2	3	4	5
5.	Told you what she/he did in a situation that was similar to yours.	1	2	3	4	5
6.	Did some activity together to help you get your mind off of things.	1	2	3	4	5
7.	Talked with you about some interests of yours.	1	2	3	4	5
8.	Let you know that you did something well.	1	2	3	4	5
9.	Went with you to someone who could take action.	1	2	3	4	5
10.	Told you that you are OK just the way you are.	1	2	3	4	5
11.	Told you that she/he would keep the things that you talk about private-just between the two of you.	1	2	3	4	5
12.	Assisted you in setting a goal for yourself.	1	2	3	4	5
13.	Made it clear what was expected of you.	1	2	3	4	5
14.	Expressed esteem or respect for a competency or personal quality of yours.	1	2	3	4	5
15.	Gave you some information on how to do something.	1	2	3	4	5
16.	Suggested some action that you should take.	1	2	3	4	5
17.	Gave you over \$25.	1	2	3	4	5

For each statement, please indicate: How often has your **MAIN SUPPORT PERSON** responded this way in helping you deal with your experience with cancer?

	1 Not at all	2 Once or twice	3 About once a week	4 Several times a week	5 About every day
18.	Comforted you by showing you some physical affection.				1 2 3 4 5
19.	Gave you some information to help you understand a situation you were in.				1 2 3 4 5
20.	Provided you with some transportation.				1 2 3 4 5
21.	Checked back with you to see if you followed the advice you were given.				1 2 3 4 5
22.	Gave you under \$25.				1 2 3 4 5
23.	Helped you understand why you didn't do something well.				1 2 3 4 5
24.	Listened to you talk about your private feelings.				1 2 3 4 5
25.	Loaned or gave you something (a physical object other than money) that you needed.				1 2 3 4 5
26.	Agreed that what you wanted to do was right.				1 2 3 4 5
27.	Said things that made your situation clearer and easier to understand.				1 2 3 4 5
28.	Told you how he/she felt in a situation that was similar to yours.				1 2 3 4 5
29.	Let you know that he/she will always be around if you need assistance.				1 2 3 4 5
30.	Expressed interest and concern in your well-being.				1 2 3 4 5
31.	Told you that she/he feels very close to you.				1 2 3 4 5
32.	Told you who you should see for assistance.				1 2 3 4 5
33.	Told you what to expect in a situation that was about to happen.				1 2 3 4 5
34.	Loaned you over \$25				1 2 3 4 5

For each statement, please indicate: How often has your **MAIN SUPPORT PERSON** this way in helping you deal with your experience with cancer?

1 Not at all	2 Once or twice	3 About once a week	4 Several times a week	5 About every day
-----------------	--------------------	------------------------	---------------------------	----------------------

35.	Taught you how to do something.	1	2	3	4	5
36.	Gave you feedback on how you were doing without saying it was good or bad.	1	2	3	4	5
37.	Joked and kidded to try to cheer you up.	1	2	3	4	5
38.	Provided you with a place to stay.	1	2	3	4	5
39.	Pitched in to help you do something that needed to be done.	1	2	3	4	5
40.	Loaned you under \$25.	1	2	3	4	5

For each statement, please indicate: How often have your **OTHER FAMILY AND FRIENDS** responded this way in helping you deal with your experience with cancer?

1 Not at all	2 Once or twice	3 About once a week	4 Several times a week	5 About every day
-----------------	--------------------	------------------------	---------------------------	----------------------

