

The Wants and Needs of Older Cancer Survivors When Searching
for Online Social Support

by

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DALHOUSIE UNIVERSITY
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Abstract

In recent years, the Internet has emerged as a popular tool for providing social support to chronically-ill populations. However, research is limited in understanding the distinct needs of older cancer survivors who are less comfortable with Internet technology than younger generations. In this qualitative study, semi-structured interviews were conducted with 10 cancer survivors over age 50. Thematic analysis was used to help understand their wants and needs when using the Internet for social support. Four main themes were found: 1) the need to take charge of health outcomes, 2) the benefits of knowing they are not alone in their cancer journey, 3) how to maximize online resources for cancer support, and 4) how the spirit of survivorship is imperative for quality of life. These findings can be used to guide the delivery of online social support interventions, as well as facilitate easy access to such interventions by older cancer survivors.

List of Abbreviations Used

BB	Bulletin Board
OSG	Online Support Group
FAQ	Frequently Asked Questions
QoL	Quality of Life

Chapter 1: Introduction

Cancer is the leading cause of death by disease in Canada. In 2011, over 177,800 new cases of cancer and 75,000 deaths from cancer will occur in Canada alone (Canadian Cancer Society, 2011). The likelihood of being diagnosed with cancer is high. According to data released this year, 52% of men and 48% of women will be diagnosed with a new cancer in their lifetime and, overall, there is an estimated five year survival rate of 62% (Canadian Cancer Society, 2011). Although overall survival rates are still low, progress is being made in improving health outcomes. Cancer was once considered incurable, but is now becoming a controllable disease for millions of people (Arora, Rutten, Gustafson, Moser, & Hawkins, 2005).

Twombly (2004) states that the term “cancer survivor” can mean different things to different people. For some, it can mean “patient”, while to others, it means someone who is “post treatment”. Still, others use the term to reflect a person who is cancer free but cares for a loved one with the disease (Twombly, 2004). There has been considerable debate regarding the terminology used to describe described those undergoing trauma as “victims” or “survivors” (Cunneen & Salter, 2008). The passivity of the concept, victim, was rejected in favour of a term that more appropriately recognized and affirmed a person’s abilities to manage, survive and integrate their experience through the recovery process (Cunneen & Salter, 2008).

Although researchers use the term differently depending on their research interests, this study defines "cancer survivor" as anyone who has ever had a diagnosis of cancer. The term is used to reflect survivorship as a continuum, beginning at the moment of diagnosis and continuing for the remainder of life (National Cancer Institute, n.d.).

Cancer survivors need to deal with the emotional upheaval created by their illness, with concerns being raised about disease recurrence, treatment options, fear of death, worries about social isolation and stigmatization (Anderson, Shapiro, Farrar, Crespin, & Wells-DiGregorio, 2005). Social support has proven effective in helping cancer survivors lessen the physical and psychological hardships that their cancer diagnosis can bring (Anderson et al., 2004; Bloom, Stewart, Johnston, Banks, & Fobair, 2001). Although social support has traditionally been given and received in-person, new technologies have enabled people to connect in a variety of ways.

Unlike conventional face-to-face support groups, online social support can provide significant improvements in cancer survivors' quality of life, including decreased anxiety and depression (Lieberman et al., 2003; Lieberman & Goldstein, 2005; Winzelberg et al., 2003), increased empowerment (Hoybye, Johansen, & Tjornoj-Thomsen, 2005), and increased perceived coping abilities (Harper Chelf, Deshler, Hillman & Durazo-Arzu, 2000). Online social support interventions can accommodate thousands of cancer survivors at any time, and can link those with rare conditions to others experiencing the same conditions (Eysenbach, 2003). They can improve the size of cancer survivors' social networks by providing them with more opportunities to draw from a variety of experiences and perspectives, to meet persons with whom they share similar experiences, and to enhance the quality of their social networks (White & Dorman, 2001).

Cancer survivors seem to be more motivated to seek interpersonal relationships with other cancer survivors than with family members (Wright, 2002), possibly because cancer survivors often feel a need to conceal their distress to protect family, friends, and

doctors (Byrne, Ellershaw, Halcombe & Salmon, 2002). The Internet may provide a comfortable medium for cancer survivors to discuss sensitive issues with others who understand their experience, while maintaining the protectiveness they feel toward their family and friends.

Cost Effectiveness of Online Social Support Interventions

Cancer is the cause of 30% of deaths in Nova Scotia and costs the province over 140 million dollars a year in total health care spending (Coleman, 2002). Studies have indicated that psychosocial interventions can offset medical costs by at least 20% (Chiles, Lambert & Hatch, 1999; Simpson, Carleson, & Trew, 2001) with these gains sustained for two years following the psychosocial intervention (Simpson et al., 2001). Given that the direct and indirect costs of cancer treatment in Canada are \$17.9 billion (Patra, Popova, Rehm, Flint, & Giesbrecht, 2007), this could result in a saving of over \$3.58 billion dollars per year.

Studies show that 35%-45% of all cancer survivors experience significant emotional distress (Carleson et al., 2004; Zabora, Brintzenhofeszoc, Curbow, Hooker, & Piantadosi, 2001). Patients with unresolved psychosocial care issues are five times more likely to use community health services, two times as likely to visit emergency departments and more likely to require third and fourth treatments of chemotherapy. All of these issues place significant demand on Canada's health care system (Ashbury, Findlay, Reynolds, & McKerracher, 1998).

Study Purpose

In recent years, many people have chosen the Internet as their medium for connecting with others. However, since approximately 90% of new cancer cases will be

diagnosed in persons over the age 50 (Canadian Cancer Society/ National Cancer Institute of Canada, 2007), it is important to know how to help older cancer survivors use the Internet for social support, since they are at an age that is known to have less proficiency with computer use (Wilbright et al., 2006). Internet proficiency for older adults has been shown to be a barrier to effective computer use, with over 50% of seniors having difficulty retrieving previously-found information and 33% of seniors stating that their lack of computer skills limits their enjoyment of this technology (Gatto & Tak, 2008). To date, little research has been conducted that aids in understanding the distinct needs of older cancer survivors, who are less likely to be comfortable with Internet technology than younger generations (Thayer & Ray, 2006). Given this shift in comfort with the Internet for older adults (Wilbright et al.), Internet-based social support interventions may be under utilized, despite their cost-effectiveness and availability.

This study explores how older cancer survivors use the Internet for social support and describes their wants, needs, and barriers to using it effectively. This study provides new information that can potentially support the development of successful Internet-based social support interventions for older cancer survivors and the development of educational programs targeting the needs of older cancer survivors in their attempts to use the Internet for social support. With increased understanding of this issue, programs and policies can be modified in public health and clinical practice to better support cancer survivors in finding the support they need (Jack, 2006). This study also provides information about how to better design online social support interventions for older cancer survivors and identifies opportunities to decrease barriers for efficient Internet use for finding what they need (such as computer training programs, increasing access to

online support venues). Designing senior-friendly online social support interventions, and teaching cancer survivors how to use them, may provide a realistic way for cancer survivors to meet many of their social support needs.

Because there are so many ways to both give and receive social support online (such as through joining online support groups, reading bulletin board postings, posting personal experiences), it is important to understand what older cancer survivors are looking for when they go online for social support, as well as to understand the barriers they face when using the Internet for their social support needs. Specifically, this study asked the following questions:

1. What are the wants and needs of older cancer survivors when they turn to the Internet in search of social support?
2. What are the barriers faced by older cancer survivors in their attempts to use the Internet for social support.

In summary, the purpose of this study was to understand the distinct needs of cancer survivors over age 50 when using the Internet for social support, in order to gain necessary information to allow health promoters to inform clinical practice and policy. The information gained by this study can also inform the development and promotion of services that will meet the needs of this distinct group.

Chapter 2: Literature Review

This chapter provides a summary of the key issues in this study, including a discussion about social support, the distinct social support needs of cancer survivors, and the health benefits of social support. It will also review how cancer survivors use the Internet for social support and what is known about the benefits of using the Internet for social support. Finally, it discusses challenges faced by older adults when using the Internet for social support.

What is Social Support?

The foundational concepts of social support have been established for several decades. Social support has been defined as "an exchange of resources between two individuals perceived by the provider or the recipient to be intended to enhance the well-being of the recipient" (Shumaker & Brownell, 1984, p.11). Cohen and Syme (1985) identified four types of social support: instrumental, informational, emotional, and sense of belonging. These types are still useful for understanding what support provides. Instrumental support is the actual provision of services (e.g., financial help) provided by friends or family members. Informational support usually involves giving health-related information, such as advice on whether to seek medical care. Emotional support is providing a listening ear, empathy, and the sense that one is cared about and loved. A sense of belonging is the feeling that one is part of a family or other group that cares about its members. In search of support, a person may seek to increase his/her social network (quantity) or develop selective, close relationships (quality). The quantity of social support is defined as the number of people labeled by the individual as part of his or her social network (Norbeck, Lindsey & Carrieri, 1981), whereas the quality of social

support has been defined as the perception of adequacy and the function of the social support provided (Goodenow, Reisine, & Grady, 1990). The socioemotional selectivity theory provides a framework for understanding how people make choices in who they include in their social support network, and explains why, in general, older adults seek quality of social networks, rather than quantity.

Socioemotional Selectivity Theory

Socioemotional selectivity theory maintains that perceived limitations on time can lead to motivational shifts that directly attend to meaningful goals (Cartensen, Fung, & Charles, 2003). The basis of this theory is that, when young, time is typically perceived as expansive. This means young people are motivated to increase their social network to develop new skills and obtain knowledge. In contrast, older people undergo a selective pruning process that maintains emotionally meaningful relationships and discards the less important or unpleasant ones (Cartensen et al., 2003).

The cardinal tenet of the socioemotional selectivity theory is that the assessment of time plays a critical role in both the ranking and execution of behaviour geared toward specific goals (Cartensen, Isaacowitz, & Charles, 1999), meaning that it is the perceived restriction in time left to live rather than age that explains shifts in contact preferences (Pinquart & Silbersson, 2006). Consequently, not only do older, healthy adults experience this pruning of social contacts, but so do all adults facing a life threatening disease. Pinquart and Silbersson (2006) found that at the start of chemotherapy, younger cancer patients showed more selectivity of social partners than a healthy, young control group. This suggested that the diagnosis of cancer may cause an existential crisis and a deeper appreciation of the importance of close relationships. Upon examining the effects of both

age and cancer diagnosis on social contact preferences, research suggests that older adults and those with cancer (regardless of age) are more likely to prefer quality of social contacts rather than quantity (Cartensen et al., 1999; Pinquart & Silbersson, 2006).

Although older persons and those faced with life-threatening diseases may naturally reduce the size of their social networks, it is possible that older persons with cancer could benefit from increasing both the quantity and quality of their social support networks. Franks and Cronan (2004) examined the importance of quantity and quality of social support in women with fibromyalgia. They found that larger social support networks predicted greater levels of self-efficacy for pain and symptom management, meaning that those with larger social support networks believed more in their ability to deal with their pain. They also found that the quality of social support was related to improvement of psychological well-being, such as lower levels of depression, helplessness, and mood disturbance. Although this study was about patients with fibromyalgia, it still suggests that both quality and quantity of social support may have implications for other chronically ill groups, such as cancer survivors, in targeting the physical and emotional issues that are faced throughout treatment and recovery.

Support Needs of Cancer Survivors

There are numerous psychological implications of receiving and living with a cancer diagnosis. A diagnosis of cancer can affect peoples' psychological well-being on different levels, depending on stage, time since diagnosis, and predicted outcome. Early in their diagnosis, cancer survivors can be concerned about survival, to the exclusion of other issues (Harmer, 2006). However, during the treatment phase, insecurities can arise about body image, fatigue, nausea, physical and sexual effects of chemotherapy and

radiotherapy, and hormonal changes associated with endocrine therapy (Harmer, 2006). These issues can lead to depression, anxiety, fears about death, and concerns about disability (Anderson et al., 2004). The ability of cancer patients to cope with these issues can have a significant impact on their health outcomes. Social support can be a helpful coping tool for cancer survivors that can have effects on both physical and psychological well being.

Effects of Social Support

Many studies have shown that positive social support can influence health outcomes by offering a variety of both psychological and physiological benefits; therefore, social support can be particularly important in dealing with a cancer diagnosis.

Why seek social support?

Psychological effects. Numerous studies have identified social support as an important factor in improving the psychological well-being of chronically ill populations. These effects include reducing anxiety (Anderson et al., 2005), improving quality of life (Bloom et al., 2001; Devine, Parker, Fouladi, & Cohen, 2003) and reducing catastrophizing of symptoms (Buenaver, Edwards, & Haythornwhite, 2007). Social support modifies the coping process and protects individuals from negative effects of stress (Cohen, Alper, Doyle, Treanor, & Turner, 2006). Miedema, Hamilton, and Easley (2006) found that young adults dealing with cancer sought to achieve a feeling of “normalcy” in their lives. Social support can provide an avenue to reach this goal, by enabling cancer survivors to learn from others about how to regain “normalcy”. This could occur by cancer survivors learning how to make major changes in their lives and

how to “pick up” where they had left off before the cancer diagnosis (Miedema et al., 2006).

Unfortunately, social support varies at different points in the illness trajectory. Incongruencies between patients’ social support needs and what they actually receive can produce dissatisfaction and distress (Martin, Davis, Baron, Suls, & Blanchard, 1994). For example, if a person reaches out to a family member for emotional support, and receives informational support, the person could feel that his/her emotional concerns were dismissed.

Although social support is generally offered with positive intentions, it is not always perceived as such by those who receive it. As a result, receiving problematic support can have adverse effects on the patients’ well-being, especially when the support underestimates or minimizes the stress experienced by the patients (Fekete, Stephens, Mickelson, & Druley, 2007). This means that social support can become a “double-edged sword”, with the potential to both alleviate stress and augment it in chronically ill patients (Boutin-Foster, 2005).

Physical effects. For chronically ill or aging populations, social support has strong implications for physical well-being. Immune system changes are impacted by stress, with greater susceptibility to illness associated with increased levels of stress (Cohen, et al., 2006). It is theorized that lowering personal stress can alter immune responses, and ultimately alter the course of disease, having a positive effect on healing, and improving histological and behavioral outcomes (Anderson et al., 2004; DeVries, Craft, Glasper, Neigh, & Alexander, 2007). Anderson et al. demonstrated that interventions for social support were successful in lowering anxiety, improving dietary

habits, and improving perceived social support, with parallel improvements in immunological responses, which could have strong implications for improving the well-being of cancer survivors.

While social support interventions have been found to have positive health-related effects (Anderson et al., 2004; Bloom et al., 2001; Devine, Parker, Fouladi, & Cohen, 2003), it is important to note that no studies to date have clearly shown that a person's risk of cancer is affected by social support. Lutgendorf, Costanzo, and Siegel (2007) examined psychosocial influences in oncology, finding that most studies have not found relationships between measures of social support and cancer risk. However, they stated that there is some indication that social support may interact with other variables in the development of cancer. For example, social isolation was associated with greater risk of cancer, but only among women. Price et al. (2001) found that in a sample of older women with suspicious mammograms, neither stressors nor social support alone were associated with increased risk of breast cancer. However, those who had experienced highly threatening life stressors and had little emotional support were nine times more likely to be diagnosed with breast cancer than those who did not have these risk factors. Although these studies examined effects of social support on cancer risk, not post-cancer diagnosis, it does highlight the complexity that researchers must deal with when researching the potential health benefits of social support. Understanding if and how social support may act as a modifiable risk factor for cancer recurrence can provide helpful information to increase positive long-term outcomes for cancer survivors.

Why provide social support? The act of helping others can bring psychosocial benefit to the helper. By explaining personal experiences with cancer to others,

“experienced” cancer survivors can help people reframe their own suffering, derive a stronger sense of meaning in life and feel a stronger awareness of the existence of a higher power (Schwartz & Sendor, 1999). It has been argued that providing support offers more health benefits than receiving support. Schwartz and Sendor found that providing support was associated with three to seven times the benefit in quality of life outcomes among those giving versus receiving help. It has also been suggested that encouraging older adults to adopt helping roles may provide them with an effective way of reducing psychological distress (Liang, Krause, & Bennett, 2001).

The act of providing social support has predicted lower morbidity (Brown, Considine, & Magai, 2005), as well as predicted higher levels of mental health (Schwartz, Meisenhelder, Ma, & Reed, 2003) and reduced depression (Musick & Wilson, 2003). Research suggests that many benefits accrue when people are able to confront a disaster or illness together, such as mutual support, and awareness, shared appraisals and cooperative action (Lyons, Mickelson, Sullivan, & Coyne, 1998). Although other factors may interplay to contribute to these benefits, such as differences in health levels of those giving versus seeking support, the positive findings do suggest that giving support may actually increase one’s quality of life.

It is important to note the reciprocal relationship between support seekers and support providers who choose to connect online. Hoybye et al. (2005) identified key differences in the motives and actions of participants using a cancer-related online support group (OSG). The newer patients who joined the group were seeking information and support from experienced members, whereas experienced women, having lived some years with cancer, were grateful to tell their stories. Winefield (2005) found that, in

cancer-related online support groups, “veteran” members are paramount in providing positive statements, information, and insights into their own experiences. For “veteran” women, providing support resulted in increased feelings of self-esteem, and made their experience meaningful. Winefield’s results demonstrate the positive impact that can occur from both giving and receiving support online.

Although, to date, researchers have not reached a consensus on the physical health benefits of social support, the findings are positive in many areas. With its potential to decrease recovery time from illness, enhance coping strategies and provide informational and emotional support, social support can be a significant factor in the outcome for a patient suffering from cancer.

Using the Internet for Social Support

With over 80% of Canadians using the Internet (Statistics Canada, 2010a), it has become a mainstream method for chronically ill persons to gain social support in the form of information and emotional support about their illness. Internet support communities are growing in popularity with thousands of messages exchanged each day (Eysenbach, 2003). These messages offer patients encouragement, information, and support, through the use of personal experiences, opinions, humor, and thanks (Klemm, Hurt, Dearholt, & Trone, 1999).

The Internet is an electronic network, linking individuals and organizations around the world in a way that removes barriers of time and place. As such, social networks of individuals and/or organizations providing support to each other are embedded as part of the Internet network (Monge & Contractor, 2003).

There are two main health events that cause a person to seek online social support: (1) an alteration in health status, such as cancer recurrence and (2) an alteration in perceived health, such as concerns about a cancer recurrence or new symptom emergence (LaCoursiere, 2001).

In recent years, the number of online support groups has risen exponentially (LaCoursiere, 2001). Online social support is defined as “the cognitive, perceptual, and transactional process of initiating, participating in, and developing electronic interactions to seek beneficial outcomes in health care status, perceived health, or psychosocial processing ability” (LaCoursiere, 2001, p. 66). Online social support is viewed as a “positive feedback phenomenon, meaning that positive experiences increase positive outcomes, in turn providing more impetus to seek support as alterations in health demand” (LaCoursiere, 2001, p. 67). Hargittai (2007) suggests that, when online, individuals participate in the dyadic relationship because group goals exceed an individual's abilities. She states that by means of collaborating and experiencing group efficacy, individuals can get a sense of contributing to a worthwhile cause.

Different Ways of Connecting With Others Online

Online social support can occur in a variety of ways, such as online bulletin boards, personal web pages for sharing experiences, communicating through email or instant messaging (Eysenbach, Powell, Englesakis, Rizo, & Stern, 2004), blogs (Kim & Chung, 2007), frequently asked question modules (FAQ) (Coleman et al., 2005), or through explicitly seeking social support through channels providing peer support experiences (Eysenbach et al., 2004). Cancer survivors can also participate in interactive cancer communication systems that provide members with the ability to gain information,

participate in discussion groups, ask questions of medical experts, and formulate computer-generated action plans (Shaw et al., 2007).

