

Online Cancer Support Groups: What the Consumer Has to Say

Erin E. Rapach

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Eric McCollum, Ph.D., Committee Chair
Angela Huebner, Ph.D.
Julia Sayre, LMFT

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Abstract

Although the research on the effects of cancer on the patient and its impact on the family system, as well as on the benefits of support groups for this population is abundant, there is relatively little research that examines the benefits of online cancer support groups, the meaning that users attribute to giving and receiving support, and the effects of use on the user's significant other. Using the theoretical frameworks of phenomenology, and Social Interactionism online surveys were conducted with seven individuals who considered themselves active members of the online Cancer Survivors Network, were all diagnosed with cancer and living with a significant other. These surveys were coded for themes using Thematic Analysis. The main themes identified included: feeling normal, belonging to a community, hope, honest and open place to talk about fears, feelings and possibility of death, that experiencing and recovering or dealing with cancer is a process, gaining understanding, acceptance and support, as well as information, a better sense of well-being related to hope and humor, and feeling helpful. The themes that emerged when looking at the partner relationships were: feelings of jealousy, and sharing the online community with their partner. Implications for clinical practice and suggestions for future research are included.

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CHAPTER I INTRODUCTION

The Problem and Setting

Cancer is one of the most prevalent illnesses in the United States, afflicting over 1.4 million people each year (American Cancer Society, 2008a), and growing each year as the population ages (Sherman & Simonton, 1999). As it stands, the experience of cancer is a “stressful event that affects nearly one of every three individuals and three out of every four families in this country” (Taylor, Falke, Shoptaw, & Lichtman, 1986, pg.608). The cancer patient can encounter feelings of shock, impaired concentration, emotional numbness, insomnia and nightmares, heightened arousal, depression, anxiety, or intrusive thoughts about dying or cancer recurrence (Scott, Halford, & Ward, 2004). While these are normal experiences to have after a cancer diagnosis, they are still difficult for people to manage on their own. In fact, people with cancer often report that their family does not, or cannot, understand their experiences. Some individuals have turned to support groups for social support, a place to share feelings and concerns, develop coping skills, gather information and education, or as a place to share fears, ambiguities, and other existential issues (Robinson, Carroll, & Watson, 2005; Taylor, et al., 1986).

Support can play a critical role in a cancer patient’s well-being and medical outcome (Klemm, et al., 2003; Klemm, Reppert & Visich, 1998; Lederberg, 1998). Research also indicates that social support can reduce psychological distress in cancer patients and increase the prospects of recovery (Taylor, et al., 1986). One study found that subjects who experienced weekly support groups reported less stress, tension, fatigue, fewer maladjusted coping responses, fewer phobias, and more vigor (Taylor, et al., 1986, pg. 608). Some researchers conceptualize illness as a social experience, suggesting that the suffering cancer patients experience “elicits intense emotions and...the desire to talk to others” (Davison, Pennebaker, & Dickerson, 2000, pg. 205). As more people are diagnosed with various types of cancer and are turning to the internet for support, the demands of online support communities are increasing quickly (Blank & Adams-Blodnieks, 2007). People turn to these groups in order to provide a forum of shared experiences, common suffering, and social learning and also to provide a “unique venue for growth, social experimentation, and change” (Davison, et al., 2000, pg. 206). A new forum of support is emerging, with little formal investigation; it is necessary for researchers to learn more about this community.

This study investigated the use of online cancer support, which can be divided into four categories: chat rooms, autobiographies, medical reports, and medical and emotional information (Radin & Landzelius, 2006). In particular, this study investigated the process of cancer patients finding online support groups, and the meaning that these patients place on such support and their recovery/managing of their diagnosis. The cancer community can be defined as people newly diagnosed with cancer or in treatment, those in recurrence, those that have completed treatment or in remission, and caregivers of cancer sufferers (found on April 14, 2007 at American Cancer Society, <http://www.acscsn.org/>). Caregivers are defined by the American Cancer Society as those “taking on new, unfamiliar responsibilities as you help [a loved one] through treatment and recovery” (found on October 13, 2008 at American Cancer Society, http://www.cancer.org/docroot/home/cgv/cgv_0.asp).

There is little research in the area of online support for the cancer community. Available research offers varied opinions about online cancer support. Some researchers have found that online support groups are useful for the cancer community because the availability of online

cancer support groups introduces a new aspect of social connection, gathering professional research, and access to other information, such as how to deal with the possibility of death (Davison, et al., 2000; Radin & Landzelius, 2006). It has been suggested that social support can reduce symptoms of distress and increase the chances of recovery in cancer patients (Taylor, et al., 1986). In fact, some researchers have suggested that being able to enter into the online cancer forums and tell one's story is a narrative experience; and it provides an opportunity for victims of cancer to join with others dealing with similar situations, which can also be a normalizing experience (Davison, et al., 2000). Radin and Landzelius (2006, p. 594) proposes that online cancer support forums act as surrogate families where patients can share in common problems, help move toward mutual goals and provide support through successes and hardships. Online cancer support groups offer alternatives to those who find their "alternative resources...inadequate" (Winefield, 2006, p. 193).

Other researchers feel that online cancer support lacks professionals to facilitate, influence, and manage the online cancer support communities. The concern is that cancer patients may be dealing with a wide range complex emotions and psychological responses, such as depression or posttraumatic stress disorder to name a few, that require "valid therapeutic interventions during the first year after diagnosis" (Kangas, Henry, & Bryant, 2005, p. 763). Some professionals argue that online information is unreliable and lacking; while others fear that the lack of a professional facilitator will turn some users away from online cancer support groups (Klemm, et al, 1998; Klemm, et al. 2003).

It is evident is that the voice of the survivor is missing from this literature. There is very little research describing the experience of the cancer survivor who turns to online cancer support groups. The cancer patients who turn to online support groups are encountering a broad range of experiences about which we know very little. Those voices and experiences need to be heard and understood, so that professionals in both the medical and therapeutic setting can make informed referrals to psychosocial support. Research has captured the demographic of online cancer support group users and the goals of these online support groups, but not the survivor's stories. It would be helpful to further understand how online support groups are useful to these patients and their family members, or why they chose to use the internet as a mode of support. With the internet as a frequent portal to support, professionals need to know more about the perceived benefits of online cancer support.