1.	Looked after a family member when you were away.	1	2	3	4	5
2.	Was right there with you (physically) in a stressful situation.	1	2	3	4	5
3.	Provided you with a place where you could get away for awhile.	1	2	3	4	5
4.	Watched after your possessions when you were away (pets, plants, home, apartment, etc.).	1	2	3	4	5
5.	Told you what she/he did in a situation that was similar to yours.	1	2	3	4	5
6.	Did some activity together to help you get your mind off of things.	1	2	3	4	5
7.	Talked with you about some interests of yours.	1	2	3	4	5
8.	Let you know that you did something well.	1	2	3	4	5
9.	Went with you to someone who could take action.	1	2	3	4	5
10.	Told you that you are OK just the way you are.	1	2	3	4	5
11.	Told you that she/he would keep the things that you talk about private-just between the two of you.	1	2	3	4	5
12.	Assisted you in setting a goal for yourself.	1	2	3	4	5
13.	Made it clear what was expected of you.	1	2	3	4	5
14.	Expressed esteem or respect for a competency or personal quality of yours.	1	2	3	4	5
15.	Gave you some information on how to do something.	1	2	3	4	5
16.	Suggested some action that you should take.	1	2	3	4	5
17.	Gave you over \$25.	1	2	3	4	5

For each statement, please indicate: How often have your **OTHER FAMILY AND FRIENDS** responded this way in helping you deal with your experience with cancer?

	1 Not at all	2 Once or twice	3 About once a week	4 Several times a week	5 About every day
18.	Comforted you by showing you some physical affection.				
19.	Gave you some information to help you understand a situation you were in.				
20.	Provided you with some transportation.				
21.	Checked back with you to see if you followed the advice you were given.				
22.	Gave you under \$25.				
23.	Helped you understand why you didn't do something well.				
24.	Listened to you talk about your private feelings.				
25.	Loaned or gave you something (a physical object other than money) that you needed.				
26.	Agreed that what you wanted to do was right.				
27.	Said things that made your situation clearer and easier to understand.				
28.	Told you how he/she felt in a situation that was similar to yours.				
29.	Let you know that he/she will always be around if you need assistance.				
30.	Expressed interest and concern in your well-being.				
31.	Told you that she/he feels very close to you.				
32.	Told you who you should see for assistance.				
33.	Told you what to expect in a situation that was about to happen.				
34.	Loaned you over \$25				

For each statement, please indicate: How often have your **OTHER FAMILY AND FRIENDS** responded this way in helping you deal with your experience with cancer?

1 Not at all	2 Once or twice	3 About once a week	4 Several times a week	5 About every day
-----------------	--------------------	------------------------	---------------------------	----------------------

35.	Taught you how to do something.	1	2	3	4	5
36.	Gave you feedback on how you were doing without saying it was good or bad.	1	2	3	4	5
37.	Joked and kidded to try to cheer you up.	1	2	3	4	5
38.	Provided you with a place to stay.	1	2	3	4	5
39.	Pitched in to help you do something that needed to be done.	1	2	3	4	5
40.	Loaned you under \$25.	1	2	3	4	5

For each statement, please indicate: How often have **PEOPLE ONLINE** responded this way in helping you deal with your experience with cancer?

When thinking about online support, please think of the people you have known primarily through the Internet. Do not include family, friends or other people you have known primarily offline (not on the Internet).

1 Not at all	2 Once or twice	3 About once a week	4 Several times a week	5 About every day
-----------------	--------------------	------------------------	---------------------------	----------------------

1.	Looked after a family member when you were away.	1	2	3	4	5
2.	Was right there with you (physically) in a stressful situation.	1	2	3	4	5
3.	Provided you with a place where you could get away for awhile.	1	2	3	4	5
4.	Watched after your possessions when you were away (pets, plants, home, apartment, etc.).	1	2	3	4	5
5.	Told you what she/he did in a situation that was similar to yours.	1	2	3	4	5
6.	Did some activity together to help you get your mind off of things.	1	2	3	4	5
7.	Talked with you about some interests of yours.	1	2	3	4	5
8.	Let you know that you did something well.	1	2	3	4	5
9.	Went with you to someone who could take action.	1	2	3	4	5
10.	Told you that you are OK just the way you are.	1	2	3	4	5
11.	Told you that she/he would keep the things that you talk about private-just between the two of you.	1	2	3	4	5
12.	Assisted you in setting a goal for yourself.	1	2	3	4	5
13.	Made it clear what was expected of you.	1	2	3	4	5
14.	Expressed esteem or respect for a competency or personal quality	1	2	3	4	5
15.	Gave you some information on how to do something.	1	2	3	4	5
16.	Suggested some action that you should take.	1	2	3	4	5
17.	Gave you over \$25.	1	2	3	4	5

For each statement, please indicate: How often have PEOPLE ONLINE responded this way in helping you deal with your experience with cancer?