Eysenbach (2003) identified two main categories into which all online social support falls: communication (email, instant messaging) and community (bulletin boards, mailing lists, chatrooms, websites with community features). For the purpose of this review, the groups identified by Eysenbach are restructured to include online mailing lists in the “communication category”, instead of the “community” category. The reason for this restructure is that, although online mailing lists are based in a “community” forum, the method of member communication is through email, which correlates more specifically to the “communication” category.

Communication. Eysenbach (2003) identifies email as an astounding resource for communication by cancer patients. Within Canada, email ranked as the number one use of the Internet, with over 93% of Internet users utilizing this communication method (Statistics Canada, 2010b). Although both email and telephone communication can help patients ask questions, share decision making and facilitate understanding, email communication has an advantage in that it can occur in an asynchronous manner (Eysenbach 2003), thus physicians and other supportive persons can have the flexibility to reply at a convenient time. It also provides the benefit of the recipient having time to think about his or her responses before replying to the patient.

Community. A virtual community has been defined as a community “which is constituted by virtue of computer-mediated communication, breaking through the barriers of geographic distance and physical representation” (Sharf, 1997, p. 68). These groups can be in many forms, being moderated or unmoderated, synchronous or asynchronous.

The most common forms of community-based social networks are bulletin boards (BBs), also known as newsgroups, message boards, and list serves (Lieberman & Goldstein, 2005). Online support groups are generally in a bulletin board format. Bulletin boards allow users to seek support from others by posting messages at any time of day. These groups are characterized as having hundreds of members, and are generally self-directed and peer-led (Lieberman & Goldstein, 2005).

Comparing bulletin boards and real-time chat. Real-time chat rooms (synchronous communication) can provide immediate supportive responses at any time of the day. Their ability to provide immediate feedback, 24 hours a day, could enable cancer patients to receive support at a time that would best suit their needs, making it beneficial if they are awake all night due to their symptoms of their illness (Doolittle & Spalding, 2005). However, there is a difference between bulletin boards and real-time chat, with the bulletin board members having time to reflect on responses before replying. This creates a dialogue that is less spontaneous and immediate, in contrast to the increased speed and tempo of writing in real-time chat (Barak & Bloch, 2006). However, with bulletin boards, there is an increased opportunity to receive support from a larger pool of people, as compared with real-time chatrooms, which restrict responses to others who are online at the same moment as the cancer patient.

Social networking sites. Social network sites can be defined as web-based services that allow individuals to (1) construct a profile within a bounded system, (2) display a list of users with whom they share a connection, and (3) view and cross their list of connections with others (Boyd & Ellison, 2007). Most social networking sites support the maintenance of in-person social networks (Ellison, Steinfield, & Lampe, 2007), but

others help strangers connect based on shared interests or activities (Boyd & Ellison, 2007). Although there are no reliable data regarding how many people use social networking sites, marketing research indicates that they are growing in popularity worldwide (ComScore, 2007). However, as Boyd and Ellison (2007) state, researchers still have a limited understanding of who is and who is not using these sites, and for what purposes. Richer, ethnographic research on populations more difficult to access would further aid in understanding the long-term implications of these sites (Boyd & Ellison, 2007).

Who Uses the Internet?

Wright (2000) suggested that as more comfort with the Internet grows, the more an individual uses it. Although the digital divide is decreasing, most Internet users are young, and are of higher socio-economic status and education level than non-users (Statistics Canada, 2010a). This means that many groups are likely not familiar enough with the Internet to feel comfortable with using it. In recognizing these differences, it is important to identify the target populations that are finding success with online support, and develop skill building programs on Internet use for the demographic groups that have a lower rate of comfort with Internet use.

Why Use Online Support?

Internet technologies can provide a link among people with common illnesses and experiences, regardless of their proximity to health services, mobility, or privacy concerns about sharing their identity. With hundreds of online cancer support groups available, and hundreds of thousands of messages exchanged each day (Eysenbach,

2003), it is possible for cancer survivors to both increase the quantity and quality of their social support networks.

Accessibility to services. Internet services can provide a realistic avenue to reach populations that may have unmet needs through conventional health promotion or peer support programs. The Internet has become a popular method for providing support to underserved populations in rural areas with little access to medical services or peer support within their own communities (Engelman, Perpich, Peterson, Hall, & Ellerbeck, 2005; Oriet, Cudney, & Weinert, 2007). In this way, the Internet can provide invaluable support to cancer patients in rural areas through obtaining information from someone who has shared a similar experience or has undergone a similar treatment (Turner, Grube, & Meyers, 2001). Similarly, for patients with an uncommon diagnosis, the vast numbers of people participating in online support communities exponentially increases the possibility that they can find a peer who has received a similar diagnosis (Turner et al., 2001).

24 hour access. Online support is available 24 hours a day, and can be accessed through home participation. This could be a strong advantage compared to face-to-face support groups, which schedule set times for meetings, and require mobility of members. The Internet enables chronically ill patients to obtain support at any time that best fits their needs, making it especially beneficial to cancer patients who may be up at night due to symptoms of their illness (Doolittle & Spaulding, 2005). Although having no person-to-person contact, online support interventions can still increase a person's sense that "someone is there" (Fogel, Albert, Schnabel, Ditcoff, & Neugut, 2003), thus decreasing his or her feelings of loneliness.

Anonymity. Although many people seek peer support from other cancer patients while hospitalized, others are fearful and avoid contact due to lack of comfort with changes in their appearance (Liu, Mok, & Wong, 2005). Many cancer patients face physical transformations due to their illness. Therefore, the anonymous nature of online support communities may be advantageous compared to face-to-face support groups in providing a comfortable forum for persons concerned with self-presentation (Turner et al., 2001; White & Dorman, 2001).

The anonymity provided by online support communities may facilitate an openness to discussing personal issues, because the absence of physical contact can make it easier to start discussions of difficult or painful subjects (Hoybye, Johansen, & Tjornoj-Thomsen, 2005). Given the health benefits of social support, the Internet has the potential to provide a meaningful avenue for increased health and quality of life for those people who cannot meet their support needs from their in-person networks.

How Cancer Survivors Benefit From Online Social Support

Although research is still limited in understanding if online support provides the same benefits as in-person support, the Internet provides many venues for cancer survivors to share their experiences and seek answers to their questions about dealing with their diagnosis. Research has shown that health-related benefits occur through narrating personal experiences and expressing emotions (Harper-Chelf et al., 2000), as well as through seeking emotional or informational support from others through online peer support interventions (Lieberman, 2007; Lieberman & Goldstein, 2005, 2006).

The effects of peer support for dealing with cancer. Ussher, Kirsten, Butow, and Sandoval (2006) qualitatively examined what cancer support groups provide to their

members that other supportive relationships may not. Both professionally-trained and peer-led support group leaders were perceived as facilitating a sense of community through providing personal support, modeling ways of coping, and facilitating an open and caring atmosphere. They found that members perceived changes in their outlook, attributing the support group with facilitating hope, optimism, tolerance, acceptance and empowerment.

Hope has been found to be a powerful tool in mediating the relationship between psychological distress and health status, suggesting that hope is an important resource for oncology patients that can impact their quality of life (Rustoen, Cooper, & Miaskowski, 2010). Furthermore, hope has been found to be positively related to coping in patients regardless of gender, age, education, site of malignancy, and even when patients knew their disease was in an advanced stage (Felder, 2004). With the knowledge that peer support can facilitate feelings of hope, peer support may be an invaluable tool in improving coping and quality of life in cancer survivors.

Traditionally, peer support for chronically ill populations occurred in the format of face-to-face support groups. However, in recent years, online support groups have emerged, providing an alternative for people who are unable or unmotivated to join a face-to-face support group for obtaining social support. Since their rise to popularity, researchers have been trying to determine the differences in experiences with Internet versus face-to-face support groups. Although, to date, research has not examined the differences in health outcomes for those using online support versus in-person support, several studies have demonstrated positive health outcomes for online support group

members (Lieberman, 2007; Lieberman & Goldstein, 2005, 2006; Winzelberg et al., 2003).

Measurable changes in quality of life. A consistent theme within studies on online support groups was that health improvements using pre and post measures were notable for online support group participants (Lieberman et al., 2003; Lieberman & Goldstein, 2005; Winzelberg, 2003). In 2003, Lieberman et al. had 67 online support group members with breast cancer complete questionnaires designed to assess depression, personal growth, and reactions to pain. The questionnaires were completed prior to participating in an online psychosocial intervention, and again, 16 weeks later. The results indicated that breast carcinoma patients significantly reduced depression and reactions to pain. The results also demonstrated a trend toward increases on two measures on the Posttraumatic Growth Inventory (PTGI). Similarly, Winzelberg et al. (2003) gave pre and post questionnaires to a number of breast carcinoma patients who participated in a 12 week online support group. They found that participation in the online support group (OSG) was successful in reducing participants' scores on depression, perceived stress, and cancer-related trauma measures.

In 2005, Lieberman and Goldstein had new members of an online breast cancer bulletin board complete measures of depression, personal growth, and psychosocial well-being when joining the group, and six months later. They found significant improvements on all three measures, resulting in an increased quality of life for its participants.

Using narratives to deal with emotions. Narratives can be an important part of emotion-focused coping, by helping patients explore issues and deal with emotions (Holmes, 2000; Robinson, 2000). In 2000, a program evaluation was undertaken to

explore the attitudes and beliefs about storytelling as a strategy for coping with cancer (Harper Chelf et al., 2000). Questionnaires were distributed to both men and women who were cancer survivors and attending a cancer-related workshop. This study found that 97% of cancer survivors agreed that storytelling was a helpful way to cope with their illness. Of these participants, over 82% were in agreement that hearing others' stories of living with cancer gave them hope and that storytelling had cognitive benefits through being an effective way of transmitting knowledge. It is possible that this also translates into a helpful coping strategy for those telling stories via an online forum.

Hoybye et al. (2005) explored how OSGs can break the social isolation that follows cancer and chronic pain, by analyzing participants' storytelling patterns within an online breast cancer support group. Using both participant observation and interviews, they found that four themes emerged from the experience of storytelling in an online forum: (1) empowerment through knowledge, (2) relief through tears and laughter, (3) a new sense of community, and (4) social intimacy. The authors also found that women with a new diagnosis sought information and advice whereas "veteran" members passed on stories about support and care, making experience meaningful and enhancing self-esteem.

Benefits of emotional expression for cancer survivors. Lieberman (2007) examined how insightful disclosure, that is, actively thinking or talking about significant experiences and acknowledging emotions, is linked with mental and physical outcomes for breast cancer patients. Lieberman's study found a significant role for insightful disclosure in improving functional well-being and reducing breast cancer concerns and a

less significant result, although positive, for the role of insightful disclosure on depression and physical well-being.

Health outcomes can also be affected by the participants' manner of emotional expression. Lieberman and Goldstein (2006) examined the role of expressing negative emotions in an online support group for breast cancer survivors. They found that participants who expressed themselves with anger showed a trend toward higher quality of life and lower depression after six months. By contrast, those who expressed themselves with anxiety showed a trend toward a lower quality of life and higher depression. The expression of sadness was unrelated to change scores on the identified measures.

Eysenbach (2003) states that there is no robust evidence on the health benefits of virtual communities and peer online support, not due to a lack of positive findings, but due to difficulties in research designs. Although Eysenbach was correct in outlining methodological problems such as small sample sizes, differences in outcome measures, and lack of control groups, current findings appear positive, showing the potential of online support to substitute for face-to-face support (Lieberman, 2007; Lieberman & Goldstein, 2005, 2006; Winzelberg et al., 2003). Further research could address Eysenbach's concern about research designs, potentially providing strengthened evidence for the usefulness of online support.

Although more research is needed, current findings suggest that online support can enable cancer survivors to reap health-related benefits of social support while decreasing their constraints of mobility, anonymity, and difficulties with access.

Although research is demonstrating the helpfulness of online support to address barriers

to in-person support, more information is needed to determine cancer survivors' preferences for which Internet modalities to best fit within their comfort levels for Internet use. Most research on measured changes in quality of life (QoL) for cancer survivors has been on users of OSGs; however, OSGs are just one of many Internet venues that cancer survivors can use. Research is lacking on the needs of specific demographic groups, such as seniors, when using the Internet for support. This research is needed to create social support interventions that take into account the comfort level and Internet preferences of older cancer survivors, given their age and physical condition.

Older Adults and the Internet

Age and Internet use. Seniors are the fastest growing segment online (Eastman & Iyer, 2004) with the percent of seniors who go online jumping by 47% between 2000 and 2004 (Fox, 2004). In 2009, 71% of Canadians aged 55 to 64 and 40.7% of seniors aged 65 and above accessed the Internet for personal reasons (Statistics Canada, 2010a) and over 96% of wired seniors go online more than once a week (Gatto & Tak, 2008). Although Internet use is increasing among all age groups, it is doing so at different rates. According to the Statistics Canada (2009a), those over age 45 increased Internet use by 10% from 2007. These data show that those aged 45 and over account for 60% of all new Internet users since 2007. The rates of Internet usage for older Francophones are 14% lower than for English-speaking Internet users, with Francophones often citing language as a barrier to Internet use (Statistics Canada, 2001). Although the digital divide is decreasing, meaning the gap between people with effective access to the Internet and those that do not is shrinking, many factors still contribute to differences in Internet usage for different groups.

Rural seniors. Rural residents are more likely to be elderly, poor, less educated, and suffer from chronic disease than their urban counterparts (Friedell et al., 2001). They also have concerns about accessing local health-related services due to the difficulties of remaining anonymous, which are related to the visibility and lack of privacy in rural areas (Ebersole, Hess, Schmidt Luggen, 2004; Garside, Ayers, Owen, Pearson, & Roizen, 2002). Therefore, even if in-person social support groups exist in rural areas, barriers due to lack of privacy can impede cancer survivors from maintaining a strong in-person social support network. This means that online social support may be a realistic option for rural cancer survivors who are looking for someone with whom to connect.

In communities with populations of fewer than 10,000, Internet usage is 10% lower than in urban areas (Statistics Canada, 2009a). The gap between rural and urban areas may reflect the interaction of other socio-economic factors, or another effect, such as high-speed Internet availability (McKeown, Noce, & Czerny, 2007). Since the average age of people residing in rural regions is older compared to urban areas (Community Counts, 2010a), both age and rurality are barriers to consider when designing Internet interventions for older cancer survivors.

Education & income level. The digital divide is also affected by education and income levels. Among those who use the Internet, there is a 23% lower rate of Internet use for those with no post-secondary education as compared with those who do have post-secondary education (Statistics Canada, 2009a). Similarly, Internet use declines with income level, with a 16% difference in Internet usage for the lowest vs. highest income groups (Statistics Canada, 2009a). Jansen (2010) found that Americans who live in households earning \$75,000 or more a year use the Internet 15% more than those who

live in households earning less than \$75,000. Given that the average household income in Nova Scotia is less than \$49,000 (Community Counts, 2010a) and significantly fewer seniors having obtained post-secondary education than younger age groups (Statistics Canada, 2009b), this is an important consideration that further enlarges the digital divide between seniors and younger Canadians.

Because low income seniors often have increased barriers to accessing health information and support, Chu, Huber, Mastel-Smith, & Cesario (2008) conducted a training program for older adults residing in low socioeconomic communities to increase their confidence with computer use. They found that, after a 5-week training program, older adults showed decreased anxiety about computer usage, increased confidence, and increased self-efficacy in using the Internet. This demonstrated that longstanding barriers to Internet use, such as age and socioeconomic status, can be addressed through computer training, if computers are made accessible.

How seniors use the Internet. Studies have shown that online seniors who email family members are likely to say they communicate more often with family members now, and a majority feel that the Internet has improved their connections with family (Thayer & Ray, 2006).

Many difficulties arise due to the normal aging process that prevent older adults from easily navigating websites. These barriers include difficulties with vision, cognition, and physical impairments (Curran, Walters, & Robinson, 2007). Although most websites have not been designed with older adults in mind, guidelines have been developed to make websites more elder-friendly, such as using larger fonts, reducing the amount of

text on a page, limiting pop-ups, and increasing the ease of navigation (National Institute on Aging 2002).

SeniorNet (2001) surveyed seniors age 50 and older to examine their Internet usage and online habits. They found that among seniors who do access the Internet, 47% report spending three or more hours per week online, and roughly 25% report spending less than one hour per week online. Fox (2004) found that wired seniors are as likely to go online to check their email and use a search engine as younger users and, in Canada, over 69% of seniors over age 55 go online at least once a day (Statistics Canada, 2010c). Although email is the number one activity of wired seniors (Fox, 2004; SeniorNet, 2001), using the Internet for research is a popular online activity, with more than half of seniors regularly using search engines (Fox, 2004; SeniorNet, 2001).

Internet proficiency remains a barrier to effective computer use for older age groups. Over 50% of seniors have difficulty retrieving previously-found information, and become frustrated by pop-ups, spam, and advertisements (Gatto & Tak, 2008). One-third of seniors said that lack of knowledge or computer skills limited their enjoyment of this technology (Gatto & Tak, 2008). In the general population, work and school are important settings for learning computer skills. However, fewer older people would have recent exposure to these (Bitterman & Shalev, 2004). With direct training and encouragement, older adults can increase their social networks through online interactions (Cody, Dunn, Hoppin & Wendt, 1999) and increase their Internet self-efficacy (Lam & Lee, 2006). Nahm, Resnick, and Mills (2003) found that, as computer knowledge increased, the size of the computer mediated social network also increased and that those with larger computer mediated social networks were receiving more

support through the network than those with smaller networks. Training sessions were also found to be a social activity for older people, leading to a more successful learning environment (Capel, Childs, Banwell, & Heaford, 2007). Weinberg, Schmale, Uken, and Wessel (1996) investigated the amount of time required for six participants with breast cancer to learn to use the computer, with encouraging findings showing quick advancement of computer skills. However, because cancer afflicts older persons at such disproportionate rates, more research needs to be conducted to better understand how seniors see themselves receiving and providing online support, in order to help them make the best use of online support venues and to develop resources that best fit their needs.

Limitations to the Use of Online Support Interventions

Online social support interventions do provide a challenge to implement, because they require the injection of new funds and have a high cost for supporting software (British Columbia Cancer Agency, 2004). However, by providing sufficient training to increase the cancer survivor's self-efficacy with computer use, minimal costs would be incurred after the completion of program development and the training phase.

OSGs provide emotional and informational support (Hoybye et al., 2005,) as well as foster a sense of belonging (Ussher et al., 2006). However, it is possible that, as time is spent seeking social support online, users' instrumental support could be limited by the reduced contact with family and friends in their own community.

Researchers have argued that time spent online decreases the time people spend with their social environment (Nie & Hillygus, 2002). However, it could be argued that the definition of a social environment needs to evolve. In searching for a social

transaction online, it could be assumed that one person is searching for support from another person's experience, or conversely, to provide support to one individual at a time. This could be assumed because of the solitary nature of Internet use, in that the medium is designed for one person to use a given terminal at any time. The computer can essentially function as one person's "voice", allowing him/her to "verbalize" thoughts and feelings to another individual with whom he/she wants to communicate; thus being analogous to using the telephone for communicating with friends and loved ones from the comfort of home. Moreover, many Internet venues allow for a social interaction to take place by reading others' postings online, thereby allowing for each posting to provide support to a large number of individuals over time. However, more research is needed to clarify the extent to which seeking online social support changes the dynamics of the cancer survivors' social networks in their own communities.

The British Columbia Cancer Agency showed leadership in piloting an online peer support program for Canadian cancer survivors. Lessons learned from this project provide important guidance for further development of online support programs. The British Columbia Cancer Agency (2004) states that cancer survivors should be made aware of all available options to them with regards to receiving psychosocial supportive care, and technologically-aided support programs need to be appropriately marketed. They also suggest that the most effective strategy for promoting web-based interventions may be for health professionals to introduce such programs to existing clients. This highlights the impact that health professionals can have in maximizing cancer survivors' social support networks.