Significance

"One out of three people will develop cancer in their life time" (Klemm, et al., 1998, p.34), affecting 75% of families in the United States (Taylot, et al., 1986). Therapists are likely to encounter this issue in their practice and are tasked with knowing about available services for their clients. There is little research on the use of cyberspace as support for victims of cancer and their caregivers. Existing research provides conflicting results regarding safety and benefits of online forums. It is the opinion of some researchers that online support groups for the cancer community should only be directed toward those who have insufficient support in their social relations outside of cyberspace, and could be classified as high-risk for adverse outcomes; these same researchers feel these groups should be facilitated by experienced professionals, and often they are not (Helgeson, Cohen, & Schulz, 2000; Helgeson, Cohen, & Schulz, 2001).

On the other hand, the majority of the literature suggests that members of the cyberspace cancer support community are experiencing great benefits from participating in support groups. In fact, with online support groups they are not only benefiting from the health information, the most common reason for using the internet (Winefield, 2006), but also from the peer-to-peer

support, connecting with people with the same problems and fears, to find loving encouragement, and finding solutions together (Davison, et al., 2000; Radin & Landzelius, 2006; Robinson, et al., 2005; Taylor, et al., 1986). People turn to online support groups for the convenience, the minimal cost, 24-hour availability, and for the privacy and anonymity (Blank & Adams-Blodnieks, 2007; Radin & Landzelius, 2006).

With the demands of online cancer support groups increasing rapidly (Blank & Adams-Blodnieks, 2007), there is a need to develop different types of therapeutic interventions to assist cancer patients, survivors and caregivers (Kangas, Henry, & Bryant, 2005). Online cancer support groups are one of these interventions; therefore it is important to understand how it is effective and useful to the cancer patient. Investigating the meaning of this support from the cancer members' perspective is one way to do that.

Rationale

There is a need for a qualitative exploration to better understand the phenomenon of online cancer support and to address the conflicts within the current literature regarding consumer safety and benefits. A qualitative study will allow the researcher to explore the meaning of finding, giving and receiving support on the Cancer Survivor's Network (CSN) online support community, using in depth interviews and constant comparison to explore meanings and themes. There is research on the importance and benefit of social support groups, but little has been explored in the area of virtual support groups. One way of exploring this is to provide a rich description of this culture, addressing some of the limitations of previous quantitative and qualitative literature.

A qualitative approach was chosen to give researchers a better understanding of this new forum of support. It may lead to an understanding of how online support benefits users in their day-to-day lives, as well as what the meaning of receiving and giving support is for this group. The exploration into the meaning of this support from the cancer members' perspectives will allow the researcher to enter the natural setting of this online community and explore the meaning members place on support. A qualitative study also explores the experiences of the members and provides a forum for their voices to be heard. This study will add to the previous research on support benefits and its value to cancer sufferers. This could be a powerful resource for therapists and other professionals working with patients and families of cancer sufferers.

Theoretical Framework

This Study uses a Phenomenological framework to understand meaning, by exploring the phenomenon of giving and receiving support online, where it naturally exists. Using this framework provides a method for taking each user's written responses and lived experiences and finding the meaning of those experiences (Morse & Richards, 2002). By asking questions that elicit a story in the user's own words, the researcher focuses on the meaning that users assign to giving and receiving support, how that support affects their day-to-day life and relationships with their significant others, as well as other people in their lives.

Symbolic Interactionism takes the research to another level of understanding the meaning that users place on their experiences and of giving and receiving support. Symbolic Interactionism guides the exploration of the online cancer support community's interpretation of effective interactions (White & Klein, 2002). This researcher explored the social behavior found in the online cancer support community, to understand the meanings these members assign to the events and actions that occur. Symbolic Interactionism allows the researcher to query in how people in a particular group assign meaning to events and things within the group's interactions. In order to understand the interactions between group members, "the researcher must understand

the meanings [people] assign to the situation and action” (White & Klein, 2002, pg. 59); accordingly, the online cancer support group members are asked to tell their story and the meanings related to giving and receiving support. Perceptions of the users will be used to present evidence of this world, through the narratives of the participants’ actual lived experiences (Morse & Richards, 2002). Focusing on the online cancer community users’ meaning of this support, its perceived benefits and effects on the everyday life and family of the user, will add data to the support group literature.

Purpose of the Study

This study will enrich the current data by listening to the voices of online cancer support group members. Through exploration and understanding the users’ meanings of giving and receiving support in their online cancer support group, the benefits, as well as the effects of use on their day-to-day relationships will add to the research and data already exploring this growing online support community. Exploring this community through a qualitative lens will promote understanding of the meanings of online support created within the community.

Research Questions

How do participants describe the meaning of giving and receiving support on the online cancer support group?

How do the participants describe the benefits they are getting from the forum or mode of communicating?

How do participants say online cancer support groups affect their day-to-day relationships in their family life, as well as other relationships?

CHAPTER II

LITERATURE REVIEW

Social Impact of Cancer

Afflicting millions of people in the United States, cancer is one of the most prevalent chronic illnesses, resulting in a growing number of families affected by this illness (Sherman & Simonton, 1999). Due to the negative psychological and physical symptoms, a cancer diagnosis has a devastating effect on the patient, as well as on their family (Neilson-Clayton & Brownlee, 2002). A cancer diagnosis can challenge roles and responsibilities within families, creating a sense of disorientation, uncertainty, and stress for each family member, as well as feelings of emotional, social, and financial exhaustion (Neilson-Clayton & Brownlee, 2002).

The quality of life is adversely affected after receiving a cancer diagnosis (Smith, Richardson, Hoffman, & Pilkington, 2005). A cancer diagnosis can cause people to feel isolated and lonely because “cancer separates people artificially. After a cancer diagnosis, the world is divided into those with cancer and those without it” (Duffy & Gillig, 2003, p.71). The individual diagnosed with cancer can go through a whole gamut of emotions and experiences. In fact, some researchers assert that those diagnosed with cancer are affected in every area of their life, due to the nature of the disease and treatment; and if coping skills are not adequate and stress is not improved, the quality of life is diminished (Nezu, Nezu, Felgoise, McClure, Houts 2003). People diagnosed with cancer report experiencing depression, anxiety, vomiting, pain, nausea, and sleep disturbances (Quesnel, Savard, Simard, Ivers, & Morin, 2003), stress, and a gradual decrease in quality of sexual and interpersonal functioning (Antoni, et al., 2006). In addition, some cancer patients’ stress reaches a level that merits a diagnosis of Posttraumatic Stress Disorder or Acute Stress Disorder (Kangas, et al., 2005). In fact, Klemm and Hardie (2002) report that “patients with cancer are at increased risk for developing depression” (p.45). They state that while some clients have depression before a cancer diagnosis, some depression is related to the type or placement of the cancer, and others experience depression due to diagnosis and the toll it can take. Significantly patients who are diagnosed with cancer and score high on depression scales were found to have an increased risk of survival; but with treatment of the depression, the prognosis can be improved (Klemm & Hardie, 2002). Citing findings that the internet can lead to high rates of depression, Klemm and Hardie (2002) note a concern about the possible relationship between depression and online support.