	1 Not at all	2 Once or twice	3 About once a week	4 Several times a week	5 About every day
18.	Comforted you by showing you some physical affection.				1 2 3 4 5
19.	Gave you some information to help you understand a situation you were in.				1 2 3 4 5
20.	Provided you with some transportation.				1 2 3 4 5
21.	Checked back with you to see if you followed the advice you were given.				1 2 3 4 5
22.	Gave you under \$25.				1 2 3 4 5
23.	Helped you understand why you didn't do something well.				1 2 3 4 5
24.	Listened to you talk about your private feelings.				1 2 3 4 5
25.	Loaned or gave you something (a physical object other than money) that you needed.				1 2 3 4 5
26.	Agreed that what you wanted to do was right.				1 2 3 4 5
27.	Said things that made your situation clearer and easier to understand.				1 2 3 4 5
28.	Told you how he/she felt in a situation that was similar to yours.				1 2 3 4 5
29.	Let you know that he/she will always be around if you need assistance.				1 2 3 4 5
30.	Expressed interest and concern in your well-being.				1 2 3 4 5
31.	Told you that she/he feels very close to you.				1 2 3 4 5
32.	Told you who you should see for assistance.				1 2 3 4 5
33.	Told you what to expect in a situation that was about to happen.				1 2 3 4 5
34.	Loaned you over \$25				1 2 3 4 5

For each statement, please indicate: How often have PEOPLE ONLINE responded this way in helping you deal with your experience with cancer?

1 Not at all	2 Once or twice	3 About once a week	4 Several times a week	5 About every day
-----------------	--------------------	------------------------	---------------------------	----------------------

35.	Taught you how to do something.	1	2	3	4	5
36.	Gave you feedback on how you were doing without saying it was good or bad.	1	2	3	4	5
37.	Joked and kidded to try to cheer you up.	1	2	3	4	5
38.	Provided you with a place to stay.	1	2	3	4	5
39.	Pitched in to help you do something that needed to be done.	1	2	3	4	5
40.	Loaned you under \$25.	1	2	3	4	5

APPENDIX G
UNSUPPORTIVE SOCIAL INTERACTIONS INVENTORY

This questionnaire asks additional questions about how your family and friends other than your primary support person have responded to you about your experience with cancer.

For each statement, please indicate: How often has your MAIN SUPPORT PERSON responded this way about your experience with cancer?

1 Never responds this way	2 Rarely responds this way	3 Sometimes responds this way	4 Often responds this way
------------------------------------	----------------------------------	-------------------------------------	---------------------------------

Felt that I was over-reacting about my experience with cancer.	1	2	3	4
When I was talking with this person about my experience with cancer, he or she did not give me enough time, or made me feel like I should hurry.	1	2	3	4
Made "should/shouldn't have" comments about my experience with cancer, such as "you should/shouldn't have _____". .	1	2	3	4
Didn't seem to know what to say, or seemed afraid of saying/doing the "wrong" thing.	1	2	3	4
Refused to provide the type of help or support I was looking for.	1	2	3	4
After becoming aware of my illness, this person responded to me with uninvited physical touching, such as hugging.	1	2	3	4
Said I should look on the bright side.	1	2	3	4
Said "I told you so," or made some similar comment about my experience with cancer.	1	2	3	4
Seemed to be telling me what he or she thought I wanted to hear.	1	2	3	4
In responding to me about my experience with cancer, this person seemed disappointed in me.	1	2	3	4
When I was talking to this person about my experience with cancer, he or she changed the subject before I wanted to. . . .	1	2	3	4
Felt that I should stop worrying about my illness and just forget about it. . . .	1	2	3	4
Asked me "why" questions about my role in my illness, such as, "Why did/didn't you _____?"	1	2	3	4
Felt that I should focus on the present and/or the future, and that I should forget about what's happened and get on with my life.	1	2	3	4
Tried to cheer me up when I was not ready to cheer up about my experience with cancer	1	2	3	4

For each statement, please indicate: How often has your **MAIN SUPPORT PERSON** responded this way about your experience with cancer?