Summary

The health-related benefits of both giving and receiving social support in an online forum include empowerment through increased access to information and enhanced self-esteem (Hoybye, et al., 2005), higher quality of life and lowered depression (Lieberman & Goldstein, 2006), and decreased perceived stress and trauma measures (Winzelberg et al., 2003). Although there are hundreds of online social support interventions available to cancer survivors (Eysenbach, 2003), and a variety of forums for both giving and receiving social support online, the particular wants and needs of older cancer survivors in using the Internet for social support have not been studied. In addition, researchers have not examined the particular constraints older cancer survivors face when using the Internet to help meet their social support needs. Although creating online social support interventions may be a cost-effective method for reducing cancer-related health care expenditures, the effects of online social support interventions for older cancer survivors can best be maximized when based on information about the wants, needs, and barriers faced by this unique group.

Chapter 3: Methodology

This chapter will provide an overview of the methodology that was used for this research project. I define online social support and explain inclusion criteria for Internet sites as having a “social intent”. I provide a rationale for using a qualitative approach for this study and for using descriptive, thematic analysis for interpreting the qualitative results. I describe my sample population, recruitment strategies and data collection procedures. I also review how I addressed the trustworthiness of the study and discuss ethical considerations.

Defining Online Social Support

The purpose of this study was to describe the wants, needs, and constraints faced by older cancer survivors when using the Internet for social support. In this study, online social support was defined as “the transactional process of initiating, participating in, and developing electronic interactions to seek beneficial outcomes in health care status, perceived health, or psychosocial processing ability” (LaCoursierre, 2001, p. 66). For the purpose of this study, Internet use that is non-transactional in nature, such as information seeking from static medical information pages, was excluded because it does not fall within the boundaries of having a “social” intent. “Transactional” sites were those generated and maintained by individuals that purposefully contained personal information about theirs’ or others’ cancer experience.

The definition of online social support describes a “transactional process” (LaCoursierre, 2001, p. 66), meaning there is a give and take relationship between the support seeker and support provider. Although some Internet sites, such as OSGs, can easily meet the criterion of a social transaction, others may not have the same clarity

when determining whether or not a “transaction” has taken place. For example, stories may be posted on personal web pages or blogs where the person posting the information does so in expectation of being able to provide support to others, but the person may or may not be aware of who is receiving the support. Although it could be argued that these sites do not meet the definition of a social transaction, this study did include such sites, since the act of posting personal information in an online forum can be considered “transactional”, because individuals posting the information are self-disclosing elements of their own experience to other Internet readers. Because the information is intentionally shared, this differs from writing in a diary. It also differs from information posted by cancer organizations, since these organizations are not self-disclosing personal experiences.

This study included any Internet sites in which cancer survivors were disclosing personal information about their experiences. The reason these were included was to encompass a broad possible range of ways that participants may give or receive support online, which can help to create a peer-to-peer relationship with other cancer survivors.

Qualitative Research Approach

This was a qualitative study, with quantitative data being collected only to provide a sense of the sample population involved in the study. Given the complexity of the issues being studied, and the purpose of understanding how older cancer survivors themselves perceive their experience, qualitative research was chosen as the main research design to provide a greater depth of understanding than that supplied by quantitative methodologies (Jack, 2004). Qualitative methods allowed the inclusion of a wide range of examples in the data presentation to show the richness of the phenomenon

and benefit from the knowledge gained by “outliers” which may allow for the identification of new areas for research (O’Neill, 2002).

This study used descriptive thematic analysis, a type of qualitative description, to provide a comprehensive summary of the wants, needs, and barriers faced by older cancer survivors when using the Internet for social support, as well as to describe the benefits of giving and receiving support online. Although thematic analysis is “a method for identifying, analyzing and reporting patterns (themes) within data” (Braun & Clarke, 2006, p. 79), descriptive thematic analysis is differentiated from that used as part of other methodologies, such as phenomenology or grounded theory, in that the analysis presents the “facts” discovered through participants’ words with relatively little interpretation (Sandelowski, 2000). This approach is preferred when the research questions asked are relatively concrete (Sandelowski, 2000) and the intention is not to attempt to determine underlying concepts that help to construct the descriptions individuals give (Braun & Clarke, 2006). Since this study asked concrete questions: what are your wants, needs, and the barriers you face, descriptive thematic analysis was the preferred method for analyzing the results. I will use the term “thematic analysis” to describe this analysis throughout the study.

Role of the Researcher

As the researcher, it was my responsibility to acknowledge my own assumptions prior to conducting the interviews. As a health care professional, I have heard first-hand from patients and caregivers who turn to the Internet in search of answers to their health concerns. Although I did not work with seniors, I embarked on this study with an assumption that people turn to the Internet to find answers they have not received from

anyone in their in-person network, and learn from others who share similar experiences. I witnessed the fear and drive of parents searching for a new treatment option for their child's diagnosis, despite having a wealth of information provided to them from their physicians. With understanding age-related differences in comfort with Internet technologies, I also entered this study acknowledging that older cancer survivors would have unique challenges in finding the online support they sought for their cancer needs.

Sampling Strategy

Purposeful sampling strategies were used in this study, meaning that individuals and sites for the study were selected because they purposefully informed an understanding of the research problem being studied. Snowball sampling was also used to identify cases of interest from people who knew others who were information-rich (Creswell, 2007). Ten participants, both male and female, were recruited through posters at local cancer organizations, libraries, and community centers throughout a large health district in the Maritime provinces (Appendix A, p. 130), as well as through snowball sampling. Participants were also recruited through emails and newsletters distributed by local cancer organizations, as well as through online bulletin board advertisements, such as Kijiji (Appendix B, p. 131). The health district boundaries included both rural and urban areas. The health district boundary ensured that I could consistently maintain a presence of recruitment advertisements posted at local organizations, libraries, and community centers, since many community organizations updated and removed posters on a weekly basis. Although initially this study sought between 20–30 participants, recruitment ceased at ten because the diversity of cancer types, treatment stages, and genders were well represented, and because it was an adequate size for the saturation of

themes arising from the data (Guest, Bunce, & Johnson, 2006). Using the definition provided by Guest et al., saturation was defined as the point in data collection and analysis when new information produced few or no changes to the codebook.

Inclusion criteria. Inclusion criteria for this study required each participant to self-identify as being a cancer survivor, an Internet user, and over age 50. Logistical considerations, such as location boundaries and English fluency were also necessary to address issues of time, funding, and communication with the researcher.

Cancer survivor. Although the term “cancer survivor” is used differently among different people and organizations, this study defines a cancer survivor as anyone who has or has ever had a diagnosis of cancer (National Cancer Institute, n.d.). This is important because research has demonstrated that cancer survivors give and seek support at different times during their illness and recovery (Hoybye et al., 2005), and that it is often this relationship between newly diagnosed and veteran members that is sought in online forums. The psychosocial effects of cancer and cancer treatment can have long latency periods, with lag time varying from months to years (Reuben, 2004). This means that cancer survivors at all points in their cancer journey can potentially turn to the Internet to address their social support needs.

This study was open to participants who have dealt with cancer within the past five years, whether it be new, ongoing, or a cancer recurrence. It was inclusive of any cancer stage: in treatment, remission, palliative, care, or cancer free. This range provided an opportunity for both newly-diagnosed and veteran members to talk about issues involved in connecting with other cancer survivors online. Because the issues of cancer survivors diagnosed at ages 5, 15, and 50 are different, since relevant issues are

dependent on a person's stage of life (Reuben, 2004), this five year limit helped ensure that the participants were all diagnosed in adulthood, and shared similarities in the issues faced through diagnosis and treatment. This five year span also helped to ensure that cancer was currently an important issue in the participants' lives while allowing room to gain insight from a broad range of participants.

Internet users. Only participants who are Internet users and who use the Internet for their cancer-related social support needs were selected for this study. This is because rich, detailed accounts of participants needs may not occur if participants do not have first-hand experience about the benefits and constraints of using the Internet to meet their social support needs. Persons who may want to seek online social support, but who have not had direct exposure to the Internet, could imagine the experience of searching for online social support differently than those who have had this direct experience, thereby providing different data from those who have been exposed to the Internet, and already know the constraints that they face with using the Internet for their social support needs. Over 96% of wired seniors go online once a week or more, with over 69% using the Internet daily (Statistics Canada, 2010c). To ensure that this study was open to participants who varied in their computer use, yet had enough experience to provide detailed information, this study recruited participants who use the Internet at least once per week and who used the Internet for connecting with others to address their cancer-related needs.

Over age 50. Age 50 was chosen because it represents the age where the risk of having cancer rises exponentially (Canadian Cancer Society/ National Cancer Institute of Canada, 2007), therefore knowledge gained by this study can be used to benefit the

maximum number of cancer survivors. It also represents an age group of persons who are found to have lower comfort with using the Internet than younger generations (Thayer & Ray, 2006). This means that to design online social support forums for the majority of cancer survivors we need to understand how to create Internet interventions that have value for persons who adapt less easily to Internet technologies.

Logistical concerns. Logistical considerations required the participants to be fluent in English in order to ensure accurate communication with the researcher.

Participants were to currently reside within the health district boundaries in order to ensure that the researcher could maintain posters consistently in community organizations throughout the district. Interview times and locations were set through negotiating the most convenient time for the participant and researcher to meet. Due to logistical issues with the researcher, telephone interviews were used to lessen constraints that would be involved with in-person interviews, such as driving time to and from interviews throughout the health district.

Data Collection

Background information. Background information was obtained through a short questionnaire that asked participants to indicate their age, sex, cancer type, prognosis, years since diagnosis, and Internet usage (Appendix C, p. 132). These questions were asked to provide information about the diversity of the population. Internet access was included in the questionnaire because some parts of the health district do not have high speed Internet available, and this could be a factor that changes the experience of searching online. Questions about types of Internet venues participants used/ did not use were asked to provide specific information about how they access online support, and for

probative value during the interviews. This background questionnaire was emailed or mailed to participants along with the consent forms, and was returned by participants with the consent forms.

The interview guide. This study used a semi-structured interview guide (Appendix D, p. 134) to draw out in-depth thoughts, feelings, and experiences from participants (Meadows, 2003). This interview guide was developed to allow participants to openly discuss their wants, needs and barriers to using the Internet for online support. Questions asked participants to reflect not only on how they preferred to search for online support, but also to reflect on positive and negative outcomes arising from its use. Participants were encouraged to think about social support in their own terms, in order to first understand how they thought about support without being influenced by categories researchers use. The last interview question asked participants to reflect on how, if at all, the support they experienced fits within the traditional types that researchers identify.

This interview guide helped ensure that essentially the same information was obtained from all participants. It also helped to keep the interaction focused, while allowing individual perspectives and experiences to emerge (Patton, 1987). In order to ensure the interview guide was appropriate for the targeted population, two people who met the inclusion criteria were pilot tested using the guide. No revisions appeared to be necessary, since the questions elicited meaningful responses. The individuals who were pilot tested were not included in the study. Each participant was contacted by the researcher to set up interview times. At that time, each participant was assigned a number so the interview would reflect his or her data by participant number, with names and

other identifiers removed. The interviews lasted between 20 minutes to one hour each, depending on how much the participants felt they wanted to discuss.

Interviewing the participants. Interviews were conducted by telephone. Opendakker (2006) describes the advantages and disadvantages of conducting telephone interviews. He argues that conducting interviews via the telephone allows for a wide geographical access, thereby reducing the time and costs of data collection as compared to face-to-face interviews. It is also allows for increased access to hard-to-reach populations, such as those with disabilities. Telephone interviews also allow for a more comfortable environment for discussing sensitive issues; however, many disadvantages also exist, such as the reduction in social cues limiting the ability to gain extra information that can arise with monitoring body language. Another disadvantage of telephone interviews is that the interviewer has no view on the situation in which the interviewee is situated. This could be relevant if a participant is discussing a sensitive issue when a family member enters the room. Being aware of the disadvantages of telephone interviews, these problems were mitigated by ensuring consistent attention to voice tone and intonation and by allowing participants to choose an interview time that allowed them to feel most comfortable and in control of their surroundings.

Interviews took place between July 10, 2009 and September 24, 2009. Participants were interviewed by telephone at a convenient time for both the participant and researcher. Before each interview, participants received both a verbal review of the study's purpose and plans for using the results. Participants were also asked to provide verbal consent to be both interviewed and audio-taped (Appendix E, p. 138). Field notes were collected during the initial contact with the participant, and also during the

interview to help focus on its main points and to provide backup to the audio recording (Rubin & Rubin, 1995). Collecting field notes during the initial contact was helpful in providing a sense to the participants in the interview that I understood the story they were trying to tell, as I referred to my notes during the interviews to create a meaningful dialogue with participants. At times, they helped to elicit a more complete dialogue with the participants than they originally may have given (such as why they wanted to be helpful in this study and what their cancer journey has been like). Field notes taken during the interview and information from the background questionnaire were used during the interview to help keep participants on-topic, and also to help clarify information during the interview and analysis.

As the interviewer, I guided the discussion and encouraged the interviewee to answer in depth and at length (Rubin & Rubin, 1995). Before beginning the interview, I established rapport with the participants by conveying a friendly, conversational, and unbiased tone (Fontana & Frey, 1994). I began the interview with non-threatening questions that the interviewee almost certainly knew about, such as how online support has helped them. Emotionally or intellectually difficult questions were asked after I established a comfortable atmosphere and encouraged the participants to talk at length about the subject material, such as questions regarding how they decide how honest they choose to be when online. The interview closed with lowering its emotional tone to ensure participants left the interview feeling calm and protected (Rubin & Rubin, 1995). This was accomplished by talking not about specific experiences, but about reflecting upon feelings of support, and encouraging participants to add any additional thoughts or feelings they had.

After each interview, raw field notes were converted into a contact summary form to develop an overview of the interview's main points (Appendix F, p. 142). The contact summary form summarized information about the field contact and captured impressions and reflections that I had during and after the interview (Miles & Huberman, 1994). After the interviews concluded, three participants contacted me by telephone and/or email to elaborate on the points raised during the interview. These data were also recorded and used in data analysis.

Data Analysis

Braun and Clarke (2006) describe thematic analysis as a method for identifying, analyzing, and reporting themes within the data. This study used thematic analysis to identify patterns and provide rich description of the data obtained during the interviews. Although no description is free from interpretation (Sandelowski, 2000), themes were identified within the surface meanings of the data and were not imposed upon it by the researcher. Data were organized in a way that best provided a comprehensive summary of the events in the everyday terms of those events (Sandelowski, 2000, p. 336).

Audio recordings were transcribed verbatim, with the exception of vocal distractions, which were removed by a professional transcriptionist. I re-checked the transcriptions with the audio-recordings to ensure their accuracy. Contact summary information was compared with the transcription to ensure views were consistent.

In thematic analysis, data collection and analysis take place simultaneously (Tere, 2006); therefore the analysis process began with the first interview, as I reflected on patterns in the data presented. Transcripts were hand-coded one at a time, in the order they were conducted. Transcripts were read multiple times, first to gain an overall sense

of the participant's story, then to identify unique characteristics of the data. Upon reviewing the initial interview, distinct categories were identified and a code list was developed. Relevant information from the contact summary forms and memoranda were also coded. After the first interview was coded, the code list was used to examine the second transcription. Codes were relabeled as categories expanded or collapsed as new data emerged through subsequent interviews. This process took place as soon after conducting the individual interviews as possible. After initial coding of three interviews, I reviewed codes with my supervisor and reworked the codes as necessary to best fit the emergent themes. This analysis process was repeated for each of the interviews. Categories expanded as new data were found to fit the previously established codes; thereby establishing strong themes. After eight interviews, extracts from the transcripts to support the codes and themes were tabulated and reviewed by my supervisor to ensure credibility of the analysis. Saturation of themes was determined after no new codes were found after 10 interviews. Themes continued to be refined by re-reading the transcripts, codes, and categories to identify the best fit in which themes and subthemes flowed most accurately and coherently. My supervisor reviewed the final set of themes and made suggestions to help ensure the themes were "internally coherent and consistent" and did not have "too much overlap" (Braun & Clarke, 2006, p. 94). After her review, themes were refined again until both my supervisor and I thought the analysis was rigorous.

Threats to Quality and Rigour

The fundamental issue regarding trustworthiness in a qualitative inquiry is how an inquirer can ensure that the findings of an inquiry are worth paying attention to (Lincoln & Guba, 1985). The criteria for trustworthiness in a qualitative inquiry include credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985).

Credibility. Credibility refers to the adequate representation of the constructions of the social world under study (Bradley, 1993). To improve the credibility of research results, a researcher may use prolonged engagement in the field, persistent observation, triangulation, negative case analysis, checking interpretations against raw data, peer debriefing, and member checks (Lincoln & Guba, 1985). For this study, I used (a) peer debriefing with my advisor, (b) negative case analysis, meaning I searched for the cases that did not fit within the pattern, (c) persistent observation, meaning I identified characteristics and elements of the situation that were most relevant to the issue and focused on them in detail (Lincoln & Guba, 1985), and (d) member checks with participants to ensure the themes identified represented their views well. Member checks were sent by mail to each participant after all 10 transcripts were coded. I received six member checks from participants, all confirming that they agreed with the identified themes. Some participants also used the member checks to elaborate on already identified themes. This information from the member checks was incorporated into the analysis.

Transferability. Transferability refers to the extent to which the researchers' findings can be applied to another context (Bradley, 1993). As the researcher, it was my responsibility to provide data sets and enough descriptions to make the judgment of transferability possible on the part of other researchers. I maintained a rich account of my sampling strategy by keeping notes on where recruitment advertisements were placed, when they needed renewal, and contact information from key people in cancer organizations who sent recruitment information via their mailing lists. I also maintained a file that contained the participants' demographic information (including age, gender, cancer type and stage, Internet access, and Internet usage) and fieldwork (information

from initial contact, field notes, and contact summary forms) that helped to allow for a rich description of the participants' experiences. However, transferability can only be determined at a later date, since readers of this study must determine how far they can be confident in transferring the results to other situations (Shenton, 2004).

Dependability and confirmability. Dependability is defined as the coherence of the internal process and the way the researcher accounts for changing conditions in the phenomena (Bradley, 1993). Confirmability is "the extent to which the characteristics of the data, as posited by the researcher, can be confirmed by others who read or review the research results" (Bradley, 1993 p. 436). An important technique for establishing dependability and confirmability is by establishing an audit trail. To establish dependability, the auditor examines the process involved in various stages of the study. The auditor determines whether this process was applicable to the research undertaken and whether it was applied consistently (Lincoln & Guba, 1985). To illustrate confirmability, a record of the inquiry process, as well as copies of all taped interviews and discussions, notes from interviews and discussions, and hard copies of all transcriptions have been maintained (Lincoln & Guba, 1985). I addressed dependability and confirmability by maintaining enough records of data and methodological decisions to ensure that each step of the study can be accounted for and that methodology can be reviewed. My supervisor and committee members were involved in aspects of carrying out the research throughout the study, such as providing input on the development of the background information questionnaire and interview guide, advising about the adequacy of variability in participant demographics, and in providing input about the fit of themes within the data. Therefore, debriefing and scrutiny by mentors was an additional means to

promote the dependability and confirmability (Shenton, 2004) of this study. Reflexive journaling was used to document my decisions by keeping a diary of how I reached decisions regarding data saturation and coding. It also provided descriptive data about judgements and ideas formed during the study. I also addressed the threat to confirmability through identifying my own researcher assumptions, and by using quotations within the reports to link the generated themes to the participants' words.

Ethical Considerations

Ethical approval for this study was sought through Dalhousie University Research Ethics Board. Because this study involves research on human beings, care was taken to protect them from harm. Ethical concerns for human subjects involve topics of (a) informed consent (consent received from the subject after he or she has been carefully informed about the research), (b) right to privacy (protecting the identity of the subject), and (c) protection from harm (physical, emotional or any other kind) (Fontana & Frey, 1994). All of these ethical considerations were outlined in the consent form given to the participants (Appendix C, p. 132).