The patient is not the only person suffering from the aftermath of a cancer diagnosis. Scott, Halford, and Ward (2004) report that a “cancer diagnosis affects the psychological well-being of both the patient and their partner...[whose] reactions [can] often involve shock, impaired concentration, emotional numbness, insomnia, nightmares, heightened arousal, depression, anxiety, intrusive thoughts about dying or cancer recurrence” (p. 1122). Couples have to navigate through hospital trips, treatments, repeated testing and awaiting test results, and day-to-day changes in roles and routines (Weingarten, 2005). All of this can take a toll on the couple as well as the family.

After receiving a diagnosis of cancer, the family can experience a sense of helplessness, powerlessness, uncertainty, ambiguity, anxiety, depression, or vulnerability (Sherman & Simonton, 1999). The family may also feel overburdened, angry and despairing (Neilson-Clayton & Brownlee, 2002) due to frequent hospital visits, loss of income, disruption to family routines, and changes in responsibilities; families experience increased stress and significant emotional distress (Watson, et al., 2006; Nezu, et al., 2003). Robinson, et al., (2005) found that

families experiencing a cancer diagnosis are facing a battle “between feelings of isolation and connectedness, to making meaning of cancer in their life, and to finding ways of incorporating cancer into their current world view” (p. 131). Families are worried about the life of the family member, but also their family and quality of life (Neilson-Clayton & Brownlee, 2002). All of these experiences affect the family unit as a whole and can create an intense range of emotions that can have negative and positive effects on families (Robinson, et al., 2005).

The cost of cancer on society is also devastating; in fact “the National Institutes of Health estimate overall costs of cancer in 2007 at \$219.2 billion: \$89.0 billion for direct medical costs (total of all health expenditures); \$18.2 billion for indirect morbidity costs (cost of lost productivity due to illness); and \$112.0 billion for indirect mortality costs (cost of lost productivity due to premature death)” (American Cancer Society, 2008a, p. 3). The American Cancer Society (2008a) estimates that almost one and a half million Americans were newly diagnosed with cancer in 2007.

Benefits of Social Support Groups for Cancer Patients/Survivors

Cancer can have devastating effects in the lives of its victims and their families. Among other resources, social support group can help mitigate the devastation. Davison, et al., (2000, p. 205) found that “suffering elicits intense emotions and hence the desire to talk to others; and that support groups...have a powerful effect on mental and physical health.” There are many other reasons that people come together in these small groups: to cope collectively with their unique challenges, social support, being able to share feelings and concerns, develop or enhance coping skills, information gathering and exchange, education and peer discussion (Davison, et al., 2000; Robinson, et al., 2005; Helgeson, et al., 2000). After a cancer diagnosis people seek others with similar experiences in order to maintain a sense of normalcy and accuracy about their experiences and emotions; in fact, they claim that this social interaction helps people to organize their thoughts and feelings about their diagnosis (Davison, et al., 2000).

Support groups can offer an opportunity for cancer patients to voice their experiences without worry of burdening or boring loved ones and friends and this can help the prognosis for a patient (Cancer, 2002). It has been suggested that a patient’s “willingness to discuss and think about their illness [is] an important factor for optimal coping” (Klemm & Hardie, 2002, p. 46). Support groups offer a safe place for cancer patients to handle all of the intense emotions and experiences that they may not feel safe or able to share with loved ones. They provide a forum for talking about the labile emotions, fears and experiences they are having or have had.

Another significant benefit to support groups is the improvement in psychosocial adjustment for those coping with cancer (Robinson, et al., 2005). As stated by Davison, et al., (2000, p.206), “the stories told and heard in this context carry the weight of shared experience, the emotional potency of common suffering, and an avenue for growth, social experimentation, and change.” Robinson, et al. (2005) found that turning to a support group can be the first step toward taking control, getting connected, and finding meaning for people with cancer. Being able to share one’s experiences with people who have similar stories and can understand and validate these experiences creates a place for the patient, survivor or caregiver to feel normal.

Others found that social support can reduce psychological distress in cancer patients and therefore increase the possibility of recovery (Taylor, et al., 1986). Through social support during this difficult time and connecting with people who understand and listen to you, the patient can improve coping strategies, reduce stress, experience humor and forming new friendships; all of these factors can improve the patient’s well-being (Cancer, 2002; Duffy & Gillig, 2003). Support group participants report less pain, greater improvement in depression

and fewer feelings of isolation than those not involved in support groups (Cancer, 2002; McTavish, et al., 1995). Another study found that members of support groups “were less isolated and better able to communicate what they felt about their cancer experience” (Klemm & Hardie, 2002, p. 46).

Research and Issues for Online Cancer Support Groups

In addition to face-to-face, or traditional, cancer support groups, the growth of the internet has created a rich resource for support. As the availability of computer information services grow, so do the possibilities for cancer patients (Klemm, et al., 1998). In fact, of the millions of Americans diagnosed with cancer, 58% use the internet for cancer support and information (Beaudoin & Tao, 2007). No one disagrees that a cancer diagnosis is extremely distressful for patients and their families, or that “information related to treatment options that are provided to patients, family members and caregivers can be extremely complex and confusing” (Anderson & Klemm, 2008, p. 56); however there is disagreement about whether internet cancer support groups can address the needs of patients and alleviate the complexity and confusion caused by a cancer diagnosis.

Internet cancer support groups are considered a “complementary supportive intervention” that can have a “positive effect on levels of distress and quality of life during treatment and rehabilitation” (Smith, et al., 2005, p. 316). This method of internet use can lead to better social support, coping skills, less isolation, and lower rates of depression and anxiety (Beaudoin & Tao, 2007). Advocates maintain that the online cancer community provides many things that the traditional support group does not, such as 24-hour availability, convenience, up-to-date information, patient friendly formats and anonymity (Anderson & Klemm, 2008; Blank & Adams-Blodnieks, 2007). Some researchers support the use of online cancer support groups because they believe that usage leads to lower rates of depression and stress due to an improvement in coping skills, which they feel can improve recovery (Beaudoin & Tao, 2007). Advocates of online cancer support groups have found that this mode of connecting with other people can be empowering for patients who might otherwise not receive support (Anderson & Klemm, 2008; Radin & Landzelius, 2006). The same advocates are also critics however, questioning the reliability of information provided and the efficacy of online support groups that operate without a professional facilitator (Anderson & Klemm, 2008); as well as concern for data supporting higher rates of depression for online cancer support use (Klemm & Hardie, 2002).