1 Never responds this way	2 Rarely responds this way	3 Sometimes responds this way	4 Often responds this way
------------------------------------	----------------------------------	-------------------------------------	---------------------------------

In responding to me about my experience with cancer, this person refused to take me seriously. 1 2 3 4

Told me to be strong, to keep my chin up, or that I shouldn't let it bother me. . 1 2 3 4

Did not seem to want to hear about my experience with cancer. 1 2 3 4

Told me that I had gotten myself into the situation in the first place, and that now I must deal with the consequences. 1 2 3 4

Did some things for me that I wanted to do and could have done myself. . 1 2 3 4

Discouraged me from expressing feelings about my experience with cancer, such as anger, fear, or sadness. 1 2 3 4

Felt that it could have been worse or that it was not as bad as I thought. . 1 2 3 4

From the person's tone of voice, expression, or body language, I got the feeling that he or she was uncomfortable talking with me about my experience with cancer. 1 2 3 4

Made comments that blamed me or tried to make me feel responsible for my illness. . 1 2 3 4

This questionnaire asks additional questions about how your family and friends other than your primary support person have responded to you about your experience with cancer.

For each statement, please indicate: How often have your OTHER FAMILY AND FRIENDS responded this way about your experience with cancer?

1 Never responds this way	2 Rarely responds this way	3 Sometimes responds this way	4 Often responds this way	
Felt that I was over-reacting about my experience with cancer.	1	2	3	4
When I was talking with this person about my experience with cancer, he or she did not give me enough time, or made me feel like I should hurry.	1	2	3	4
Made "should/shouldn't have" comments about my experience with cancer, such as "you should/shouldn't have _____". .	1	2	3	4
Didn't seem to know what to say, or seemed afraid of saying/doing the "wrong" thing.	1	2	3	4
Refused to provide the type of help or support I was looking for.	1	2	3	4
After becoming aware of my illness, this person responded to me with uninviting physical touching, such as hugging.	1	2	3	4
Said I should look on the bright side.	1	2	3	4
Said "I told you so," or made some similar comment about my experience with cancer.	1	2	3	4
Seemed to be telling me what he or she thought I wanted to hear.	1	2	3	4
In responding to me about my experience with cancer, this person seemed disappointed in me.	1	2	3	4
When I was talking to this person about my experience with cancer, he or she changed the subject before I wanted to. . . .	1	2	3	4
Felt that I should stop worrying about my illness and just forget about it. . . .	1	2	3	4
Asked me "why" questions about my role in my illness, such as, "Why did/didn't you _____?"	1	2	3	4
Felt that I should focus on the present and/or the future, and that I should forget about what's happened and get on with my life.	1	2	3	4
Tried to cheer me up when I was not ready to cheer up about my experience with cancer	1	2	3	4

For each statement, please indicate: How often have your OTHER FAMILY AND FRIENDS responded this way about your experience with cancer?

1 Never responds this way	2 Rarely responds this way	3 Sometimes responds this way	4 Often responds this way
------------------------------------	----------------------------------	-------------------------------------	---------------------------------

In responding to me about my experience with cancer, this person refused to take me seriously. 1 2 3 4

Told me to be strong, to keep my chin up, or that I shouldn't let it bother me. . 1 2 3 4

Did not seem to want to hear about my experience with cancer. 1 2 3 4

Told me that I had gotten myself into the situation in the first place, and that now I must deal with the consequences. 1 2 3 4

Did some things for me that I wanted to do and could have done myself. . 1 2 3 4

Discouraged me from expressing feelings about my experience with cancer, such as anger, fear, or sadness. 1 2 3 4

Felt that it could have been worse or that it was not as bad as I thought. . 1 2 3 4

From the person's tone of voice, expression, or body language, I got the feeling that he or she was uncomfortable talking with me about my experience with cancer. 1 2 3 4

Made comments that blamed me or tried to make me feel responsible for my illness. . 1 2 3 4

This questionnaire asks some additional questions about how people online have responded to you about your experience with cancer.