Informed consent. Each participant was asked to provide written and verbal consent before participating in the research to ensure that the participants understood the study's procedures and their rights during data collection (Creswell, 2003). This consent form (Appendix C, p. 132) included information ensuring that the participants knew (a) that their participation was voluntary and that they could withdraw at any time, (b) the purpose of the study, (c) the procedures of the study, (d) that they had the right to ask questions, obtain a copy of the results, and have their privacy respected, (e) any benefits that would accrue to them (Creswell, 2003).

Right to privacy. In conducting this research study, it was important to consider how this study would protect the privacy of the individuals involved. Privacy and confidentiality were addressed by removing all identifiers from the transcripts, and by using generic descriptors for participants when quotes were used within the study (e.g. female, 56, colon cancer). A signed letter of confidentiality was obtained from the transcriptionist, and she received the data with names and other identifiers removed. The data were protected by storage in a secure, locked location in a filing cabinet in my home office. Electronic copies of the data were saved to a disk and the files removed from my computer. The ownership of the data, audio-tapes, and notes is with Dalhousie University and will be stored at Dalhousie in compliance with University procedures.

Protection from harm. Although risk to participants was minimal, minor discomforts to participants could have included fatigue associated with the interview process and re-living emotional events when responding to interview questions. Interviewing the participants by telephone may have reduced minor discomforts by enabling them to be interviewed in the comfort and privacy of their own homes.

Ethics in writing and disseminating. Creswell (2003) discusses several ethical issues to consider when writing the final report. In accordance with his recommendations, I ensured that I used language that was unbiased when issues were discussed about gender, sexual orientation, disability, or age. I also accepted my moral obligations as the researcher to ensure that I presented an accurate portrayal of the data and did not engage in the suppression of findings or falsifying of data to meet my expectations as a researcher or my audience's needs. If published, I will release both the details of the

research and the study design so that readers can determine for themselves the credibility of the study.

Chapter 4: Results

This study allowed participants to reflect on both the reasons they sought social support online, and the specifics of what it was that they found helpful in this experience. It also allowed participants to discuss barriers to effective use of the Internet for social support. Although each participant experienced a unique journey in his/her search for cancer support, there are many commonalities that were shared among the participants. The following section will describe participants' profiles and the findings that reflect the opinions and thoughts of the participants in their quest to find online social support. In order to give a sense of how many people expressed a given concept, I use the term "most" to represent 8-9 participants, "many" represents 5-7 participants, "some" refers to 3-4 participants, and a "few" refers to 2-3 participants. Participants' quotes are written verbatim, with vocal distractions removed.

Participant Profiles

Participants in this study varied in age, gender, cancer diagnoses, treatments, Internet usage, and preferences for Internet venues. There were 10 participants and they were from 52-67 years of age. Eight different types of cancer were reported: endometrial, prostate, non-Hodgkin's lymphoma, melanoma, breast, leukemia, colon/rectal, and ovarian cancer. Six participants were female, and four were male. All participants were diagnosed more than a year prior to the interviews, with the earliest diagnosis occurring in 1999 and the most recent one being diagnosed in 2007. Four participants were in remission, four were cancer free, and one was in treatment. One participant was symptom-free, but in treatment that might be considered palliative:

My multiple answers to your question #5 come down to how one defines "palliative care" and "remission". I am symptom free (hence "remission"), but

under treatment (hence “in treatment”); yet I am past the point where any known treatments are curative (hence technically my treatments are “palliative”). (Male, 63, prostate cancer)

All participants had high-speed Internet, and accessed the Internet from home. Four participants also accessed it from work. Internet usage varied from 3-50 hours a week, with 8 participants spending more than 10 hours a week online. When asked about the types of Internet sites they used, all participants used email, four participants used chatrooms, four used bulletin boards, four used FAQs, six used online support groups, two used social networking sites, and two used blogs. No participants indicated that they used real time chat with messenger, audio or video. Of the four identified types or provisions of social support: instrumental, informational, emotional, and sense of belonging (Cohen & Syme, 1985), all participants indicated that they received informational support from others online. Seven participants received emotional support online, six felt a sense of belonging, and no participants received instrumental support online.

Themes

Four major themes and 11 subthemes were found in this study (Table 1): 1) the need to take charge, 2) it helps to know I'm not alone, 3) maximizing the net's usefulness for cancer support, and 4) the spirit of survivorship.

Participants felt a need to take charge of learning as much as they could about their cancer, treatment options, and the life issues that they faced. The Internet provided participants a venue to learn about these issues in an environment where they could control who they engaged with and how they chose to do so.

Participants consistently observed the emotional value of knowing they were not alone in their cancer journey. By finding someone to connect with who matched in cancer type and experience, participants were able to find out practical information about coping with their disease, and hope that the disease could be overcome.

Pitfalls of Internet support were discussed, such as difficulty finding helpful support, and its limited help for coping. Participants observed many areas that could be improved to make an Internet site more helpful for cancer support.

Many participants discussed the spirit of survivorship as having changed their outlooks on life, and that their lives are lived differently because of this change.

Table 1: Summary of Themes

Themes	
1.	<p>The Need to Take Charge</p> <ul style="list-style-type: none"> • Inadequacy of Information Given by Medical Team • The Value of Being Your Own Advocate • Physicians' Responses to Internet Information • Online Support Facilitates Control <ul style="list-style-type: none"> • Removing Barriers of Time and Space • Controlling the Emotional Tone • Privacy
2.	<p>It Helps to Know I'm Not Alone</p> <ul style="list-style-type: none"> • Importance of Matching & Experience • Different Ways of Connecting • Importance of Honesty and Openness
3.	<p>Maximizing the Net's Usefulness for Cancer Support</p> <ul style="list-style-type: none"> • It's Hard to Find What You Need • Access to Computers • Design • Content
4.	<p>The Spirit of Survivorship</p>

The Need to Take Charge

Inadequacy of information given by medical team. Many participants began their journey of searching for online support as a quest to further their knowledge about their illness, as they felt unsatisfied by the information given to them by their medical team. Some participants lacked confidence that their own oncologists were up-to-date on the most current treatment information.

It's your life, you're looking for a cure for your cancer and things are moving so fast in the cancer world that your oncologist can't keep up and you have to be aware, you are the person that is going to save your own life, you're the person that's going to find out what supplements are real you should be taking, which drugs interfere with chemotherapy, you have to find that stuff out by yourself because the oncologists don't know. (Female, 62, colon cancer)

Many found that the information they received from health care organizations was inadequate, observing that the information was too general in nature to address concerns about their diagnoses. Participants felt compelled to ensure they were informed about all aspects of their illness.

They [health care professionals] don't tell you anything in there, they just . . . take care of you but you know it's very limited what anybody tells you, they give you the brochures and that but it has nothing to do with kind you've got or anything. (Female, 57, endometrial cancer)

One participant observed that physicians can be unwilling to discuss cancer-related issues that are not specifically concerning diagnosis or treatment. This participant also observed that broaching secondary cancer issues with physicians can lead to feeling punished. He stated: *"I felt like I was getting a slap on my hand. So you know the Internet provided me with some of the information that I was looking for that I wasn't getting from my surgeon"* (Male, 52, prostate cancer). This response led to his online search for answers to those questions that the physician was unwilling to answer.

I had a lot of questions about sexuality when it came to prostate cancer and I felt that when I asked those questions of my surgeon, I was made to feel that you've got other things to worry about other than this, so you've got more important issues to worry about other than sexual dysfunction. (Male, 52, prostate cancer)

The value of being your own advocate. Several times, participants observed that their cancer treatments were changed through their commitment to being educated about their disease, through journaling their cancer experience, finding information about new treatments, feeling more confident in advocating for a particular course of action, or empowering others to question their physicians about the best course of action. Many participants were passionate about being able to make informed decisions throughout the cancer journey and some observed that the knowledge they received online influenced how their cancer was treated: *“Certainly, without the Internet I would never have found the therapy that I ended up getting and because it was never presented to me” (Female, 59, breast cancer).*

Physicians' responses to Internet information. Although participants felt strongly about the usefulness of the Internet for increasing their knowledge of cancer issues and treatments, their opinions differed about how their doctors respond to Internet information. Although three participants indicated that they could openly talk to their doctors about the information they acquired online, three others discussed their physicians' critical responses to online information. Those who felt supported by their physicians in discussing Internet information described their physician/ patient relationship as positive in nature, while those who were not supported in discussing Internet information felt conflict in the physician/ patient relationship. The differences in these experiences are illustrated by the following quotes.

When I read this paper and I got to the point where I did understand the medical jargon because it was specific to my case, I ran into it all the time so I knew what it meant so I printed that out and I took it to my oncologist and asked him if he would read it and he knew I was only bringing him good stuff, so he did read everything I brought him. He was on my side the whole way, he was trying to help me, he gave me hope too, even though I was a no hoper he gave me hope.
(Female, 62, colon cancer)

Right now doctors have this position: it's us versus the Internet, which is . . . a bad waste of time for everybody, it undermines the confidence [in] the doctors and the Internet when we need consistency not conflict. (Male, 63, prostate cancer)

Ultimately, participants felt empowered by taking control of learning everything they could about their cancer, and how to manage it in their lives.

Online support facilitates control. As well as helping participants increase their knowledge about their medical care, the Internet also enabled them to have more control through increasing their capacity to remove space and time barriers, controlling the emotional tone of the online relationship, and increasing their sense of privacy. However; for some participants, the control sought was compromised because the time barrier was not eliminated.

Removing barriers of time and space. Some participants observed that, at times, it can be helpful to know about treatments from across the world, thereby facilitating information exchange from those who have access to different treatments and medical systems worldwide. Some participants expressed that this advantage was very important in helping them get the support that they needed: *“People from all countries belong to this [Association of Cancer Online Resources group]. I found out what the leading edge was, what the gold standard was in colon cancer”* (Female, 62, colon cancer). At times, the Internet was also found to help rural people connect with others who share a similar

experience, thereby taking control of finding support regardless of geographical barriers to doing so.

A woman I remember that I talked to for a couple of years she felt so alone, she was out in the middle of nowhere and it's not like I was going to find somebody in her neighborhood that was an ovarian cancer survivor. (Female, 64, ovarian cancer)

Many participants stated that Internet support was helpful by allowing access to support at a time that was most convenient instead of waiting to have questions answered at an appointment or in-person support group: *"I could log in at two o'clock in the morning and ask the question and get the answer whenever they had time to give it to me"* (Female, 59, breast cancer). It also gave participants control over how much they absorbed at a given time, since their capacity to absorb new information was variable over time.

You can leave it at arms' length, if you didn't feel like reading it at the time you didn't have to, you could wait and read it later . . . it was really nice to have that flexibility built in and really nice to be able to say o.k. I can take this much in and then leave it alone and then go back and read the email or the information later. (Female, 59, breast cancer)

A few participants also discussed the value of the Internet as a way to take control of reaching more people than they could through giving and receiving in-person support. The reasons cited for this were being able to help the most people in the most efficient manner and being able to receive varied responses from others, as a way of finding the right person to provide effective support : *"You can reach more people faster online"* (Female, 64, ovarian cancer).

For a person with cancer, time is a valuable commodity that is not to be wasted. Although the Internet increases the potential for finding support, participants were careful to only access the help they needed, based on the time they had available to them. In

some cases, online resources did not allow more control because of the time needed to use them.: *“Videos, who has time for videos, I mean really what are they going to show you” (Female, 62, colon cancer)*. At times, some online resources were not effective in breaking down the time barrier enough for participants to find them helpful.

They also have like phone chats, I haven’t been able to access those because they come at all kinds of odd times, and that was the other thing that I found is that most of these chat rooms and talk times were at a time when I couldn’t access it, either when I was working ‘cause at that time I was working shifts or it was . . . so there wasn’t much flexibility. (Female, 59, breast cancer)

As well as managing issues relating to space and time, participants valued the opportunity offered by the Internet to manage the emotional tone of the online relationship.

Controlling the emotional tone. Participants commented that it was helpful that they could gather facts about their illness while keeping the relationship at arm’s length, essentially removing or controlling the emotional connection and depth of the relationship with others: *“I didn’t want a site where I could whine and cry, I was looking for a site that was going to help save my life” (Female, 62, colon cancer)*. Some participants indicated that it is more difficult to connect with others in person, and that their control over their level of engagement was helpful: *“I find it comforting from the point of view that you’re able to talk about what it is without bringing personalities into it . . . it’s a cleaner way of looking at it” (Male, 67, leukemia)*.

The Internet was also viewed as beneficial for participants to be able to gain support without concern about affecting in-person relationships with friends and family. Participants were cautious about discussing cancer issues with friends and family in an

effort to spare them from the emotional burden, and also because they knew that friends/family could not provide them with the “experienced” support that they needed.

In dealing with other cancer survivors and that sort of thing it's really brutally honest that you do share that stuff that's gone on, and again as I said before it's more difficult with friends and family, you have to be a bit more guarded whereas you know when you're dealing with other survivors you can tell them nitty gritty all the truth because they know what you're going through and you can't hide anything from them. (Male, 53, non-Hodgkin's lymphoma)

One of the features of the Internet that led participants to feel comfortable being “brutally honest” about their questions and advice is its ability to allow participants to control their level of privacy.

Privacy. Bulletin boards, online support groups and chatrooms afford participants a medium in which they can connect with others, yet choose how much personal information they want to reveal. Participants felt that online support through these media gave them a sense of freedom to discuss personal issues in an anonymous environment, as well as controlling the level of privacy they wished to maintain while searching online for support. This ability to control their privacy allowed for a feeling of openness in discussing intimate issues that were difficult to raise in the off-line environment. It also fostered an open environment with others who felt the same about protecting their privacy while discussing difficult issues: *“The Internet is a good starting point because there's . . . you don't have to introduce yourself, you're faceless so it kind of breaks the ice a little bit” (Male, 52, prostate cancer).*

While participants had varying degrees to which they were comfortable revealing personal information online, they were consistent that privacy was an important aspect of their quest for support in an online environment, and influenced their choices of resources when searching for support online: *“I reveal very little other than probably my age, I*

don't even use my real name in chat rooms and things like that" (Female, 54, breast and colon cancer).

One participant also observed that she felt safe about connecting with others when there was a feeling of control over privacy and computer safety: *"I guess it depends on what you're revealing and I feel my computer is really safe" (Female, 52, melanoma).*

Privacy was an important factor in avoiding social networking sites, such as Facebook, for cancer-related issues. In other online venues, cancer survivors felt more control of their anonymity, and over who read their postings.

I don't have a tendency to do the chat room type thing and the things like Facebook or blogs, yeah . . . you don't have, with those avenues, you have less control to who gets to actually see it. (Male, 53, non-Hodgkin's lymphoma)

One participant did state that although she may initially connect with other cancer survivors through a social networking site, she would ultimately gather additional contact information from the person so they could communicate about their cancer issues in a more private manner.

If it's a networking site, [I don't reveal] much, not till I get to know people and then generally what I do is I'll pick someone and I'll communicate through with them, I'll give them my email address and then we'll kind of go away from the networking site and talk. (Female, 59, breast cancer)

Some participants thought that social networking sites did not fit within their value system. The need to keep a profile updated with trivial events and the superficiality of its content led some people to avoid the sites altogether. They were avoided both because of disinterest and also from the recognition that in-person relationships can suffer due to the cultural shift of people sending updates online instead of speaking to other people in person.

I've hooked up on Facebook just to see what the hell it's all about and by the way I'm not impressed . . . why would I care whether somebody did the dishes at ten o'clock at night or why is there a need, and again it's a value system I guess. (Female, 64, ovarian cancer)

While using the Internet helped participants to feel more in control of their interactions, for all of them, it helped them to feel less alone. Some preferred to search for in-person experiences with others who understood their journey, and for others, online support was enough to meet this need.

It Helps to Know I'm Not Alone

Participants felt strongly that online support helped them know they were not alone in their cancer journey: *"It's nice to know you're not alone, I guess that's what I'm trying to say"* (Male, 67, leukemia). Most acknowledged an emotional benefit from being able to connect with another person who was experiencing the same difficulties, or who was more experienced in the cancer journey. This was particularly beneficial for those who felt most stigmatized by their diagnoses.

Well I think the biggest way that its [online support] help is that it helped me develop friendships. At that particular time with people who were travelling the same road that I was who were as confused, who were as frightened and who were as stigmatized by the diagnosis that I was. (Male, 52, prostate cancer)

At times, the Internet was a starting point for a deeper relationship with those they connected to online. Once an online relationship developed with a person they felt connected with, other means of communication were often used to further the relationship. For example, some people followed up online contacts through email, telephone calls, or in-person meetings.

More than once I have sort of developed an Internet trust with guys and then have met them in person for a coffee and ended up you know turning that into lasting friendships. (Male, 52, prostate cancer)

Participants described the importance of building a relationship through trust and sharing of similar experiences in order for a personal connection to develop. They pursued relationships with others who were experienced in their cancer journey and who matched their cancer type.

Importance of matching and experience. Participants valued having sites that helped them connect with others who matched their cancer type and experience. In general, participants preferred sites that focused on their particular type of cancer, or that were general sites that had links guiding them to support for their particular cancer. This was emphasized most strongly by participants who had a rare form of cancer and/or had difficulty finding others in their area to share information and/ experiences: *“There was one site, I don’t know what it was called, but it was a forum for clear cell cancer patients, now they had it in all different parts of their body, but it was still clear cell, that’s what I was looking for”* (Female, 57, endometrial cancer). Matching was also reflected in participants’ choices of which sites to use. Having local content was desirable as a way for participants to feel more connected with other survivors, since the people they wanted to be in touch with online would be going through the same experiences with the health care system, treatment options and service issues.

I would like to see for patients in [this province] . . . some way of having it [OSG] through some kind of local organization so that you’re . . . feeling a little more I guess touched by it in a way . . . I know in a lot of other cancer patient situations, treatments are very different across the world and the availability of treatments across the world is very different, so to me it would be [helpful] to be able to go on line and even to go into the local website . . . and to be able to link through that way, I think that would be fabulous. (Female, 52, melanoma)

As a 67 year old man with leukemia said, *“Matching is important”*. When searching for information, participants reported that matching of cancer types provided

participants with critical knowledge about what to expect through their cancer treatments, information about treatments in other regions, current advances in research, and a sense of partnership in not being alone in their healing journey.

In a forum where you're dealing one-on-one with the exact same thing so there is a kinship there, you know, they understand and they know. (Female, 57, endometrial cancer)

One participant also observed that the online support she received was limited by her difficulty in finding a person who matched her experience, and emphasized the importance of making it easier to connect online with others who are a strong match.

There could also be a section [in creating a website], do you want to connect with someone in your situation as far as your level of disease and all that kind of stuff and then have . . . a third party monitor it, and somehow within the registry they can say, of the people who say yes I will be a support person within the registry, then they're linked. I think if it could be done in such a way that it was private and initially and it can be one on one and then if you realize you know what there's lots more out there like me then maybe I will go to a group or at least I'll participate in something. (Female, 52, melanoma)

Participants emphasized the importance of connecting with someone who shared a similar cancer type as their own, as well as for providing first-hand information about what to expect through the cancer journey and a sense of hope that the disease can be overcome.

If any website can give you hope by you being able to speak to other cancer victims or patients or survivors online where you can ask direct questions it's all done by email I would just email in and say my oncologist is giving me. . . I'm having terrible cramps two days after, has anyone experienced this? Someone would write back and say yes I have experienced that and after a few drugs I found one that works, here's the name of it, give it to your doctor. That's what that ACOR group is all about. (Female, 52, melanoma)

The information given by experienced others was considered thoughtful in its intent, often providing practical information about cancer, treatments, coping with side effects, and hope for the future.