Research regarding online cancer support has produced conflicting evidence for turning to the internet for support. The investigations of Klemm, an oncology certified nurse, and her colleagues exemplify this conflict in the field of online cancer support. In the 1990’s, Klemm and her colleagues first began exploring the world of online support groups for cancer patients, reporting many positive benefits of online support for patients and their caregivers. As Klemm’s research interests developed and continued to add to the foundation of research, her data started to show a different trend, where the costs might outweigh the benefits for online cancer support groups (Klemm & Hardie, 2002). This literature review will track the relevant research of the last decade through Klemm’s work, noting supporting data and non-supporting data from other researchers.

In 1998, Klemm et al. published their first study examining the benefits of online cancer support groups for patients. The research team analyzed 300 messages posted by 48 men and 46 women in an Internet Cancer Support Group in June of 1996 and January of 1997 (Klemm, et al., 1998). After a content analysis of the 300 messages, Klemm and colleagues identified eight categories or themes in the messages: information giving/seeking, personal opinions,

encouragement/support, personal experience, thanks, humor, prayer and miscellaneous. While the identified themes like information giving/seeking, encouragement/support, humor and prayer are self explanatory, the themes personal opinions, personal experience and thanks are not. Personal opinions are described by Klemm and colleagues as the user's own opinions on treatments, cancer politics, experimental therapies and research studies; personal experiences cover shared experiences related to their personal fight with cancer, including, but not limited to, quality of life issues, new treatments, side effects of chemotherapy and other issues related to stage IV cancer. The thanks theme includes gratitude toward other users for their support, postings, willingness to listen, sharing, explanations and opinions. These themes are similar to those found in traditional support groups; but they also found that online cancer support groups allow the patient to reach out to patients in different cities, states and countries, decreasing isolation while maintaining anonymity.

Klemm, et al. (1998) also found that the idea that the availability of the anonymous internet would actually attract users less likely to go to traditional support groups. Such new users include men, people who are not interested in face-to-face support, people with mobility problems, people with hearing and speech disabilities and those with caregiver responsibilities (Broom, 2005; Finfgeld, 2000; Klemm, et al., 1998; White & Dorman, 2001). Broom (2005) completed a study exploring masculinity and prostate cancer, comparing online support groups to face-to-face support groups. Overall this study found that the men who preferred using online cancer support groups over traditional ones felt like they were able to speak openly about vulnerabilities, their illness, feelings, and fears without concern of public ridicule of their manhood (Broom, 2005). In fact, according to Klemm and colleagues (1998), while women typically outnumber men four to one in traditional support groups, these researchers speculate that online cancer support groups will attract more men.

In addition to advantages, this study discovered some of the disadvantages such as: the cost of the equipment, high volume of electronic mail, lack of professional facilitator, one-on-one personal contact that discourage participation for some, unreliable information, lack of a phone line for modem connection, limited access for the illiterate and the visually impaired (Klemm, et al., 1998). The team's conclusions cited the need for more research in the area of online support groups and a deeper exploration into the implications this research can have for professionals.

Two other studies report disadvantages to online support, such as lack of equipment or computer/internet skills, lack of nonverbal and visual cues, highly active postings, possibility of poor or inaccurate information, postings that criticize health care professionals which could delay users from seeking medical help, lack of guidelines and professional facilitation, exacerbating internet addiction problems, increased social isolation and lag time between posting and receiving a response (Finfgeld, 2000; van Uden-Krann, et al., 2008a). However, van Uden-Krann, et al. (2008a) concluded that many of these reported disadvantages are actually not a problem overall and that online support groups can be useful and supportive for cancer patients.

Klemm continued her research (Klemm, Hurst, Dearholt & Trone, 1999), focusing on gender differences within the online communities. This team of researchers analyzed approximately 950 postings by 160 men and 175 women from a prostate cancer group, breast cancer (a predominately women's) group and mixed (both men and women) online cancer support groups. Four categories emerged from all three sites, encompassing about 80% of all communications. These categories were: "information giving/seeking, encouragement/support, personal opinion and personal experience" (Klemm, et al., 1999, p. 65). They also found that

when they compared the men's online cancer support group to the women's, "men were more than twice as likely to give information and women more than twice as likely to give encouragement and support" (Klemm, et al., 1999, p. 65). This research team recommended that future research explore the link between online cancer support groups and depression, quality of life and survival time. This team's findings conclude that health professionals have a responsibility to learn more about online cancer support and share their findings with patients.

As people increasingly turned to the internet for information and support, other researchers began to explore this new forum of online cancer support. Finfgeld (2000) added to the previous research by exploring other possible advantages and disadvantages to online cancer support groups. The very act of typing one's thoughts, feelings and comments can be therapeutic (Finfgeld, 2000). In fact, this study found that due to the nature of electronic communication and its permanence once it has been sent, it is likely that members will be thoughtful and reflective in their responses. This was supported by White and Dorman's (2001) study, which found that "online communication allows members to think carefully and deliberately before sending messages or responding to postings" (p. 702). In addition to the advantages others have found, White and Dorman (2001) suggest that the potential for online support groups to have endless numbers of members is an advantage over face-to-face support groups which are limited in their numbers. They also found that online support groups can act as a supplement between meetings for those who want or need more support than offered by their face-to-face meetings.

Some of the disadvantages to online cancer support reported by other studies have alternatives: incorrect information can be quickly corrected by other members; unofficial leaders come forward in online groups that do not have official leaders or facilitators; and the lack of visual cues could be considered an asset (Finfgeld, 2000). Some have found that online cancer support communities share common interests and experiences which can make these groups powerful additions or alternatives to other resources (Finfgeld, 2000; White & Dorman, 2001). In addition, caregivers, family members and friends may benefit from online cancer support groups. Through membership these users gain information, insight and understanding for those who are diagnosed with cancer (White & Dorman, 2001).