For each statement, please indicate: How often have PEOPLE ONLINE responded this way about your experience with cancer?

1 Never responds this way	2 Rarely responds this way	3 Sometimes responds this way	4 Often responds this way
------------------------------------	----------------------------------	-------------------------------------	---------------------------------

Felt that I was over-reacting about my experience with cancer.	1	2	3	4
When I was talking with this person about my experience with cancer, he or she did not give me enough time, or made me feel like I should hurry.	1	2	3	4
Made "should/shouldn't have" comments about my experience with cancer, such as "you should/shouldn't have _____". .	1	2	3	4
Didn't seem to know what to say, or seemed afraid of saying/doing the "wrong" thing.	1	2	3	4
Refused to provide the type of help or support I was looking for.	1	2	3	4
After becoming aware of my illness, this person responded to me with uninviting physical touching, such as hugging.	1	2	3	4
Said I should look on the bright side.	1	2	3	4
Said "I told you so," or made some similar comment about my experience with cancer.	1	2	3	4
Seemed to be telling me what he or she thought I wanted to hear.	1	2	3	4
In responding to me about my experience with cancer, this person seemed disappointed in me.	1	2	3	4
When I was talking to this person about my experience with cancer, he or she changed the subject before I wanted to. . . .	1	2	3	4
Felt that I should stop worrying about my illness and just forget about it.	1	2	3	4
Asked me "why" questions about my role in my illness, such as, "Why did/didn't you _____?".	1	2	3	4
Felt that I should focus on the present and/or the future, and that I should forget about what's happened and get on with my life.	1	2	3	4
Tried to cheer me up when I was not ready to cheer up about my experience with cancer	1	2	3	4

For each statement, please indicate: How often have PEOPLE ONLINE responded this way about your experience with cancer?

1 Never responds this way	2 Rarely responds this way	3 Sometimes responds this way	4 Often responds this way
------------------------------------	----------------------------------	-------------------------------------	---------------------------------

In responding to me about my experience with cancer, this person refused to take me seriously. 1 2 3 4

Told me to be strong, to keep my chin up, or that I shouldn't let it bother me. . 1 2 3 4

Did not seem to want to hear about my experience with cancer. 1 2 3 4

Told me that I had gotten myself into the situation in the first place, and that now I must deal with the consequences. 1 2 3 4

Did some things for me that I wanted to do and could have done myself. . 1 2 3 4

Discouraged me from expressing feelings about my experience with cancer, such as anger, fear, or sadness. 1 2 3 4

Felt that it could have been worse or that it was not as bad as I thought. . 1 2 3 4

From the person's tone of voice, expression, or body language, I got the feeling that he or she was uncomfortable talking with me about my experience with cancer. 1 2 3 4

Made comments that blamed me or tried to make me feel responsible for my illness. . 1 2 3 4

Vita

Jessye Cohen was born in Syracuse, NY. She received her Bachelor of Arts in Comparative Literature and Women's Studies from Smith College in 1995. After graduating from Smith, she worked as a grant writer for nonprofit organizations in New York City before returning to Richmond, Virginia. Jessye worked in residential psychiatric facilities for children and adolescents. She received a Master of Science in Rehabilitation Counseling from Virginia Commonwealth University in 2002. During and following her Master's Program, Jessye worked as a clinician in a community mental health agency and a regional jail. She also worked as a research assistant in the Division of Addiction Psychiatry in the Department of Psychiatry at VCU Health System. Jessye continued her work in the Division of Addiction Psychiatry as a research coordinator in clinical health psychology from 2002 to 2005 before returning to VCU to pursue her Ph.D. in Counseling Psychology. She became interested in psychological issues related to coping with serious or chronic illness during this time. She has developed strong interests in research methodology and health psychology, with an emphasis on psychosocial oncology. She will begin her predoctoral internship at the Portland VA Medical Center this summer.