Well you know what some of the best advice that I got on this journey was from other people who had been diagnosed with prostate cancer, it did not come from . . . I got good advice and information from my medical team but the most practical, useful information came from other guys who have travelled this road before me. (Male, 52, prostate cancer)

Many participants shared their opinions on whether or not the online support they received matched their needs. Participants varied in these experiences, with some participants having more success than others in meeting their needs. Although almost all participants believed that others were trying to provide support, the support received was, for some, a perfect match to what was needed, and for others, was unhelpful in nature. Sometimes support, even if given by others who were a matched cancer type, was viewed as unhelpful because it did not match the participant's value system and so was not experienced as supportive.

They just kept saying over and over again you know that I needed to what was the phrase they used . . . oh take one day at a time. I didn't have time to take one day at a time. I was in the process of trying to get some help and trying to sort out all the information. (Female, 59, breast cancer)

Matching was also an important aspect for those who chose to give online support. Participants were most comfortable giving support if they thought that they could offer advice or information to others based on similarity of personal experiences.

At one point there was someone that came on who was just starting the same process I was in the middle of so I just tried to offer encouragement and let them know it's not as bad as you might think it's going to be kind of thing. Hang in there, it will end. (Female, 54, breast and colon cancer)

Matching was also a factor in why participants preferred to connect with other cancer survivors rather than friends and family. Most participants agreed that friends and family lacked understanding of what they were going through during their cancer

journey: “*Cancer survivors know exactly what you seem to need more than friends and family, put it that way*” (Female, 54, breast and colon cancer).

One participant also discussed the different types of support he receives from different people. Although he communicated online with others who matched his cancer type, he also observed that matching was less important when discussing the emotional experience of dealing with cancer.

Cancer is cancer. It’s helpful if it can be the particular one that you do have, but generally it doesn’t matter whether it’s colorectal or prostate or breast, it’s . . . the same experience that you need to talk to people about that have gone through that experience. (Male, 53, non-Hodgkin’s lymphoma)

Although participants valued connecting with others who match in cancer type and experiences, the ways in which they received this support was highly individualized.

Different ways of connecting. It was clear that participants thought that other cancer survivors understood their experiences better than friends and family because other cancer survivors share a similar experience to their own. Nevertheless, there is another element of support that is exclusively offered by friends and family. Some participants indicated that, although they prefer to talk about cancer issues with other survivors, friends and family offer a loving support that is different from the support offered by other survivors. Having support from friends and family may not fill informational needs or help survivors feel less alone in their experiences; however, the embracing nature of support that friends and family can offer is a form of emotional support that is not duplicated online.

Friends and family haven’t been through the treatments and the whole physicality of it, let alone the emotional part of it, so that support is different, they support me as an individual and re-boosting my self-confidence and what they’ve known of me before. (Female, 54, breast and colon cancer)

For some participants, having enough in-person support meant they did not have the need to search online for someone who matched their needs. This in-person network primarily involved people who were knowledgeable about cancer. It was clearly a factor in why these participants felt less need to search for online support than others who were lacking in support from their in-person network.

I mean I might [search for online support] if some issue comes up, but you know I have fantastic access to the medical community here in [my city] so it's almost why would I go to a secondary source when I can get the answer I need right away? (Female, 64, ovarian cancer)

Another participant thought that the companionship of friends, whether understanding of cancer or not, also played a role in feeling supported through the cancer experience. She also noted that, as her support needs decreased, she felt more adequately supported by her in-person network: *"I have a tendency to stay away from some of that [online groups] now that I'm not in active treatment and have made a circle of friends that I can connect with if I need to"* (Female, 54, breast and colon cancer).

Although in-person relationships were considered important for feeling supported through the cancer journey, one participant observed that having cancer has made his support network smaller, since friends sometimes avoid contact when they are unsure about what to say: *"I have friends, not close, close friends, but I don't hear from anymore because they don't know what to say"* (Male, 67, leukemia).

Some participants noted that there is a different depth of information that is reserved for in-person contact. For more personal issues, or specific cancer information, participants preferred to give support in-person whenever possible.

I think that there are times in fact when the Internet fails . . . there's a certain amount of where you need the actual person in front of you to get the confidence that they're credible and their argument is credible. (Male, 63, prostate cancer)

The benefits of in-person contact are noticeable when trying to help others deal with intimate cancer-related issues, such as sexuality. One participant who is experienced in the field of Internet support commented that since you cannot see the person's body language, expressions, and other important aspects of non-verbal communication when helping someone through the Internet, it is harder to deal with sensitive issues. His opinion was that such sensitive issues are most effectively dealt with face-to-face.

If I'm giving real support I'll arrange to have a conversation with a person one-on-one and I would say at least once every ten days I have a prostate cancer patient from somewhere in the world calling me up as a follow-up to something I said in an email cause I guess it is so much easier to talk...what you can't get through the Internet, is a certain sense of how comfortable a person is with an idea, and you can get that from a phone call, better I guess from in person. (Male, 63, prostate cancer)

This comment is in contrast to those who found it easier to raise such issues online due to the anonymity and control over the emotional tone that can be achieved online.

In addition to limiting the quality of information exchange, the Internet was also observed to provide less of a feeling of connection than that which can be obtained in face-to-face interactions. The inability to see or hear the person with whom one is communicating limits the depth of the online relationship.

When listening in person you get a feel for the person, more comes out, I think you get a little bit of their value system more than you can online. (Female, 62, colon cancer)

As well as differences in preferences for in-person and online support, cancer needs also changed over time, depending on their diagnosis or stage of their cancer journey. Some participants stated that their cancer prognosis played an important part in determining the level of support required. Those who had cancers that were caught early or who were cancer free sought less support than those who had a later stage cancer.

I also felt, to be honest, a little embarrassed to do that 'cause I found that mine [cancer prognosis] was so fortunate, so early that even though it was cancer and probably more so important because of my previous cancer, I wouldn't go to them 'cause I would feel almost facetious because most likely the people that are there would have more severe types than my type of cancer. That held me back for sure. (Female, 52, melanoma)

When searching online, some participants chose to be more interactive, while others preferred reading others' comments and/ or postings without seeking a dialogue with another person. For many participants, reading others' postings and searching frequently asked question modules (FAQs) were valuable sources of information, as participants were successful in finding information that related to their own needs: *"I read you know their conversations and somebody will be asking another person a question and it might help me for what I want to know"* (Female, 57, endometrial cancer).

For most participants, email was used as a method of both giving and receiving support from others to supplement the support exchanged through an in-person relationship, or as a primary means of communicating with others who shared a similar cancer experience, when they could not connect in-person with others who lived in another part of the country or world.

She [email contact] actually lived out west and she was going through you know like six, eight months ahead of me in terms of her cancer journey and that turned out to be invaluable . . . she gave me all kinds of tips about ointments and things like that. (Female, 59, breast cancer)

Participants commented that they regularly used email to connect with friends, family members, medical professionals, and other cancer survivors who they had met in their communities. It often supplemented their in-person relationships by increasing contact between times they could meet each other in person: *"Lately [I've connected with*

others] via email because I made friends with some of the dragon boat survivors”
(Female, 54, breast and colon cancer).

One participant also observed that email was a useful venue for receiving relevant information from cancer organizations in the form of an online bulletin or journal:
“[local cancer Internet site] regularly sends us [a] newsletter, and I love being able to get that directly in my email box” (Female, 59, breast cancer).

Social networking sites, such as Facebook, were not seen as a strong resource for credible cancer information and the communications received through social networking sites were viewed as superficial in content: *“You know those people [on cancer sites] are going to be there for a serious purpose, not just browsing around you know”* (Female, 57, endometrial cancer).

A common issue raised by participants was the desire to use chatrooms for support, and the disappointment about the reality of using this type of Internet venue. Participants often recognized the value in connecting with others using real time chat, but had little success in finding support that was appropriate in nature. One constraint to using chatrooms was limited participation by others: *“Most of the websites that were supposed to have chat rooms that you could go to for support there was never anybody in them”* (Female, 59, breast cancer). Another issue was the cliquish nature of the chatrooms: *“It [the chatroom] became like a little clique . . . so that didn’t work, that wasn’t really helpful”* (Female, 59, breast cancer). Others commented that they had concerns about the trustworthiness of some people in the chatrooms: *“The online chat room that I was involved with started to have some suspicious people”* (Female, 64, ovarian cancer).

Although most people were unsuccessful in finding meaningful support through chatrooms, some people still stated that the concept of connecting through a chatroom is something they would consider useful: *“If they [chatrooms] had worked it would have been great” (Female, 59, breast cancer).*

The importance of honesty and openness. Of those who chose to connect in OSGs, many participants observed that they thought that the people in the groups were honest in their experiences and advice, and this seemed to be important for finding the right person to connect with: *“I did feel they were honest. Yeah I didn’t really get a feeling that there was a lot of bull being bandied back and forth” (Female, 52, melanoma).*

Participants talked about how being online changes their comfort with being open with others about their own experiences. Two stated that it was easier to be open online than it is in person, because of the anonymity that can be maintained in online relationships.

I think when you’re on the Internet it’s not the same as one-to-one, you know face-to face and people will tend to . . . I think offer more information because they’re never going to see you. (Female, 57, endometrial cancer)

A few people also observed that, by modeling honesty and openness about cancer experiences, a person can help others become more open as well. This ultimately added to the strength and effectiveness of the group by enabling participants more accurately to determine whether or not another cancer survivor is a match for their support needs.

I think that when you’re going to a medical site where you’re discussing your cancer ramifications, all these little, everyone has these little idiosyncrasies, no two people are going to react the same way, you just have to have every detail out there because that extra little detail might be what clicks and makes someone say hey this drug worked for me when I had that problem. (Female, 62, colon cancer)

Many participants also discussed the importance of being able to discern honest information from dishonest information provided from those in support groups or chatrooms. Although participants thought that most people were being honest about their experiences, questions were still raised about some peoples' motives and honesty in discussing cancer issues.

If you just typed in the type of cancer you have you can end up with some really weird stuff out there and there are some snake oil salesmen out there that are touting their particular product . . . and they're trying to sell you something and they're also trying to impose their views on diet and health and life, you know what I mean? (Male, 53, non-Hodgkin's lymphoma)

Personal stories. One aspect of credibility involved people's attitudes toward narratives, testimonials, and blogs. Although many participants discussed finding personal stories from others who matched in cancer type, such stories were not considered helpful for informational support. Although reading personal stories of others was thought to have merit in helping people feel as though they were not alone, and in having a therapeutic benefit for the writer, participants were often critical of the value of the content within the personal story for gaining credible information about their disease.

When you're talking about cancer cures then you find a site that has testimonials on it you have to realize that the people who died taking that treatment weren't around to give testimonials so it's all biased data. And if I come to a site, if I come to a site which is telling me of something new and different with testimonials, I immediately suspect it as being unproven and the same strategy. (Male, 63, prostate cancer)

Participants were clear about the types of online resources they prefer, and the constraints they face when searching for support. Their experiences gave them practical insights into modifications that would make searching for online support more effective.

Maximizing the Net's Usefulness for Cancer Support

Participants discussed a variety of aspects of Internet access and website design and content. While the issues discussed by participants varied in specifics, their overall views were similar in that they wanted to easily navigate and find useful content. Overall, participants wanted to find helpful support efficiently, be able to access it easily, and have computers available to them.

It's hard to find what you need. Most participants noted that it is not always easy to find helpful support online. As one participant stated: *"To find a site that's a patient friendly site, an appropriate patient friendly site is difficult"* (Female, 52, melanoma). Many participants discussed their difficulties finding helpful Internet sites and that they would, at times, give up their search for online support: *"I'm not a very patient person and sometimes I'll just give up, this is a waste of time . . . after 10 minutes if I can't find what I'm looking for"* (Male, 67, leukemia).

Although many participants were admittedly computer-savvy, they still recognized the need for computer training early in the cancer diagnosis. Some participants observed that many people do not consider Internet support an option because of their lack of computer training.

I know people a little older than me . . . my father for instance there's no way he would go online and ask for information or even discuss anything, but if they have the information and they're more comfortable with it, why [they] may find some support that they're not getting locally or in the family side of things. (Female, 54, breast and colon cancer)

Training was also noted to be an important issue for improving people's abilities to find helpful support. Specifically, participants observed that direct training could be

beneficial for improving basic computer skills, searching strategies, typing skills, and providing a guide to credible sites.

There are maybe quite a few people out there that are maybe not quite as computer savvy as myself, of an age like my parents are totally computer illiterate that would have a hard time . . . trying to explain to my father how to operate a mouse was a major accomplishment, but you need somebody there to help them, providing . . . just providing a computer isn't enough, you would have to have somebody there to help them with it or even somebody that they can call to help them with problems with finding the proper sites to get on to, telling them that they should try the NIH [National Institutes of Health] or the Caring Bridge or other things that . . . somebody that does know the system and how to work it. (Male, 53, non-Hodgkin's lymphoma)

Having someone guide a cancer survivor to appropriate sites was considered essential, not only for credibility, but also to help cancer survivors save valuable time and frustration with the trial-and-error process of finding someone who matches their needs. This issue was highlighted strongly by some participants who were looking for specific cancer-related information that they could not obtain anywhere else, such as information regarding their rare cancer diagnosis, or specifics about cancer and sensitive issues such as sexuality and sexual orientation.

One thing that I found lacking in terms of resources for me, it's very personal, for me . . . I'm gay and I had a tough time finding resource information specifically geared to prostate cancer in gay men, I had a hard time in finding that. (Male, 52, prostate cancer)

Many participants felt strongly that direct training needs to be available for cancer survivors to help them learn to tell the difference between honest information and information that should be disregarded. Concerns arose about being a victim of fraudulent claims from companies selling alternative treatments, the harms of accepting advice from others who believe, correctly or not, in non-conventional treatment practices,

and wasting valuable time on persons who are not providing credible information or honest experiences.

Without training the patients on to how to tell what is good and what is bad, like those simple rules that I said, then the doctors and the patients are wasting a huge amount of time and probably losing years of their life without it and nobody seems to think that there's a site where we should be educating them, about how to use the Internet. (Male, 63, prostate cancer)

As previously discussed, participants with rare forms of cancer, or who are in need of specific information, often have difficulty finding the support that they need. Such participants noted that it is helpful to have a person guide them to the sites that would best meet their needs. Some people found help with navigation from friends, family, or others in the medical community: *"Patience will get you there and many times . . . my wife will find it, maybe not quickly but she'll find it"* (Male, 67, leukemia). Some participants who did not personally need guidance still noted the importance of others being able to obtain this type of direction to be successful online: *"The simplest thing that ought to be done . . . is there should be a flier in every doctor's office which says how to use the Internet"* (Male, 63, prostate cancer).

Access to computers. Some participants discussed the usefulness of having computers available in medical clinics to help make the process of searching for support efficient, as a way of utilizing waiting time and enabling patients to search for information that they can then bring to their appointments. Some participants found that hospitals do have computers that are meant to serve this purpose; however, participants reported that the computers generally do not work and/or are not set up for easy access.

They had . . . supposedly had computers at the hospital that you could get information from, they never worked, or nobody knew what the password was or they just didn't have time so that was very frustrating so unless I could . . . so I'd have to wait until I could get home and had the time. (Female, 59, breast cancer)

Design. Most participants agreed on the basic features that are helpful on an Internet site, with some participants discussing their thoughts more in-depth than others. Overwhelmingly, participants stated that a site needs to be user-friendly. Issues that were discussed as being an impediment to ease of use included having “too much” (too many links, too many graphics for uploading, and too much information on FAQs): *“There’s too much info out there on FAQs” (Female, 64, ovarian cancer).*

A lot of them [Internet sites] have the flash, a lot of them have a lot of graphics because they want to make it attractive, well that’s all well and good but you have dial up you’re never going to get that thing open. (Female, 59, breast cancer)

Participants also discussed the importance of having a simple Internet design with easy-to-find links to relevant information: *“Good links to sites where you can get definitions or do a little bit of research that pertains to that particular cancer that you’re going through” (Female, 54, breast and colon cancer).* Although links were considered important, two participants also noted the importance of limiting the number of links to ensure the site is not too overwhelming to navigate: *“Everything very clear, very clear links and not too many . . . only good specific small number of links” (Female, 62, colon cancer).* Some participants also discussed the importance of listing cancer types in a clear manner to make it easy to find type-specific information: *“If you had a listing that said . . . alphabetically the types of cancer, I could go into C, clear cell, I want to know what is it” (Female, 57, endometrial cancer).* One participant also discussed the importance of being able to search within a site to easily find specific cancer-related information with ease.

A patient could go in to type in, almost a Google within the site, and they could type in sore mouth and it could bring them to what was already said, o.k. well that

isn't what my sore mouth is all about, they could still ask the question. To me that would be very important. (Female, 52, melanoma)

One participant also observed that cancer-related Internet sites can be hard to navigate because they list cancers by location instead of cancer type. For a person with a type of cancer that is not localized in a particular area, this is an impediment to finding online support.

The Cancer Society's website is wonderful, they have everything there but there's still things that I would look for that aren't on there and you know it says . . . there's a box you can open up and it's fantastic and it says . . . list your cancer type. Well to me, it's not the location of the cancer, it's what type I am. To me type is you know is it a sarcoma or carcinoma or you know mine was a clear cell cancer, well it's rare and you can't find hardly anybody that has it so when I open up the box I thought it would list types, meaning you know that, but they list it as lung, liver, organ wise. (Female, 57, endometrial cancer)

Content. Content of websites was important to most participants, with many participants suggesting improvements to online content. The major issues participants raised were that they would like content to include different types of information that they cannot obtain elsewhere and that the presentation and terminology to be improved. Participants often discussed improvements such as putting content into layperson's terms, providing supplementary information about the functions of different body organs, and being very clear about the subject matter.

It isn't so much reading level that counts, it's not using the technical terms that are used within that particular profession. It has to be put into terms that non-medical people will understand. (Male, 53, non-Hodgkin's lymphoma)

So there would be a nice little glossary and a map of the human body so you could find out where it is and . . . 'cause a lot of people don't understand when they tell them they have swollen lymph nodes in one part of your body or other, they use terms that they don't understand. (Male, 53, non-Hodgkin's lymphoma)

A few participants discussed the importance of being able to find new research in the field of cancer. These participants discussed the importance of being knowledgeable about new treatments and outcomes for cancer.

Of each disease area if there's any breaking news I think it would be nice for people to know like even any new treatments that come out, just breaking news such and such, now I know there might be a barrage of calls to physicians, but patients have a right to know what's available. (Female, 52, melanoma)

One participant also observed that although reading research is important, there is a strong need to have a site that puts the research into layperson's terms: "*Part of that site has to have some relevance to what's happening in the world of cancer*" (Male, 67, leukemia), then elaborated on the importance of having a link to new research.

Yeah, a link to research, a link to . . . and you know research isn't the right word, 'cause you have to read the research to find out . . . it's mumbo jumbo sometimes, 90% of it you read between the lines and try to figure out what's going on, people don't talk English when they're talking research so, but you know . . . and that would just confuse, that would be . . . if you're reading that you could read the wrong thing into it too. I think you need to find a friendly resource that would at least just tell me to take the time to just or to have just a brief explanation as to what it is in English and if you want to go on the site, there's a link to go on the site, link on that, you can read, if you can absorb it fine. (Male, 67, leukemia)

One participant noted the importance of including basic information about how to navigate a site efficiently, such as providing instructions on how to create a folder for information and giving clear choices about which type of information he/she could have sent to his/her email: "*Give instructions on how to make a folder for these emails to come into. You've got to get right down to the basic*" (Female, 62, colon cancer).

Local content was important for many participants to learn about activities and support groups within their own community.

It would be nicer if Canada had the initiative to make that forum for somebody with that type but you know with . . . because you know where they are dealing with the exact same issue. (Female, 57, endometrial cancer)

Another important issue discussed by participants was having one site that includes all the information and support that a cancer survivor needs to improve his/her quality of life and cancer outcome. Participants varied in their ideas on this form of improvement; however, they did not conflict in any of their responses. Some participants discussed the benefits of being able to have questions answered by medical professionals, either through bulletin boards, FAQs or chatrooms.