In 2002, Klemm and Hardie took a more assertive stance on the importance of research for testing the effectiveness of online groups. They noted that traditional support groups were shown to be beneficial for patients of cancer, and without knowing more about the reliability and validity of online cancer support groups and their effectiveness, professionals should use caution and more research should be conducted (Klemm & Hardie, 2002). To address some of these limitations, Klemm and Hardie (2002) examined depression scores from members of a face-to-face (traditional) support group and online cancer support group. Subjects were already members of their respective support groups. Using a convenience sample of 40 cancer patients, 14 from traditional support groups and 26 from the online support groups, researchers used the Center for Epidemiologic Studies Depression Scale (CES-D) to measure depression and a Spearman correlation "to examine the relationship between level of depression and time on the internet" (p.48). The online cancer support group CES-D scores reflected that about 92% of the online cancer support group suffered from depression, while none of the traditional support group members did. This finding would suggest that traditional support groups lead to lower rates of depression for cancer patients than do online support groups.

Although Klemm and colleagues concluded that the "data suggest that more depressed patients with cancer use internet support groups instead of face-to-face support" (p. 45), it appears they may not have taken into account all of the differences between the two samples. In

their limitation section they discuss the, as well as the “variance between the types of cancer, gender, or the self-selection of subjects participating in both groups...the inherent biases found when groups lack randomization” and the small sample size (Klemm & Hardie, 2002, p.49). One such significant difference between the two groups not mentioned includes the number of people in active treatment. Fourteen out of 26 members from the online group were in current cancer treatment compared to 2 out of 14 from the traditional support group. Additionally, the traditional support group members reported average duration of group membership of approximately 34 months, whereas the online members reported membership of approximately 12 months (Klemm & Hardie, 2002).

Cancer patients who spend more time online tend to spend less time with family or friends leading to “social withdrawal, lack of direct interpersonal contact and reduction of interactions” (Klemm & Hardie, 2002, p. 48). This is important to the field of research because “depression in patients with cancer has been reported to increase length of hospitalization, interfere with treatment and adversely affect quality of life” (Klemm & Hardie, 2002, p. 46). Based on the data from this study, Klemm and Hardie (2002) note that “traditional support groups can help people with cancer function more effectively with their disease” (p. 50). This research team concluded that professionals should recommend traditional support groups over online support groups due to the lack of research supporting the online support group’s ability to provide psychoeducational and psychotherapeutic interventions.

White & Dorman (2001) reported that the act of writing about cancer, thoughts, feelings and experience can reduce symptoms of depression and loneliness as well as lowering feelings of pain and stress. The act of group members sharing their experience of cancer and diagnosis through poetry, drawing and storytelling can “aid in recovery and promote self-esteem” (p. 703).

The use of online cancer support continued to increase through the past decade, as reflected in the growth of related research. In 2003, Klemm and her colleagues completed a literature review of the online cancer support group research. They found that nine articles included ten online cancer support group studies, of which seven were quantitative designs and three were qualitative designs (Klemm, et al., 2003). This literature review compared traditional support groups to online cancer support groups. From this review, Klemm and colleagues found that the samples in six out of the ten studies reviewed pertained to breast cancer patients, and four included samples from mixed cancer online support groups; one of those samples included caregivers. Of the 573 subjects in the ten studies, 222 were men, 271 were women, and 80 were undeclared; most of the studies included pilot studies, and were comprised mostly of “small groups of Caucasian women with breast cancer” (p. 140). These samples varied in ages and education, but they all had cancer and were recruited to online cancer support groups for the purpose of research.

Whether through traditional support groups or online support groups, “cancer survivors empathize with each other and draw strength from each other’s similar experiences, leading to bonding and cohesiveness” (Klemm, et al., 2003, p. 138). In one of the nine studies reviewed, this was called universality, and the participants ranked this universality as one of the top three best benefits of online cancer support. The first two benefits were hope and group cohesion (Weinberg, Uken, Schmale, & Adamek, 1995). All of the nine articles reported that traditional face-to-face support groups can lead to decreased rates of depression, mood disturbances, less phobic behaviors, less pain and increased coping skills. Their review of these studies showed that online cancer support groups can lead better coping with diagnosis, treatment and recovery to cancer for survivors, patients and caregivers. Hope, group cohesion, sharing information and

providing support, both online and face-to-face, can lead to decreases in isolation and adaptation to cancer for patients (Klemm, et al., 2003). Information seeking/giving was a common theme found in all of the studies, as were “gender differences, negative psychological effects, and barriers to using online groups” (Klemm, et al., 2003, p.136). However, of the nine studies, only three of the studies explored and included gender, and Klemm was a co-author of all three. Klemm and colleagues concluded that, due to the limited subject pool in these studies, the effectiveness of online cancer support groups is questionable. The limitations from many of the studies appeared to be similar and included small sample sizes, low number of male participants and primarily focused on Caucasian women with breast cancer (Klemm, et al., 1999; Fernsler & Manchester, 1997; Sharf, 1997; Gustafson, et al., 1993; Klemm & Hardie, 2002; McTavish, et al., 1995; Weinberg, et al., 1995; Weinberg, Schmale, Uken, & Wessel, 1996; Klemm, et al., 1998). This author notes that each study’s participants were from the same geographic area and some from the same oncologist; many were also given personal computers and instructions as to how to use the online support forum, and some were facilitated by a leader, all important factors that could impact their findings. Klemm and colleagues (2003) concluded that there is a need for research with an experimental design and outcome measures, and larger, more diverse samples in order to increase the applicability of results.

Klemm and colleagues (2003) also found criticisms of online cancer support in the research literature. One criticism included the differential depression rates reported between traditional support groups and online support groups. One of the nine articles included a study that found that members of online cancer support groups scored higher rates of depression for longer periods of time over members of traditional face-to-face support groups. However, not all studies concluded this; in fact, many studies found that online cancer support groups can offer support and relief in the form of social connection among people undergoing similar life crises, understanding, information, hope, prayer and encouragement (Gustafson, et al., 1993; Klemm, et al., 1999; Klemm, et al., 1998; McTavish, et al., 1995; Sharf, 1997; Weinberg, et al., 1995). They also reported that eventually the higher rates of depression diminished over time for online members; they are not sure if this is related to online cancer support or other factors (Klemm, et al., 2003). This team also found a theme in the literature suggesting that, with over seventy-three million people accessing health-related information online, the information available to cancer patients is not always reliable, and the quality of that vast information is questionable (Klemm, et al., 2003).