Have updates or physicians . . . give periodic information about some of the treatments or some of the side effect managements of the disease because every cancer has so many different aspects and needs around it. (Female, 52, melanoma)

One participant discussed in-depth the benefits of having an Internet site that provides clear direction about how to navigate the cancer system for drug reimbursements and accessing services.

The other thing I'd have on there is reimbursement stuff because a lot of patients don't realize that there are different avenues of help for reimbursement and for . . . even for your cancer drugs, we know there are cancer drugs that aren't funded, and we know, unfortunately, we'll be coming to two-tier medicine; however, there are companies that help you now even the company themselves or there are different support areas that may help. (Female, 52, melanoma)

Some participants observed the usefulness of having a website that provides easy-to-find information about where to go in their own communities for in-person support, such as local support groups or cancer-related social events so that they could remain connected to others.

If you could put the local support groups 'cause those are the really good ones . . . local people that have gone through the same thing, that needs to be done. (Male, 53, non-Hodgkin's lymphoma)

Some participants identified that they were more able to cope with their cancer diagnosis since they can receive practical answers to their questions from others via the

Internet. However, a few participants discussed the need to directly address the psychological trauma that accompanies a cancer diagnosis, and did not think that the support they received online was adequate for teaching these skills: *“I think articles, which are completely lacking in anything I’ve ever seen, professional articles giving you some guidelines, as to how to mentally cope with what you’re going through or have been through that would be an unbelievable resource”* (Male, 67, leukemia).

A few participants also observed the importance of having a website that maintains a positive tone about the cancer journey: *“The other thing I was going to say [in creating a website] . . . in bold letters at the very top of the site, is that cancer is not necessarily a death sentence”* (Male, 53, non-Hodgkin’s lymphoma). While most websites list cancer facts, such as survival percentages and outcomes, these participants discussed the importance of giving cancer survivors hope for recovery and this was often considered essential for the healing process: *“I think being able to give a cancer patient hope is probably the number one thing”* (Female, 62, colon cancer).

When considering the design of online support groups, moderators were considered valuable for keeping interactions focused in a positive way, as well as in increasing feelings of credibility of the information discussed.

Moderated boards are best. Moderated boards were thought to have the most appropriate information, the ability to keep participants on-topic, a greater likelihood of correcting misinformation, and a general sense that the information is more credible, both from a disease perspective and a treatment perspective. Participants who were experienced with bulletin boards reported that the best boards are moderated by a person who is knowledgeable in cancer issues.

We are not allowed to talk about homeopathic methods, we're not allowed to talk about anything that isn't . . . well we have to stick to the medical, we have to stick to the tried and true, no one talks about artsy fairy remedies. (Female, 62, colon cancer)

Although many participants consistently stated the importance of having a board moderated, participants were also clear that the moderation does not need to be provided by a health care professional. While it was important that a moderator be experienced in the cancer field, some participants stated that having a site moderated by health care professionals could be a hindrance instead of a help.

It [a website] doesn't necessarily need to be run by health care professionals either, it's more for survivors. 'Cause unfortunately the health care professionals seem to perpetuate the terminology they use. (Male, 53, non-Hodgkin's lymphoma)

For two participants both of whom worked in the field of cancer research, the frustration of reading misinformation online was amplified. The need for a strong moderator became paramount for these participants both to ensure the accuracy of information and to relieve a feeling of obligation to correct misinformation posted by others.

There was a few times that I would see that someone else had answered somebody else's question and they didn't know what they were talking about or had it wrong or you know it could have just been misinterpretation so I would answer trying to help by giving the right information. (Female, 52, melanoma)

Professional sites are best. The issue of credibility was critical in how the participants chose which sites to use for support. Some participants stated that they felt more comfortable with professionally created sites that were maintained by hospitals or cancer organizations.

I try to go to recognized sites as opposed to just typing in my type of cancer and see what comes up because there are some sites out there that aren't terribly

reliable in terms of the validity of their content. (Male, 53, non-Hodgkin's lymphoma)

Some stated they would actively avoid a site that did not appear to be from a professional organization in order to ensure they were receiving information that was credible in nature: *"I avoid it [non-professional sites] because a) I probably can't trust the information I get there, and b) I'm uncomfortable with the security level that might be on that website"* (Female, 59, breast cancer).

The Spirit of Survivorship

The "spirit of survivorship" was woven throughout all major themes the participants' discussed. It impacted their attitudes, decisions to take control of their health, and decisions to give support to others. It was also reflected in how participants felt supported online, and in their recommendations for improvements to online resources to ensure they reflect messages of hope.

Some participants discussed how cancer had changed their attitude on life, in a way that had made them more positive in spirit. They talked about having a new perspective on life and also noticed the same attitude in other cancer survivors.

You know sometimes you think you would find people that would go on and on about simple things, they don't, they're very positive people, I don't know what happens to you when you get cancer, it changes your attitude, it really does.
(Female, 57, endometrial cancer)

Many participants discussed the importance of providing support to others, as they transitioned into being "experienced" in their cancer journey. Although all participants received support online, the methods of giving back were very individual to each person. Some people chose to give back by providing online support, while others

chose to give back in more varied ways, such as through advocacy, artistic expression, and media attention.

And I say to people, download the song [I wrote about cancer]. I'm sure . . . listen to the song it's there please, it's for you, I'm saying this to the survivors, to people like me, to the families, to anybody . . . and actually I have a project and this is kind of like what . . . and I don't know if I can pull it off, but there's four songs, three are mine and one is somebody else who wrote a song for their little girl, they're musicians these people and they lost their daughter who was about four years old, so I want to record these with a bunch of professional musicians, and then I want to distribute it free to the survivors association. (Male, 67, leukemia)

I get emails from the ACOR group, I make comments, I give advice to other people, I listen to what is going on because I'm now a cancer coach and I need to know everything. (Female, 62, colon cancer)

Many cancer survivors consider the process of giving back important enough to make it a priority in their lives. In recognizing its importance in their own healing, these participants emphasized that they actively sought out others that they could help: “*My whole approach to life, to healing the disease, is to help others*” (Male, 67, leukemia).

Other participants thought that giving back to others was necessary to give to others the help that they received during critical times in their own illnesses.

I wanted to spread the love and I wanted to give back and I just want to pay it forward because the people that reached out to me made such a huge impact and made such a big difference in my journey that I want to make sure that I do it for others as well. (Male, 52, prostate cancer)

By giving support to those in need, participants felt that they were contributing to the empowerment of others less experienced in their cancer journey.

I find that most of the time people thank me for what I'm doing but what I find is that they're . . . more willing to document their problem, more thankful and feeling empowered by my openness and honesty. (Male, 63, prostate cancer)

One participant stated that her own cancer stage was a factor in determining who she would choose to give support to, being most comfortable providing messages of hope

to others who shared a similar prognosis as her own. This participant felt a responsibility to provide hope and help to others based on her own cancer experience.

You don't want to reach out to someone who is at stage four melanoma and has gone through millions of treatments and stuff and yet . . . you know it just wouldn't be fair to them to reach out to them I don't think. (Female, 52, melanoma)

This thoughtfulness and honesty in ensuring that advice given was done so with utmost credibility was essential to this participant's comfort with giving back to others. This illustrates that credibility was considered highly important for both support seekers and providers alike.

Summary

This chapter presented participants' views on why cancer survivors seek online support, as well as how the Internet has been successful or unsuccessful in supplementing their social support networks for cancer-related needs. The following long quotation, given here exactly as the participant sent via email, summarizes well why cancer survivors seek online support, as well as what it is like to be newly diagnosed and feel unprepared for the emotional upheaval that a cancer diagnosis cancer diagnosis can bring.

If you pretend that you are now a cancer patient, and start your journey on the internet . . . You had a test and the phone rings "Hello Kathryn, this is Dr. ? and the test shows that you have cancer!! We will call you with an appt. with the cancer center within the next week or two!!! HMMMM!! That night and the next 2 weeks you spend wondering what do I have? What stage? Area? Type? Prognosis. God can't do that till I know what type it is!! The day has arrived-- you had to pry the type etc. out of the cancer doctor-- now you get brochures-- wonderful info-- none of it tells me what I need to know. Ok I will look it up. Is there a site that tells me about what I have? Now you have to tell your mom-dad-family etc. Probably hubby was with you and knows what impact the news was like!! Your mom is delicate and so you gather strength for her and hubby- the more they see you are ok-- the better the whole thing will be. So Kathryn-- you can select a type of cancer and location and set out on your quest for knowledge. Would you like to talk to someone with same type-- maybe they

have a list with a forum for that kind! You can use my scenario--- Uterine cancer that is called - clear cell cancer and is rare 4% [of the] population has it!!! Oh yes path lab called doctor and even though the doc thought the cancer was contained in your uterus --- path lab says no - it was found in the blood vessels in the outer wall of the uterus!!!! Oh dear doctor-- blood flows where did it flow too ??? Don't know Kathryn -- we will give you chemo and hope for the best. Can't have radiation as your all scarred from old fashioned cobalt radiation. So I search the Internet for any info that will relate to my dilemma and then I can educate myself and ask doctor what I need to know!! (Female, 57, endometrial cancer)

Participants felt a need to be educated about all aspects of their disease. At times, this was due to a lack of confidence in their physicians, as well as a lack of physician support for discussing secondary cancer-related issues, such as sexuality and family issues. At times, participants believed that their cancer outcome had changed due to the support they received online from others who provided them advice on treatment options and how to navigate the health system.

Although participants were highly individualized in how they used the Internet for support, they discussed the value in knowing that they were not alone in their cancer journey. The Internet was an important tool that facilitated connecting with others with whom they could share a meaningful connection. Matching and experience were considered essential for participants to feel supported by others, as well as feel that the support they gave back could be received in a meaningful way. The honesty and openness of other cancer survivors aided in the connection participants felt to others who shared a similar cancer journey.

Participants were clear about how to maximize the use of the Internet for social support. They discussed the importance of having access to computers, a user-friendly Internet design that eases connecting with others, and clear, credible content written in lay terms.

The spirit of survivorship was discussed as an essential part of life with cancer. Participants emphasized the importance of positivity and hope, regardless of cancer prognosis. Many participants thought that it was essential for them to provide hope to others and that doing so was fundamental to their own healing.

Chapter 5: Discussion

This study sheds new light on many aspects of older cancer survivors' wants and needs when searching for social support online. Although researchers have begun to understand how such individuals use the Internet for social support, information has been lacking on how older cancer survivors perceive their use of the Internet for support, and what we can do to reduce the barriers they face when trying to connect with others online. This section describes how this study adds to current research in helping to understand the wants, needs and barriers faced by older cancer survivors when using the Internet for social support. It also identifies many new areas for future research that could help to clarify issues outside the scope of this study. This section also describes the implications of this study for health promotion, limitations, and plans for dissemination.

Participants discussed the spirit of survivorship with such passion that it had to be identified as an important part of the journey toward healing. Renowned cyclist and cancer survivor Lance Armstrong eloquently described its importance in the following quote:

If children have the ability to ignore all odds and percentages, then maybe we can all learn from them. When you think about it, what other choice is there but to hope? We have two options, medically and emotionally: give up, or fight like hell. (as cited in PRWeb, 2010, para. 3)

Much the same as Lance Armstrong, this study's participants emphasized the importance of the spirit of survivorship, meaning having a fighting spirit, being positive and maintaining hope, in life with, and after, cancer.

Rustoen, Cooper and Miaskowski (2010) found that hope mediated the relationship between psychological distress and health status, as well as the association between psychological distress and life satisfaction; thereby concluding that hope may be

an important resource for oncology patients that impacts quality of life. Honoring the “spirit of survivorship” within a website, in a credible fashion, may be a particular challenge. Future research can examine whether use of sites that are designed with messages of hope has an effect on health, life satisfaction, and site utilization as compared with sites that convey less positive emotions and are more information-based.

Many people discussed the importance of giving support to others, not only to repay the support they received in their journey, but also as an important component of their own healing. Participants’ views on the benefits of giving back are matched in many studies outside of cancer-related literature which show benefits for psychosocial and physical well-being (Brown et al.; 2005; Musick & Wilson, 2003; Schwartz & Sendor, 1999). Further research could determine differences in outcomes between those who make a deliberate decision to give back compared to those who only seek support.

This study also outlines the motives behind choosing to give support to others; people feel a need to give back to others the support that was offered to them. Interestingly, the modality of giving back was not dependent on the venue in which the support was received, since many people who received support online chose to give back by other means, such as advocacy or artistic expression. Future research can examine the number of people who do choose to give back, since it is likely not being captured by analyzing the number of support seekers and providers online.

Implications for the Physician/ Patient Relationship

Studies have shown that most cancer survivors want to be involved in collaborative decision-making (Davidson, Parker, & Goldenberg, 2004; Parker, Baile, deMoor, Lenzi, & Cohen, 2001). Participants in this study confirm these findings.

Increased patient involvement is an important part of quality improvement, and is associated with improved health outcomes (Stewart, 1995). Future research could explore the current needs and expectations of today's patients for information exchange in order to help the medical community bridge the gap between what is expected and what is currently provided.

Not all cancer survivors believe they were getting the basic information they need about their diagnosis and treatment options from their physicians. Furthermore, participants lacked confidence that physicians were up-to-date on new treatment information. Say (2003) found that patient trust was regarded as the key facilitator for collaborative decision making, and that trust in the physician is one of the most important factors when reaching a treatment decision. This study suggests that, although patients search for online support for a variety of reasons, some patients feel a necessity to search online for treatment options due to a lack of confidence that their physicians have given them the most up-to-date information on treatment options. It is possible that cancer survivors who feel less confident in the information and support from their physicians feel more need to use Internet support. Or, as Eysenbach (2003) suggests, it may also mean that Internet users become more dissatisfied than non-Internet users when they realize how much information it is possible to receive via the Internet, thereby changing their expectations of their physicians. Future research could investigate how such dynamics interact to affect the patient-physician relationship and feelings of need for online support.

Although some participants felt supported by their physicians in discussing online information, others felt criticized for bringing Internet information to their medical

appointments. Murray et al. (2003) found that the effect of taking information to the physician on the physician-patient relationship is generally positive as long as the physician has adequate communication skills, and does not appear challenged by the patient bringing in information. Nevertheless, since most patients do not know how their physician will respond to the Internet information, patients risk damaging their confidence in their relationships with physicians at critical times during their illness. This study also suggests a relationship between physician responses to Internet information and patient satisfaction with the patient-physician relationship, since participants who felt supported in bringing Internet information to their appointments also felt positive about their relationship with their physician, while those who felt unsupported in doing so, were not. Solves, Santacreu, Martinez and Remon (2009) showed that, although many physicians believe that the Internet helps patients to learn more about their disease, physicians also perceive many disadvantages to the Internet such as erroneous information, generating a loss of confidence in the physician, or generating conflict in the doctor-patient relationship. It is possible that these issues could be resolved by physicians guiding patients to sites that they themselves view as evidence-based. Future research could focus on outcomes of patients who felt their physicians supported their quest to educate themselves compared to the outcomes of those who felt unsupported.

Although participants noted the benefits of taking charge of educating themselves about cancer, they also expressed caution about the potential for others to use alternative treatments found online instead of treatments that are evidence-based. Research has shown some validity to this concern. Culver, Gerr, and Frumkin (1997) analyzed bulletin board composition and posts of an online support group for persons suffering from a

repetitive strain injury, finding that the advice offered frequently had little basis in biomedical science or accepted medical practice. They also found “posters” appeared to assume that what was stated by other “posters” was true, and there was a conspicuous absence of critical evaluation of conclusions drawn. This current study differed from Culver et al. in that participants were careful about trying to discern credible information online and valued online support groups that had moderators who kept interactions focused on proven treatments. It is possible that, since this current study involved participants with a life-threatening illness, they critiqued online information more deeply than those in Culver et al.’s study due to the seriousness of their illnesses and because of the potential loss of time that could be wasted on alternative approaches to healing. It could also be that Culver’s et al.’s study involved younger participants who were less critical of the credibility of online information (Hesse et al., 2005). Future research on cancer-related online support groups needs to focus on the acceptability of the advice being offered to cancer patients, and the patient’s attitudes toward the advice given.

Socioemotional Selectivity Theory

The socioemotional selectivity theory focuses on two main types of goals: acquiring knowledge (best attained through large social networks) and balancing emotional states (best attained through close relationships with a select group of people) (Cartensen et al., 2003). Research suggests that older adults and those with cancer (regardless of age) are more likely to prefer quality of social contacts rather than quantity (Cartensen et al. 1999; Pinqart & Silberson, 2006). However, contact preferences in relation to different types of support is a currently unstudied area, as is the understanding of the socioemotional selectivity theory in relation to online contact preferences. Since

this study's participants primarily were drawn to the Internet to search online to increase their knowledge about cancer, it is possible that quantity, rather than quality, would be more important for meeting knowledge-related needs. However, similar to Cartenson et al. (1999) and Pinqart and Silberson (2006), this study found that the quality of social contacts was the most important feature of online support, in that it aided finding experienced persons who matched their cancer-related needs. Although the quantity of messages exchanged via the Internet was considered a helpful feature of online support; ultimately the quantity of messages enabled cancer survivors a wider platform in which to find an experienced person with whom to connect. In addition, although participants turned to the Internet to fulfill knowledge-related needs, they also felt supported through messages of hope and a sense of belonging with others. Ultimately, feeling supported through any of the three types of support depended upon the connection with an "experienced" person or a small network of people from a highly-specific online support group.

Online Support Allows Control

The advantages of online support for decreasing the barriers of time and location are well documented in the literature (Engelman, et al., 2005; Oriet et al., 2007; Turner et al., 2001). This study adds to the body of research that emphasizes that advantage and shows that older Internet users value that accessibility. However, this study also raised the importance of local content on an Internet site. Having local content was considered important for finding ways to connect with others in-person, either through events, organizations, or through furthering relationships that arose in the online environment.

The ability to control the emotional tone of the online relationship and privacy were important features of online support, which is similar to the findings of Ussher et al. (2006). In this study, the privacy afforded by online support created an ease of communication with others when discussing difficult issues. Hoybye et al. (2005) similarly found that the absence of personal contact can make it easier to start difficult discussions. The anonymity afforded online is an important feature for anyone who wants to discuss sensitive issues such as sexuality, although, in this study, one participant also felt that people are less likely to accept advice about intimate issues when it lacks the element of personal contact. This highlights the differences in support needs for cancer survivors, and demonstrates the importance of individuality in meeting such needs.

Nature of Support Received Via the Internet

This study sheds light on the types of support users receive online, how the Internet and in-person support are balanced, and how users go about finding the right person with whom to connect.

Researchers have divided social support into different types: instrumental, informational, emotional, and sense of belonging (Cohen & Syme, 1985). Instrumental support is the actual provision of services (e.g., financial help) provided by friends or family members. When participants were given definitions of social support, they discussed the types of support they received online. All participants stated that they received informational support from others online. It was considered essential for learning about new treatments, dealing with side effects, and for having other practical questions answered about how to deal with cancer. Most participants received emotional support, while some discussed their feelings of having a sense of belonging with others.

Only three people noted both emotional support and a sense of belonging with others. Although several participants described their experiences and feelings about online support similarly, some participants identified more strongly that they felt it was either emotional support or a sense of belonging, not both. It is possible that these two types of support overlap enough to make it difficult for participants to understand the distinctions researchers make between these two types of support. It is not surprising that participants did not feel that they received instrumental support online considering the lack of opportunity to provide “tangible” support via the Internet.

This study adds to the body of literature showing that cancer survivors can be successful finding emotional support online (Hoybye et al., 2005; Ussher et al., 2006). However, participants varied in their feelings of having helpful emotional support through online interactions. At times, the support did not match what was being sought due to differences in personal values and opinions. Since such incongruencies can potentially produce dissatisfaction and distress (Martin et al., 1994), further research is needed to understand the effects of unhelpful support received online as well as to help clarify the factors that lead to cancer survivors feeling positively supported online.

Hoybye et al. (2005) showed that participants valued connecting with others who matched their cancer type, and that finding the right person to connect with is most important when newly diagnosed. Participants in this study used the trial-and-error process of searching for someone similar in diagnosis, experience, and values. In finding someone who fits their profile, participants gained informational support, emotional support, and a sense of belonging to help them feel empowered about the process and give them a sense of hope about the outcome. This was particularly important for those

with rare cancers or for those who had other barriers to connecting in-person with someone who matched in cancer type and experience. Since participants noted that their desire to feel connected with others drew them to maintain relationships online, it is encouraging that this study supports findings that online support can provide a sense of belonging, thereby helping cancer survivors to feel that they are not alone (Ussher et al., 2006). However, this study also provided new insight about the difficulty that people have in connecting with others that match in cancer type and experience; especially for those with rare cancers. This is important information that can be used to tailor websites to make connecting with others an easier process. In this study, many participants were successful in finding someone whom with to connect, while others were not. It is possible that such differences in results can be attributed, in part, to differences in communication styles. Hui-Jung (2009) analyzed which posts were answered in an online social support group. They found that posts with more asking, less crying, and less hinting were answered more frequently than those with more crying, more asking and more hinting. This study did not look at different communication styles when seeking support since it was based on participants' own views, but the way they interacted may be a factor in why some people were successful finding helpful online support while others were not. It may be helpful to teach people the best communication methods for eliciting responses in an online forum when trying to seek guidance from others.

Although this study did identify many important issues pertaining to matching support needs, it did not specifically examine whether or not the type of support received was a match to what was being sought. For example, a person may search online for informational support, yet find online contacts providing emotional support in return.

Future research could help to identify the helpfulness or unhelpfulness of online support interactions by determining if the type of support found matches what was sought, as well as how to best match those who have particular support needs.

Matching of values and/ or life experience may prove as important as matching cancer type in finding helpful support related to life's issues that accompany a cancer diagnosis. This study also added to the findings that matching is not only helpful for finding support, but also for giving support as well. Some participants deliberately searched for someone they thought they could help, by identifying with another cancer survivor through similarity of diagnosis or life experience. Website designers may need to consider this need when developing a cancer-related internet site, so they can create easy-to-use profile matching systems for both support seekers and providers.

The value of connecting with experienced others was paramount, especially when newly diagnosed and shifted to providing experienced support later in one's own cancer journey. Hoybye et al. (2005) and Winefield (2005) found similar patterns in the evolution of new cancer survivors, but their research did not identify the particular issues for which participants were seeking support. This study suggest that cancer survivors seek and give support on a variety of meaningful issues, such as dealing with treatments, practical considerations for living with cancer, and education about treatment methods. This is important information that should be further explored to continue to understand the nuances of being in a dyadic relationship of giving and receiving cancer support online.

One participant was clear that, although he valued the "experienced" information provided by others who matched his cancer type, he also felt that "cancer is cancer" when

talking about emotional well-being. It is possible that, for someone with a rare cancer, he/she may need to connect with an experienced person online, but may still benefit from a local support group for emotional support. This distinction warrants further investigation to understand how to match people for different support needs. It could be possible that matching is different for those seeking informational support than for those seeking emotional support. Cancer survivors may benefit from several forms of online support to meet a variety of support needs. Future research can further identify such distinctions to be able to connect people efficiently to others who can meet their support needs.

This study supports the findings of Barbee, Derlega, Sherburne, and Grimshaw (1998) who found that chronically ill persons overwhelmingly preferred to connect with others who match their experience instead of friends and family for certain types of support. This study also adds further context to the research of Barbee et al. by addressing the two reasons cancer survivors prefer to speak to each other rather than friends and/ or family. Participants preferred to avoid seeking cancer-related support from friends and/ or family to protect them from the emotional burden, and because friends and family could not provide them with “experienced” support.

Although many people stated that the help they received was useful in supplementing their social support needs, many participants also clarified that the shift toward online support is not necessarily positive if it is taking away from a person’s in-person relationships with friends and family. This study adds new findings in that participants described “loving support” that is exclusively given by friends and family, and not reproducible by other survivors, either in-person or online. This important

distinction merits further understanding of how friends and family can contribute to the support network of cancer survivors in a meaningful way. Nie and Hillygus (2002) cautioned about the Internet being used at the expense of time spent on other social activities. Although the Internet can be helpful in increasing the size of a network, participants in this study also cautioned that Internet support should be used as a supplement, and not replace other forms of personal contact.

Li et al. (2006) illustrated the positive impact of family support for HIV/AIDS survivors in the areas of instrumental support, support for disclosure, daily routines, and psychological support. This study similarly showed that cancer survivors need many forms of support to meet their needs. Although connecting with experienced others was considered important for cancer-related support, participants still needed in-person support for practical help and feeling genuinely “loved” throughout their journey. Future research may continue to examine not only the differences in peer support compared to family support, but also how both forms of support complement one another in a way that can help a person feel embraced by all four functions of social support.

Support Changes Over Time

This study highlighted the fluctuating nature of support, with no formula to describe when and how it will change over time. Some participants discussed having less need for online support after they made in-person connections in their communities, while others discussed how their in-person networks became smaller once they were diagnosed as friends did not know what to say to them.

Consistent with Hoybye et al. (2005), support needs changed over time, with the most support needed when newly diagnosed. This study found that a major reason for

newly-diagnosed cancer survivors to go online is because they believe their in-person support network is insufficient to deal with cancer issues, such as providing practical information and feelings of hope. Future research is needed to continue to look at reasons for fluctuations in support, and also to create meaningful interventions for long-term survivors to facilitate adjustment over time.

Limitations of Online Support

This study found that the inability to see or hear the survivor with whom one is communicating limits online support. However, future technology could remove these barriers. In a pilot study conducted by Collie et al. (2007), the authors found that videoconferencing for cancer patients in rural areas was feasible and acceptable for the provision of facilitated support and formation of emotional bonds for cancer patients. Although this study demonstrates the potential of videoconferencing as a method of providing online support, research will be needed to evaluate how such technology affects the feelings of anonymity that provide comfort to many online users. It is possible that videoconferencing may provide an avenue for increased support that feels more like an in-person contact. On the other hand, it may make discussing personal issues, such as sexuality, more uncomfortable.

This study highlighted that a potentially unmet need of online cancer support sites is addressing the psychological needs of coping with cancer. Further research on online interventions could focus more specifically on this issue, thereby providing more immediate help than that which can be attained through the medical system.

In this study, participants who were more educated in the cancer field appeared to feel less supported online, with one participant reflecting that her education about cancer

made her needs fewer to begin with. New research could examine the nuances of individual characteristics of those who benefit most from online support.

Roles of Various Online Tools

Eysenbach (2003) identified two main categories into which all online social support falls: communication (email, instant messaging) and community (bulletin boards, mailing lists, chatrooms, websites with community features). As is consistent with other research, this study found that email was a well used modality for connecting with others (Eysenbach, 2003; Statistics Canada, 2010c). Nevertheless, there is a difference in the quality of support received via email versus other online means. Most times, email was considered a supplement to meeting face-to-face with others, which possibly affects the depth of email content. Friends and family were the most common emailed recipients, and this support was, in most cases, not considered helpful for cancer information. However, one participant connected with a cancer survivor through email as his main type of support, since it was the preferred method of communication by someone who matched his cancer type. His experience differed in that his support needs were effectively supplemented through email for receiving practical information about what to expect in his cancer journey. Differences in feelings of helpfulness of email support may lie in how email is being used, not in the medium itself. Since email is the most well-used Internet modality, website designers could use this information to provide cancer survivors with a means to connect with others through email, as an alternate option to bulletin boards or chatrooms.

One of the most interesting new findings from this study is that social networking sites appeared to be unhelpful for meeting needs of older cancer survivors. Although

some participants did use such sites for other purposes, social networking sites were not considered “credible” or “serious” enough to provide the level of support required for addressing cancer-related needs.

Chatrooms were also being underutilized for cancer support needs. Clark (2002) found that older adults are not interested in chatrooms due to a lack of trust. However, in this study, chatrooms were something that cancer survivors would want, but in reality, they did not provide helpful support. Future research could be aimed at determining how to create a chatroom that removes the barriers faced by cancer survivors when using this Internet venue. It may be possible to assess the value of having chatrooms that are moderated, having people sign up for different time zones, times, and having group rules that discuss the importance of welcoming members and remaining non-cliquish in nature. Until such challenges are addressed, it may be beneficial for website designers to focus on offering more preferred methods of communication with fewer constraints, such as email or bulletin boards.

Maximizing the Net’s Usefulness for Cancer Support

This study provided new information about how and when cancer survivors want to search online for support, as well as how to design an Internet site tailored to their needs.

Although all participants had computer access at home, they still wanted access to computers at the medical clinics. Evaluations could be done to explore the factors involved with Internet support accessed at clinics. It is possible that, if physicians bookmarked particular sites on computers or guides for patients to applicable sites, it would increase the acceptance of Internet information by physicians, and assist cancer survivors in finding credible sites.

Site design and content. This study provided clear direction about the importance of user-friendly Internet design. Similar to findings of the National Institute on Aging and National Library of Medicine (2002), this study found that it is important to limit links and graphics and have good navigability when developing a site to cater to the needs of older cancer survivors.

One of the most important aspects of Internet design is making it easy to connect with the right person. As identified by Im et al. (2007), cancer survivors want to be able to search by cancer type, not only body location. Using cancer type would simplify the search for online support for people who have cancers that are not localized to a particular body location. Otten, de Man, Toussaint, Westenbrink, and Zwetsloot-Schonk (2010) found that organizing search facilities by story topic (instead of by writer profile) increased search success and patient satisfaction. This study supports this finding that each cancer survivor is unique in his/her journey, and has unique needs depending on his/her own cancer “story”.

User-friendly Internet language and navigation help people understand their disease and its effects. Cancer survivors in this study wanted to have an Internet site that was written in layperson’s terms, with links that take the user to an easy-to-read map of the body, and with easy-to-read glossaries of terms. In this study, cancer survivors also described the benefits of being able to periodically receive online support from a medical professional, to help understand new medical developments and make sense out of some of the information they have learned. They also emphasized the importance of having updated, local information online, to make it easier for cancer survivors to know when and where they can connect with others in their own communities.

Monnier, Laken, and Carter (2002) found that 80% of adult cancer patients and caregivers were interested in utilizing the Internet to increase their knowledge about their illness, with no significant differences due to age. This study supports this finding. Many participants truly did not know what they were looking for when they went online. They had a need to learn more and were taking control of finding it. When newly diagnosed, the first thing a cancer survivor does not think is “How do I find someone to connect with?”, but “How do I find out everything I need to know?”. Through the trial-and-error process of searching online, participants found many answers to their questions by connecting with others who have been through the journey on which they were embarking. Despite whatever they thought they would find online, social support was ultimately the connection that fulfilled their need. Website designers need to understand not only the content of what to include in a website, but also need to understand the starting point of each cancer survivor: the need to know everything they can. This does not mean that cancer survivors should type into a search engine that they want to “join an online support group” or “read postings from others”. They simply need an easy way to find what they need. Ultimately, sites can be designed with search engines focused to provide easier-to-find opportunities for joining online support groups or bulletin boards when people are attempting to “google” such issues. Organizations that create such sites can work with search engines to ensure clarity and that their urls come up as a top choice when searching to allow for the quickest route possible to find what the cancer survivor is searching for.

Cancer survivors in this study highlighted the different choices they made in how they found support online, based on their skill and comfort level with using the Internet

for support. Some participants were more interactive than others, with some seeking support by reading the postings of others who matched their needs, while other participants searched for a dialogue with another person to ask questions in a more direct manner. Interestingly, all participants, regardless of how interactive they chose to be online, felt supported by connecting with others online. This is similar to the findings of van Uden-Kraan, Drossaert, Taal, Seydel, and van de Laar (2008) that lurking (reading others postings without asking questions or commenting) in online support groups can have the same profound effect on the lurker's feelings of empowerment as posting has on posters. However, in the van Uden-Kraan et al. study, lurkers' feelings of enhanced social well-being were not improved. Further research can continue to provide information about such subtle differences in outcomes for those using online support in different ways.

Importance of credibility. When online, cancer survivors expressed that they often searched haphazardly for support that meets their needs, while expending the one thing they value most: their time. Participants discussed several elements that contributed to feelings of credibility: focusing on evidence-based treatments, professionalism in sites they use, and honesty and openness of others online. Teaching cancer survivors how to efficiently find credible sites and avoid the pitfalls of finding misleading information were considered essential. New research could focus on training older cancer survivors to find and recognize credible online information. This would save time on two levels: by helping cancer survivors find what they need more quickly, and by helping cancer survivors focus on credible treatments and emotional support that will improve quality of life and cancer outcomes.

This study clearly outlines the importance of having a support group that is moderated to increase comfort that the treatments discussed are evidence-based. Moderators increased feelings of credibility of the board, its usefulness for connecting with others, and trust in the information provided. Price, Butow, & Kirsten (2006) showed that moderated boards are highly preferred over non-moderated boards since active intervention from support group leaders can impact psychological outcome and quality of life. This study contributes new information in that participants preferred moderators to be experts in the field of cancer, but not necessarily medical professionals, since professional moderators were viewed as perpetuating medical terminology and having limited ability to keep information current. New research needs to be conducted to better understand the differences between professional and non-professional moderators, and further outline which moderator qualities are most important.

Professionalism of the site was key in the decision-making process of determining whether or not a site was credible, and influenced choices to use or not use particular Internet sites. Further research could investigate other issues regarding professionalism, such as the importance of having affiliations with recognizable institutions, or other factors that could affect site use and participation.

An important issue that was raised in this study was the importance of honesty and openness in communicating with others online. Although participants raised strongly-felt concerns about the need to be able to discriminate between truthful and non-truthful information, most thought that the people they communicated with online were very honest, and that the openness they themselves shared helped the online support groups to be more effective. This is important information for understanding what makes

an online support group effective. If a support group is moderated, and has participants who share the same philosophy of openness, a group can be a strong support to others in search of help.

Participants in this study were cautious about accepting the credibility of information given through personal stories. However, others thought that posting personal stories was a valuable way to give back in hope that others can learn and feel connected from their experiences. Although this study clarified that personal stories are not helpful for informational support, more research should be conducted to determine whether or not personal stories are considered valued in a different area of support, such as emotional support or sense of belonging.

Implications for Health Promotion

According to the Ottawa Charter for Health Promotion (2010), health promotion is the process of enabling people to increase control over and improve their health. This study clearly found that gaining such control over health potential is the driving force behind why cancer survivors go online to meet their cancer-related needs. This study highlighted how the Internet allows cancer survivors to feel more in control of treatment decisions and obtaining answers to secondary cancer issues. It also showed the importance of control over accessing support in a manner individualized to his/her needs, such as by maintaining privacy and control over the emotional tone of the relationship with the person whom they chose to engage. With the information gained from this study, programs and policies can be modified in public health and clinical practice to better support cancer survivors in finding the support they need (Jack, 2006). Specifically, health promoters can play an important role in knowledge translation for delivering

Internet-based information for cancer-related needs, identify avenues for patient training for Internet-based cancer support, physician training, and site development.

The use of the Internet for social support is a relatively new field of study. With emergent trends in Internet use, new technologies for connecting with others, and diverse attitudes about the helpfulness of connecting with others online, it can be difficult for health professionals to be up-to-date on research involving how and why the Internet is considered valuable for cancer survivors. Health promoters can work with health organizations to help translate and disseminate relevant information that cancer survivors are seeking online as well as help organizations understand their roles in supplementing social support needs; thereby improving patients' feelings of health and well-being.

As noted by Levi and Stronbeck (2002), the Internet has changed the traditional roles of patients and clinicians, it is imperative that physicians be knowledgeable about where patients are likely to go for online information and guide patients where to go in their online search. Cancer survivors in this study searched online for cancer related support regardless of whether or not they were satisfied with the information presented by their physicians. However, cancer survivors in this study clearly wanted and valued the ability to have an open dialogue with their physicians regarding information they found online, and was a factor in how supported participants felt by their physicians. This sheds light on important avenues for improving patient care through increasing the quality and quantity of information given at the time of diagnosis, and by maintaining a relationship with the patient that accommodates the need for different information as needs change. As indicated by Farrell, Robinson and Scott (2003), it also highlights the need for physicians to be knowledgeable about where to send patients for credible online

information and support. By guiding patients on where to go for credible information, and encouraging them to bring it to their appointments, physicians will have the ability to improve the mental and physical well-being of cancer survivors on a new level, as well as to improve opportunities for collaborative decision-making.

Research has shown that online social support can have positive effects for cancer survivors' physical and psychological well-being (Hoybye et al., 2005; Lieberman & Goldstein, 2005; Winzelberg et al., 2003). However, researchers have not examined the impact of age on cancer survivors' ability to use the Internet for their social support needs and how to best design Internet sites to meet their needs. Many participants in this study were admittedly computer-savvy. Participants in this study ranged in aged from 52-67, and data indicate that persons in this age range are vastly more connected to the online world than those in older age brackets. Fox (2004) found that 46% of Americans age 59-68 had Internet access, whereas only 17% of Americans over age 69 had access. Although participants were computer savvy, they did acknowledge the need for computer training for others similar to themselves in age, or older. The literature supports this finding. Forty-four percent of new cancer cases and 60% of cancer deaths occur among those who are at least 70 years old (Canadian Cancer Society, 2011) and less likely to use the Internet than younger generations. In addition, Thayer and Ray (2006) suggest that people in the middle-to-late age groups may be less easily able to adjust to the changes in communication and relationship building that the Internet brings. This study suggests that cancer survivors may not use such sites due to the difficulty in finding them, highlighting a need to train cancer survivors how to find and use online support groups that are available to them. Health promoters could work collaboratively with other community

agencies to develop training programs that could be implemented in a cost-effective manner, such as through nurse practitioners, cancer navigators, home care workers, or trained volunteers.

Monnier et al. (2002) found that over 65% of cancer patients expressed interest in utilizing online support groups. Yet Fogel, Albert, Schnabel, Ditcoff, and Neugut (2002), who also examined Internet use characteristics of women with breast cancer, found that, of the 60% of women who used the Internet, less than 4% actually participated in online support groups. Considering that over 65% of cancer patients express an interest in using OSGs (Monnier et al., 2002) and actual participation is at 3.7% (Fogel et al., 2002), it could be assumed that significant barriers exist that prevent cancer survivors from participating in OSGs. This study added a qualitative perspective to these findings and clarified that, although online support is a desired method for increasing social support, many cancer survivors do need training to use the Internet effectively for cancer-related needs. This gap in interest and skill level can help to explain the difference in those who have an interest in Internet-based support and those who actually use it.

Health promoters can help organizations understand how to enable cancer survivors to efficiently connect with one another by allowing for matching of support needs, experiences, and preferences of Internet venues. However, challenges exist in creating a resource that allows people to connect in a manner that respects their individual needs and preferences. Computer proficiency must be addressed to deliver outpatient interventions using web-based technology (Wantland, Portillo, Holzemer, Slaughter, & McGhee, 2004). This study provided valuable information needed to empower older cancer survivors to use the Internet, and to create tailored online social

support interventions targeted to their distinct needs (Appendix G, p. 143). Ultimately, this study contributes to the knowledge necessary for enhancing service delivery and improving potential health outcomes for older cancer survivors.