Klemm & Wheeler (2005) continued to explore online cancer support, pertaining to the emotional reactions of the cancer patient’s caregiver. Klemm found online support for caregivers to be scarce, with less research than that addressing online cancer support groups for patients; this provided a valuable addition to the literature, exploring other possible benefits of online support groups. Findings in this study suggested that, like cancer patients, caregivers of cancer patients report suffering from “emotional stress, depression, hopelessness, loss of control, anger, guilt, resentment, and increased anxiety related to their caretaking activities” (Klemm & Wheeler, 2005, p. 39). Caregiver well being appears to be related to patient status; caregivers of patients with advanced cancer scored higher on levels of depression, anxiety and poor sleep (Klemm & Wheeler, 2005). In this study the researchers explored 38 female caregiver’s online postings, a total of 330 messages. Three major themes emerged from the caregivers’ postings: hope, tremulous emotions, and the physical, emotional and psychological toll (Klemm & Wheeler, 2005). The caregivers that turn to the online community use this forum as a place to discuss problems or setbacks, seek advice, share personal experiences, treatment results and

emotional highs and lows (Klemm & Wheeler, 2005). While there appear to be many positive effects of online cancer support groups for patients and caregivers, the research comparing the traditional support groups and online support groups for caregivers is not well documented; there is a need for more research testing the outcomes of online cancer support on caregivers, as well as awareness among professionals of the needs of cancer patients and caregivers (Klemm & Wheeler, 2005).

The most recent chapter in Klemm's exploration into online cancer support was a literature review exploring the efficacy of the internet in providing cancer patients with education (Anderson & Klemm, 2008). While they report many of the same advantages of online cancer support groups reported in previous literature, this literature review focuses on the concerns found with online cancer support groups. For example, the accuracy and timeliness of information given to patients is critical to their welfare, and "online discussion groups that are not reviewed or facilitated by a healthcare professional... may disseminate incorrect information" (Anderson & Klemm, 2008, p.59). In fact, after reviewing the literature, Anderson and Klemm reported that some of the disadvantages of online cancer support are the lack of a professional facilitator, lack of visual cues, not having face-to-face interaction, posting of incorrect information, the risk of social isolation, the cost of equipment necessary to access the internet, the poor quality of information, increased rates of depression and feeling overwhelmed. This was supported by reports from patients who found that the internet "can be intimidating, confusing and frightening" (Beaudoin & Tao, 2007, p. 589). However, in other studies many of the online cancer support groups users reported an ease of use; these users included men and women with different education levels, from different countries, with different cancers, different levels of treatment or recovery and at different ages (Broom, 2005; Gustafson, et al., 1993; McTavish, 1995).

Another study found that, not only were online cancer support groups useful, users reported feeling more informed and confident about their physicians, treatment and social interactions (van Uden-Krann, et al., 2008b). van Uden-Krann, et al. (2008b) also found that using the internet for support helped users accept their disease, increasing optimism and a feeling of control, as well as improved self-esteem and social well-being. Online cancer support groups are meeting treatment and information needs, but also social needs at a time when people are facing healthcare challenges (Fingfeld, 2000). With the need to feel in control and informed, patients, survivors and caregivers have been turning to online cancer support groups (White & Dorman, 2001).

The research into the usefulness of on-line support for cancer patients and their caregivers is still developing, and currently presents a mixed picture. There are reasons for and against the use of online cancer support groups, even as millions of people turn to online cancer support. Current research lacks the consumer's voice. This study will consider the viewpoint of online cancer support group users and their perspectives regarding online group usefulness and how online support group membership affects their family life. It is important for professionals to be aware "of the advantages and disadvantages of using [online] cancer support groups and share this information with their patients" (Klemm, et al., 1998, p. 34). Who better to teach professionals than the users themselves?

CHAPTER III METHODS Design of the Study

This study examined the meaning and impact of online cancer support groups for individuals and their caregivers through a qualitative research design. The researcher entered into the online cancer support group community through the American Cancer Society's online CSN. The researcher used a qualitative, open-ended questionnaire that was accessible online. The researcher chose to use an online survey for two reasons: entering the cyberspace world, the researcher could join in participants' natural setting, likely increasing honesty and openness. By choosing to enter the online social support group of the participant, an attempt at eliciting responses using their mode of communication, typing, was made. With this design occurring in the users' natural cyberspace environment, the safety of privacy and anonymity may have led to the in-depth, candid interviews. It also allowed room for exploration and provided the opportunity to look for themes and patterns in this particular culture. Also an online survey potentially increases geographic diversity.

Study Participants and Procedures

Study participants consisted of members of the American Cancer Society's Cancer Survivors Network, an online forum created for support and as a resource for cancer patients, survivors and caregivers. Eight CSN members completed the screening survey, and seven completed the research survey. Of the eight, number five did not complete the second survey. Each participant was thanked via email by the researcher for their participation in the study.

After receiving IRB approval, the researcher discussed the proposal with the CSN website moderators and received written permission to conduct research through their site by publishing a recruitment letter on their discussion board. This process with CSN took over four weeks, effected the timeline and perhaps led to a lower number of participants than previously anticipated due to the surveys only being open for two weeks.

Participants were recruited online from the American Cancer Society's CSN. Using snowballing and convenience sampling, participants were recruited in two ways: a point-of-contact with the CSN, who I am related to, conducted outreach through personal email providing potential participants with a recruitment letter. This recruitment letter was also posted at the CSN discussion board. The letter directed interested participants to the researcher's email address. CSN members interested in participating contacted the researcher via email. The researcher then emailed the potential participants and provided them with a brief overview of research objectives and goals, as well as the screening questionnaire. Contact through email provided an opportunity for the researcher to establish a connection using participant's medium of communication, the internet.

The eligibility were: they were at least 18 years old, they were living with a significant partner, they had been diagnosed with cancer, and consider themselves an active member of the CSN on-line cancer support community. The participants completed an online 7-question screening questionnaire (Appendix B), created in order to limit those not meeting the eligibility criterion. Once a member was deemed eligible, they were invited to give consent by completing the survey online, wherein consent was implied. This implied consent was explained to participants in the recruitment letter, approved by the IRB. The consent included a clause about

ending anytime without penalty. The link to the research survey was provided to the participants via email. The survey then went into directions that were clear and comprehensible. Participants completed the research survey through multiple choice and essay type questions. All surveys were available anonymously to the researcher by the Virginia Tech survey manager.

The survey took approximately 30 to 45 minutes to complete. Due to the nature of the research survey, being essay and multiple-choice, the length of time for completion was dependent on the length of answers provided by each participant. Practice runs through the survey, by two volunteers, took an average of thirty minutes. After each participant completed the survey, it was coded and themes were defined.

Instruments/Methods of Measuring Constructs:

Participants completed a seven question screening questionnaire (Appendix B). When criteria were met, they completed a fourteen question online survey, comprised of both qualitative and quantitative components. This survey was made up of a multiple-choice, 'select all that apply', open-ended questions and was followed by seven demographic questions (Appendix C).

The quantitative questions were created by searching the CSN site for available options to members. All of the research survey questions were then given to the researcher's CSN point-of-contact to capture any missed categories, and to make sure they were clearly written and made sense.

Proposed Analyses

Thematic Analysis is the approach used to notice, identify, code and organize the data for meaning, themes, telling a story with the data (Braun & Clarke, 2006). When using thematic analysis to explore the data, the researcher is taking an active role in finding meaning and themes of interest (Braun & Clarke, 2006). An inductive/semantic analysis is the process of coding the data without having an existing coding framework. This allows for a rich, data-driven analysis. Using this approach to read the data allows for the data to represent itself (Braun & Clarke, 2006). Thematic analysis in this study consisted of six recursive steps: immersion or repeated reading of the data; generation of codes; searching for themes; refinement of themes/development of overall story; creating a thematic map and more refinement of themes; and writing the report (Braun & Clarke, 2006).

The analysis process began with reading and rereading the research questionnaire responses from each individual participant. The next step included reading and rereading all participant responses for each individual question. Through examining the responses this researcher assessed for words, concepts and phrases that seemed important using a Phenomenological and Social Interactionism lens. Determining importance was subjective, and based on the researcher's experience of the participants' stories. By using phenomenological and Social Interactionism lenses, the researcher saw codes and themes that suggested meaning of giving and receiving online cancer support, benefits of such support, and affects of membership on day-to-day relationships of the participant.

Responses were again reread for each question in which the researcher's own notes of possible codes were written in the margins. Each concept, word or phrase was placed on its own index card, this helped to identify and organize codes. When comparing codes to one another to find similarities between them, themes began to emerge. The original responses were reread using the thematic lens generated by the data to ensure inclusion of all data. The data was then organized into a three staged thematic map (Appendix D).

The first stage of this thematic map was to organize the identified codes for each question. The second stage was to read and reread all of the codes, grouping them together, if appropriate, and begin to notice themes. The final stage of the thematic mapping was to organize the themes in order for each theme to be considered through the three examined research questions:

- 1) How do participants describe the meaning of giving and receiving support on the online cancer support group?
- 2) How do the participants describe the benefits they are getting from the forum or mode of communicating?
- 3) How do participants say online cancer support groups affect their day-to-day relationships in their family life, as well as other relationships?

CHAPTER IV

RESULTS

Introduction

Throughout this study I explored the meaning of giving and receiving online support, the benefits of online communication, and how this online support has affected the member's day-to-day relationships. This study was comprised of two online surveys, the first a screening questionnaire, and the second with the research questions. Seven participants completed both the first and second surveys. During the coding process I read the data using a Symbolic Interactionism and Phenomenological lens, which yielded some new themes, as well as others previously described by other researchers.

Demographics of the Sample:

The participants were adults between the ages of 40-60 years, three between 40-to-49 years and four between the ages of 50-to-59 years. Participants included five females and two males; six stated that they are Caucasian and one, "American". The participants are currently married and have been for five to thirty-one years and all consider themselves active members of the Cancer Survivors Network. The participants were diagnosed with either breast cancer, colon cancer, Non-Hodgkin's Lymphoma, small cell and non-small cell lung cancer or tongue and neck cancer, all at various stages. One participant was first diagnosed in 1997, while the majority were diagnosed in 2005, 2006, 2007 or 2009. Five of the participants have been diagnosed with cancer more than once since their first diagnosis. Seven stated that they are out of treatment and in remission or have No Evidence of Disease (NED), and one of the eight who completed the screening survey is still in treatment. Six of the participants completed the question about state of residence, representing California, Indiana, Massachusetts, Texas, West Virginia, and Virginia. Due to one participant not completing the questionnaire, it is unknown if there were international participants.

The following section introduces the research participants and their stories. It will provide more detailed information on the meaning of giving and receiving support, the effects of online cancer support group use on their own cancer experience, to include treatment and recovery, and the effects of online support group use has on their relationships with their spouse, family, friends and coworkers.

Table 1-Participant Data

| Participant | Sex | Between the Ages of | Length of marriage | Living in | First diagnosed | Last diagnosis | Type of cancer | Stage of treatment | Length of CSN membership | Hours spent online |
|--|---------|---------------------|--------------------|----------------|------------------|-------------------|---|---|--------------------------|---|
| One (P1) | Female | 50-59 | 31 years | California | 1997, 1998 | 2007 | stage 2 breast cancer | currently in remission | 5 years | 14 hours/week, same as before CSN membership |
| Two (P2) | Male | 40-49 | 27 years | Massachusetts | 2006 | n/a | stage 2 Colon Cancer | “survivorship” stage of treatment. | More than 2 years | 10 hours/week, same as before |
| Three (P3) | Female | 40-49 | 15 years. | did not answer | 2006 | August of 2007 | Non Hodgkin’s Lymphoma (NHL) | “currently in remission and doing very well.” | 3 years | 3 hours/week, however she used to log on 10 hours or more/week., more than before |
| Four (P4) | Female | 40-49 | 6 years | West Virginia | 2007 | n/a | breast cancer | “finished at last” with treatment | 3 years | 3 hours/week, the same as before |
| Five (P5) This participant did not complete the second survey | unknown | is at least 18 | unknown | unknown | 2006 | 2008 | small cell and non small cell lung cancer | currently in remission | unknown | unknown |
| Six (P6) | female | 50-59 | 35 years | Texas | February 4, 2009 | February 25, 2009 | breast cancer | currently still in treatment | 2 months | 3 hours /week., more than before |
| Seven (P7) | female | 50-59 | over 5 years | Indiana | 2007 | n/a | colon cancer | No Evidence of Disease (NED). | Over 2 years | 3 hours/week, the same as before |
| Eight (P8) | Male | 50-59 | 31 years | Virginia | 2005 | 2008 | tongue/neck and lung cancer | NED prognosis. | 3 years | 28 hours/week, same as before |

Participant one

Participant one (P1) is a female between the ages of 50-59, and has been married for thirty-one years. P1 is from California and did not answer the questions about race. P1 was diagnosed with stage 2 breast cancer on the left side in 1997; in 1998 it metastasized to her chest wall and the sentinel node, classified stage 4. In 2007 it returned in the right breast, stage 2. P1 then had a mastectomy as well as more chemo-therapy and radiation for treatment. P1 is currently in remission, and has quarterly checks with her oncologist. P1 logs on to the CSN an estimated fourteen hours a week; this is the same amount of hours she logged onto the internet prior to CSN membership. P1 considers herself an active member of the CSN, and has been a member of CSN for five years.