A particular challenge may be in honoring the “spirit of survivorship” within a website in a credible fashion. In creating a site for cancer survivors, data should be collected and presented in a way that deliberately focuses on hope. Knowing that the main users of a cancer-related website will be those who are affected by cancer, either having been diagnosed with it or knowing someone diagnosed with it, website designers should decide on the tone of the site, ensuring it does not add to the psychological distress experienced by its viewers. For example, in searching for sites on skin cancer, one of the first sites I discovered stated that “one person dies every hour from melanoma”. It is doubtful that this message would be one that a newly diagnosed person would benefit from hearing and is in direct contradiction to honoring the “spirit of survivorship” as described by the participants. While there may be appropriate places to list such statistics, caution should be exercised on where to place such information, and, if used, to ensure it is balanced with positive messages of hope for survivorship.

Study Limitations

Homogeneity of population. Since the study was conducted in a large Maritime health district, most participants would have access to medical services within a relatively short distance, and all participants had access to high-speed Internet. Therefore, this study did not address the wants, needs, and barriers for more rural cancer survivors who face the most challenges in accessing medical care and in connecting with others in-person or

due to a lack of high-speed Internet service or without regular access to the Internet at home.

Because this study only included cancer survivors who have had previous experience with the Internet, I was not able to determine the wants, needs and barriers faced by those cancer survivors who want to benefit from online social support, but who currently do not have experience with the Internet.

Participants in this study ranged in age from 52-67. Fox (2004) found that 46% of Americans aged 59-68 had Internet access, whereas only 17% of Americans over age 69 had access. The findings of this study are not transferrable to those in older age groups, who may have different needs and barriers to overcome when searching for social support due to more limited use.

Non-English speaking cancer survivors may be faced with unique challenges when trying to use the Internet for social support. Although two percent of Nova Scotia's residents speak languages other than English at home (Community Counts, 2010b), I did not recruit participants from who were not fluent in English. They were not represented in the study.

Studies have shown that different cultures have different communication styles (Liu et al., 2005) as well as different beliefs about the credibility of cancer information on the Internet (Friedman & Hoffman-Goetz, 2007). Participants were not asked about their culture nor was the impact of culture and cultural relevance of online support venues on the wants, needs, and barriers faced by older cancer survivors explored. Although two participants identified that they were highly educated in the cancer field, this study did not explore whether they had different needs than those with less education about cancer.

None of the participants were newly diagnosed. This limits the transferability of the findings to this group, since the voices of newly diagnosed cancer survivors were not represented in this study.

Structural issues with the instruments. The clarity of the background questionnaire presented to the participants may have provided inaccurate results. Although all participants completed the background questionnaire without seeking assistance, it became evident in the interview that many participants were unclear about some of the terms used to describe different Internet venues, such as bulletin boards, blogs, and frequently asked question modules. Also, the closed questions in the interview guide resulted in some participants answering questions differently than if the questions had been asked in a qualitative manner. For example, in my initial phone conversation with one participant, she discussed the many different ways she received support online. However, during the actual interview, she replied “No” to the question of “did you receive support online”, because she found the support to be unhelpful. With the closed-ended questions removed, participants felt more comfortable telling the story of finding online support, whether helpful or not. Although I used probes to try to compensate for the inaccurate answers produced by the quantitative questions, the flow of the interview was, at times, disrupted by these inconsistent responses and the discussions that followed.

Dissemination

The information gained by this research project provides important information for the development of Internet-based social support interventions that are properly suited to the older cancer survivor’s distinct needs. This information will be disseminated to relevant community-based cancer organizations and through publications in cancer-

related newsletters and websites in order to promote the development of online social support support interventions, to highlight the need for training cancer survivors to use the Internet as a feasible option for increasing the quantity and quality of their social support networks, and to guide health professionals in helping patients use the Internet as a resource for their cancer-related needs.

Summary

This study highlighted the reasons cancer survivors search online for support: to take control of their health and cancer outcomes. Upon diagnosis, cancer survivors took charge of finding out everything they needed to know about their cancer, which led to finding online support. When communicating with others online, cancer survivors valued being able to remove barriers of time and space, control the emotional tone of the online relationship, and maintain their privacy.

Peer support and family support can complement one another to make a strong support network for cancer survivors. Participants were consistent in their views that they prefer to talk about cancer issues with other survivors rather than friends and family; either in-person or online. However, they also reflected on how in-person support contributes to different types of support than that received by peers, such as in “loving support”, instrumental support, and meeting psychological needs.

This study provided further evidence that there is no “one size fits all” for cancer needs. Cancer survivors clearly want and need to find someone who understands their journey and matches their needs. The particulars of what they need can change over time, experience, or diagnosis. When faced with a life-threatening diagnosis, time is not a commodity to be wasted. However, many barriers are faced when cancer survivors

attempt to find support online, such as difficulty navigating sites, difficulty discerning credible information, feeling unsupported by their physicians in searching for online information and difficulty finding the right person with whom to connect. The efficiency and effectiveness of an Internet site for helping cancer survivors find whatever support they need is key for success.

This study also highlighted the importance of positivity and hope in healing from cancer, as well as the importance of transmitting messages of hope to others. Many participants found this to be of utmost importance in their cancer journey. By honoring the importance of this issue in the development of any new cancer resource, cancer survivors can feel supported not only through information and advice, but also through the spirit of hope.

Will online support someday replace in-person support? Likely not. It was clear that online support was sought as a supplement to in-person support; not the reverse. Drawbacks to online support were given that are not easily fixed, such as the lack of “loving” support and the lack of relationship depth. However, Internet support is proving to have a place in connecting cancer survivors, even older ones, in ways never before possible. With future advances in virtual technology and real time chat, cancer survivors will continue to have new and improved methods of connecting with others from around the globe.

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Appendix B

Electronic Recruitment Announcement

Attention Cancer Survivors**Do You Use the Internet to Connect With Other Cancer Survivors?****Have You Had Cancer In the Past 5 Years?****Are You Over Age 50?****Do You Reside Within the Capital Health District?****Do You Use the Internet At Least Once a Week?**

If so, you are invited to participate in a study to talk about your experiences with using the Internet for connecting with other cancer survivors. Your participation will help us to design better Internet programs to connect cancer survivors.

For more information, or to take part in this study conducted through the School of Health and Human Performance at Dalhousie University, please contact:

Student Researcher: Kathryn Fraser, B.Sc., M.A. (Candidate)

Ph: 902-802-7069 Kathryn.Fraser@cehha.nshealth.ca

Supervising Professor: Dr. Lynne Robinson

Ph: 902-494-1157 Lynne.Robinson@dal.ca

Appendix C

Background Information Questionnaire

1. What is your age (in years)? _____
2. Are you:
 - Male
 - Female
3. What type of cancer do/did you have:

<input type="checkbox"/> Breast Cancer	<input type="checkbox"/> Skin Cancer
<input type="checkbox"/> Bladder Cancer	<input type="checkbox"/> Thyroid Cancer
<input type="checkbox"/> Melanoma	<input type="checkbox"/> Lung Cancer
<input type="checkbox"/> Non-Hodgkin's Lymphoma	<input type="checkbox"/> Prostate Cancer
<input type="checkbox"/> Colon and Rectal Cancer	<input type="checkbox"/> Kidney (Renal Cell) Cancer
<input type="checkbox"/> Pancreatic Cancer	<input type="checkbox"/> Leukemia
<input type="checkbox"/> Endometrial Cancer	<input type="checkbox"/> Other _____
4. What was the month and year of your diagnosis?
mo____yr____
5. At what stage are you in your treatment of cancer:

<input type="checkbox"/> In treatment	<input type="checkbox"/> Remission
<input type="checkbox"/> Cancer Free	<input type="checkbox"/> Palliative Care
6. When you are connecting with other cancer survivors, do you use the internet at (Check all that apply):
 - Home
 - Coffee Shop
 - Work
 - Hospital/ Cancer Clinic
 - Library
 - Other (please describe) _____
7. Do you have high-speed Internet:
 - Y
 - N: What type of Internet connection do you have?

8. On average, how many hours/ week do you spend on the Internet? _____

9. There are lots of ways to receive social support online.
Please tell me if you use the following (Check all that apply):

- Chatrooms
- Bulletin boards
- Email
- Blogs
- Frequently Asked Question Modules
- Online Support Groups
- Real Time Chat with :
 - Text (MSN Messenger)
 - Audio (Skype, Ventrilo)
 - Video (Web cameras)
- Social Networking sites (MySpace, Facebook)
- Other _____

Appendix D:
Interview Guide

Code No. _____

What Older Cancer Survivors Want and Need From the Internet When Searching
for Social Support

Introductory Script

This study has been designed for you to talk about your experiences with using the Internet for connecting with other cancer survivors. Your participation will help us to design better Internet programs to help connect cancer survivors for support.

I would like to ask you a series of general questions that have been designed to help me understand your experiences with using the Internet for social support. You can provide as much or as little detail as you wish. If I ask a question that you feel you have already provided an answer for, or are uncomfortable answering for any reason, please let me know and I will move on to the next question. You are free to terminate the interview at any time. The interview will take approximately 30 minutes to 1 hour to complete.

Before we get started, I want to ensure that you know that our conversation will be audio-recorded. Are you okay with me audio-recording our conversation?

I also want to ensure that you know that the final report could include direct quotations from the interview. If quotes are used, your name and any identifying information about you will not be used. Are you okay with me using direct quotes from our conversation in the final report of this study?

Do you have any questions before we begin?

Interview Guide

NOTE: This was a guide only. Actual interview questions varied to some degree.

As people go through their cancer journey, they often look to other people to give them help and support. Sometimes they also themselves give help and support to others. More and more, people are using the Internet as a way to both get support from others and to help others. Some people do this by using email, going to sites where other people talk about their experiences, or they use online support groups. We would like to understand how you have used the Internet as a way to get support for yourself and to give support to others during your cancer journey.

Connecting with People: Receiving Help

First, I would like to ask you questions about any ways you have received support from other people through the Internet.

1. When using the Internet, have there been times that you received support from another cancer survivor?
 Y
 N
2. If No: Can you tell me what has kept you from seeking support others online? (skip to question 20)
3. If Yes:
In what ways did it help you?
4. Can you tell me about any times when someone's support was not helpful to you?
5. Can you tell me about how the support you get through the Internet is different or the same as other ways you get support?
6. When you are online, you can connect with family members, friends, or other cancer survivors. Are there any ways that you can tell me how the support you get from friends or family is different or the same as the support from other cancer survivors?
7. The Internet allows people to decide how much or how little they want to reveal about themselves. How do you decide what to reveal about yourself when online?
8. The Internet also allows people to decide how honest they are in what they do reveal. Can you tell me how that fact affects you, if at all, when online?

9. Can you tell me about any cancer-related Internet sites that you avoid because you are concerned about your privacy?

Connecting with People: Giving Help

Next, I would like to understand any ways you have tried to give support to others through the internet, if you have done so.

10. When using the Internet, have there been times that you provided support to another cancer survivor?

Y

N

11. If No: Can you tell me what has kept you from providing support to others online?

(skip to question 26)

12. If Yes:

In what ways were you helpful?

13. Can you tell me about times when you felt your support was not as helpful as you intended?

14. Can you tell me about how the support you give through the Internet is different or the same as other ways you give support to cancer survivors?

Managing the Medium

Next, I would like to understand how you go online. I am going to ask you some questions about how you use the Internet to find support. This could include sites you use, computer skills, or types of technology you use.

15. Can you tell me what it would take for you to be as comfortable as possible with using the Internet for support?

16. There are lots of obstacles that you can run into when trying to use the Internet for social support, such as difficulties searching for information, navigating websites, computer lingo, or physical challenges. Can you tell me about any obstacles you have faced in using the Internet for support?

(Probes will ensure participants address potential obstacles for searching for information, entering information, navigating websites, internet connection problems, computer lingo, and physical challenges).

I would like to discuss why you chose to use or not use different online resources.

17. There's lots of different ways you can go online to give or receive support, like chatrooms, bulletin boards, email, or personal web pages. Can you help me understand why you use or don't use different types of Internet sites?

(Probes will ensure participants address all sites listed on item 9 of Background Information Questionnaire).

18. There are lots of different sites to go on to connect with other cancer survivors. Can you tell me about the sites you prefer and why you prefer them?
19. I would like to know about ANY improvements to Internet resources that you would like, such as access to computer services, ability to find good sites, changes to the programs themselves, or anything else that would be beneficial to you.

Closing Questions

20. There are lots of different things that can be included in an Internet site, (like real-time chat, using audio or video, FAQ boards, etc). If you could design your own Internet site to help people like you with cancer, what would it look like?
21. Social support can come in many different forms. As researchers we often define it as being one of 4 types:
- i. Instrumental support involves providing a person with something tangible they need (such as a drive to the hospital or financial help).
 - ii. Informational support usually involves giving health-related information, such as advice on medical care.
 - iii. Emotional support is providing a listening ear, empathy, and the sense that one is cared about and loved.
 - iv. A sense of belonging is the feeling that one is part of a family or other group that cares about its members.

Thinking back about the support you have described, can you tell me which of these types you consider yourself to have received?

CONSENT FORM

Project Title:	What Older Cancer Survivors Want and Need From the Internet When Searching for Social Support
Primary Researcher:	Kathryn Fraser, B.Sc. MA Health Promotion (Candidate) School of Health and Human Performance Dalhousie University 6230 South St. Halifax, N.S. B3H 1K5 (902) 802-7069 Kathryn.Fraser@cehha.nshealth.ca
Faculty Advisor:	Dr. Lynne Robinson School of Health and Human Performance Dalhousie University 6230 South St. Halifax, N.S. B3H 1K5 (902) 494-1157 lynne.robinson@dal.ca

We invite you to take part in a research study being conducted by Kathryn Fraser, a graduate student at Dalhousie University, as part of the requirements for the Masters in Health Promotion degree. Taking part in this study is entirely up to you and you may decide not to continue at any time. Please read the study description below. This description tells you about the risks, inconvenience, or discomfort which you might experience. The study might not help you, but we might learn things that will help others. You should talk about any questions you have with Kathryn Fraser, or the faculty advisor for the project, Lynne Robinson. Thank you for your interest in the project.

1. *Purpose of the Study:* The purpose of this study is to understand the wants, needs, and barriers faced by older cancer survivors when using the Internet for social support.
2. *Study Design:* You will take part in a private telephone interview.
3. *Who Can Participate:* Any person who:
 - has been diagnosed with cancer in the past 5 years;
 - has used the Internet to try to connect with other cancer survivors;
 - is over age 50;

- lives in the Capital Health District of Nova Scotia;
 - uses the Internet at least once every week; and
 - speaks English.
4. *Who Will Be Conducting the Research:* The principal investigator carrying out this research project is Kathryn Fraser, a M.A. Health Promotion student from the School of Health and Human Performance at Dalhousie University.
 5. *What You Will Be Asked to Do:* If you agree to take part in this study, you will be asked to complete the enclosed set of questions and return it with your consent form. You will also be asked to take part in a telephone interview to talk about your views on the pros, cons, and areas for improvement in using the Internet for connecting with other cancer survivors. This will take place by an audio-taped, telephone interview at a time that works for you. The interview will take about 30 minutes to 1 hour of your time. You will also be asked to look at a summary of the findings from your interview to make sure it matches your views well. This could take about 10-20 minutes of your time. You may choose to take part in any or all of these activities.
 6. *Where the Research Will Take Place:* You will be asked to be available by telephone in the time and place of your choosing, and I (the researcher, Kathryn Fraser) will call you there, from a private office.
 7. *Possible Discomforts and Risks:* For some people, interviews can be tiring or involve stress from re-living emotional events. Unexpected harms can be associated with all research, including this study. Aside from this, no other harms or discomforts are known to be associated with this research.
 8. *Benefits:* By taking part in this study, you will help us to better understand the wants, needs, and barriers faced by older cancer survivors when they use the Internet for social support. This could give us important information needed to help older cancer survivors use the Internet, and to help professionals create online social support resources that meet the needs of older cancer survivors. In time, the information we get from this study could improve service delivery and potential health outcomes for older cancer survivors. However, these benefits are by no means guaranteed.
 9. *Compensation:* Taking part in this study is completely up to you and you will not be compensated for being involved.
 10. *Confidentiality:* I will not reveal to anyone else the information you tell me. If you agree to take part in this study, your signed consent form will not be kept with your responses, and your interview responses will not be labeled

with your name. Instead, your interview will be coded with a random four digit number, and any information that might help others to know who you are will be taken out. A master list of names and contact information will be kept separate from interview responses in case that you choose not to be part of this study after your interview is finished.

The interviewer will be in a private room with the door closed when she calls you, but we cannot guarantee that the telephone call will not be monitored by someone else. Efforts will be made to make sure the telephone lines used are secure, and that the interview is recorded as a private talk between the researcher and yourself. Your identifying information will not be included in any presentation or publication of the results of the study. If you choose not to be part of the study, you can ask that information from you be removed from the study at any time before the study is complete. You can contact me by email at Kathryn.Fraser@cehha.nshealth.ca or by calling (902) 802-7069 to withdraw your information from the study.

11. *Right to Ask Questions:* If you have any questions before, during, or after taking part in this study, please contact Kathryn Fraser at (902) 802-7069 or by email at Kathryn.Fraser@cehha.nshealth.ca. You may also contact the faculty advisor, Dr. Lynne Robinson, at (902) 494-1157 or by email at lynne.robinson@dal.ca.

12. *Problems or Concerns:* Should you experience any difficulties with or have concerns about any aspect of taking part in this study, please contact Patricia Lindley, Director of Dalhousie University's Office of Human Research Ethics Administration for assistance: by phone at (902) 494-1462, or by email at patricia.lindley@dal.ca.

13. *Return of Study Results to Participants:* If you take part and you want a summary of the results from the study, I will send one by e-mail or letter mail, whichever method you prefer.

You are not required to take part in this study. You have the right to stop taking part at any time. If you give consent to take part and understand the list of items above, please type or sign your name on the line labeled "participant" to indicate that you agree to participate.

Participant : _____ Date: _____

If you agree that the interview can be audio-recorded, please type or sign your name on the line labeled "Permission for audio recording".

Permission to audio record interview: _____ Date: _____

If you agree that the researcher can use direct quotations from your interview in the final report, please type or sign your name on the line labeled "Permission to use direct quotations".

Permission to use direct quotations : _____ Date : _____

Principal Investigator: _____ Date: _____

Please return the signed consent form and completed background information questionnaire by mailing them in the enclosed self-addressed envelope to:

Kathryn Fraser
Victoria Court, Suite 205
14 Court St.
Truro, NS
B2N 3H7

Or by email to: Kathryn.Fraser@cehha.nshealth.ca

Appendix F

Contact Summary Form

Contact Date: _____

Participant #: _____

Today's Date: _____

Written By: _____

1. What were the main issues or themes arising from this contact?

2. Summarize the information you got (or failed to get) on each of the target questions you had for this contact.

Question	Information
Demographics	
How Participants are Supported Online	
How Participants Provide Support Online	
How Participants Use the Internet for Support	

3. Anything else that struck you as salient, interesting, illuminating, or important in this contact?

Appendix G

Recommendations

Designing Online Resources for Older Cancer Survivors

Computer Training

- Provide support for basic computer skills and site navigation
- Provide list of credible sites related to specific cancer diagnosis
- Provide training on how to discern credible cancer information

Computer Access

- Make computers accessible at cancer clinics
- Credible, evidence-based sites bookmarked by medical professional

Site Design

- User-friendly site, limit flash and large graphics
- Easy to navigate, limited number of links
- Capability to search by cancer type and/or body location
- Capability to search for others who match in cancer type and other events relating to cancer diagnosis

Site Content

- Maintain moderated bulletin boards/ chatrooms
- Develop professional site, affiliated with reputable cancer organization or hospital
- Include glossary of medical terms and map of human body
- Use layperson's terms
- Maintain positive tone of site, focusing on hope
- Include links to:
 - new cancer-related research
 - healthy coping strategies
 - accessing services, drug reimbursements
 - local cancer-related events, in-person support groups