Participant two

Participant two (P2) is a male between the ages of 40-49, and has been married for 27 years. He is from Massachusetts and stated that he is an American for his race. P2 was diagnosed with stage 2 Colon Cancer in 2006. He receives bi-annual CT scans, and considers himself in a “survivorship” stage of treatment. P2 logs onto the CSN an estimated ten hours a week; this is the same amount of hours he logged onto the internet prior to CSN membership. P2 has been a member of the CSN for more than two years.

Participant three

Participant three (P3) is a Caucasian female between the ages of 40-49, and has been married for 15 years. P3 did not answer the question about which state she lives in. P3 was diagnosed with Non Hodgkin’s Lymphoma (NHL) in April of 2006 and again in August of 2007.

P3 is “currently in remission and doing very well.” P3 considers herself an active member of the CSN, and currently logs on an estimated 3 hours per week; however she stated that she used to log on about ten hours or more per week during treatment. This is more time spent online than prior to membership. P3 has been a member of the CSN for three years.

Participant four

Participant four (P4) is a Caucasian female, between the ages of 40-49, and has been married for six years. P3 is from West Virginia. P4 was diagnosed with breast cancer in September of 2007, and is “finished at last” with treatment. P4 considers herself an active member of the CSN, and has been a member for three years. P4 logs onto the CSN an estimated 3 hours a week. This is about the same amount of time she logged on prior to membership.

Participant five

Participant five (P5) is at least 18 years of age and was diagnosed with both small cell and non small cell lung cancer in May 2006 and again in October 2008. P5 is currently in remission and considers him or herself to be an active member of the CSN. This participant did not complete the second survey.

Participant six

Participant six (P6) is a Caucasian female from Texas, between the ages of 50-59, and has been married for 35 years. P6 was first diagnosed with breast cancer on February 4th then in the other breast, on February 25th, 2009. P6 is currently still in treatment. P6 considers herself an active member on the CSN. P6 has been a CSN member for about two months and logs on about three hours a week. This is more than she logged onto the internet before membership.

Participant seven

Participant seven (P7) is a Caucasian female from Indiana, between the ages of 50-59, and has been married for over five years. P6 was diagnosed with colon cancer two and half years ago and finished her chemo-therapy treatments about a year and half ago. In January 2009 her doctors told her that her status was no evidence of disease (NED). P7 considers herself an active member of the CSN and has been a member for over two years. P7 logs on the CSN site about three hours a week, and this is about the same about of time she logged onto the internet prior to membership.

Participant eight

Participant eight (P8) is a Caucasian male between the ages of 50-59, and has been married for 31 years. P8 is from Virginia and was diagnosed with tongue/neck and lung cancer in August of 2005, and again in January 2008. P8 also received a NED status. P8 considers himself an active member of the CSN and logs on an estimated 28 hours per week to the CSN; this is about the same amount of time online as prior to membership. He has been a member for three years.

Common Themes across the Data

There were many common themes across the data. The following section will explore themes that were noticed and how these themes fit the three research questions, exploring how participants describe the meaning of giving and receiving support in the online cancer support group, how participants describe the benefits they are getting from the forum or mode of communicating, and how participants say online cancer support groups affect their day-to-day relationships.

To add context to the stories and meaning that participants attributed to online cancer support and its role in their lives, it is important to be aware of other forms of support they tried

and how useful they found them (Table 2). Participants also were asked what attracts them to online cancer support. There were many things that the participants thought were important or attractive about the CSN online support group (Table 3), but only two qualities were selected by all seven of the participants: the ability to assist others and finding people who can understand their cancer experience and are willing to talk about it. These two qualities of online support were represented throughout the data, and were addressed by many of the participants. Six out of seven of the participants found that their expectations of the online CSN were surpassed, and one felt that they were partially met.

Table 2-Other forms of support and their level of usefulness

| | |
|---|-----------------|
| Face-to-face support group(s) run by a professional facilitator | |
| Tried it, it wasn't useful | <u>1</u> (14%) |
| Tried it, it was useful | 0 (0%) |
| Currently using it | 0 (0%) |
| Didn't try | <u>6</u> (86%) |
| Face-to-face support group(s) not facilitated by a professional | |
| Tried it, it wasn't useful | 0 (0%) |
| Tried it, it was useful | 0 (0%) |
| Currently using it | 0 (0%) |
| Didn't try | <u>7</u> (100%) |
| Cancer specific support group(s) | |
| Tried it, it wasn't useful | 0 (0%) |
| Tried it, it was useful | <u>1</u> (14%) |
| Currently using it | <u>2</u> (29%) |
| Didn't try | <u>4</u> (57%) |
| Turning to family for support | |
| Tried it, it wasn't useful | 0 (0%) |
| Tried it, it was useful | <u>2</u> (29%) |
| Currently using it | <u>5</u> (71%) |
| Didn't try | 0 (0%) |
| Turning to friends for support | |
| Tried it, it wasn't useful | <u>1</u> (14%) |
| Tried it, it was useful | <u>1</u> (14%) |
| Currently using it | <u>4</u> (57%) |
| Didn't try | <u>1</u> (14%) |
| Church and fellowship | |
| Tried it, it wasn't useful | 0 (0%) |
| Tried it, it was useful | <u>1</u> (14%) |
| Currently using it | <u>2</u> (29%) |
| Didn't try | <u>4</u> (57%) |
| Taking advantage local and/or national charities and/or services | |
| Tried it, it wasn't useful | 0 (0%) |
| Tried it, it was useful | <u>3</u> (43%) |
| Currently using it | 0 (0%) |

| | |
|----------------------------|----------------|
| Didn't try | <u>4</u> (57%) |
| Therapy | |
| Tried it, it wasn't useful | 0 (0%) |
| Tried it, it was useful | <u>1</u> (14%) |
| Currently using it | 0 (0%) |
| Didn't try | <u>6</u> (86%) |

Table 3- Attractive Qualities of the CSN Online Support Group

| Qualities of online support participants found most attractive | # participants who selected this category | % of participants who selected this category |
|--|---|--|
| Assisting others | 7 | 100% |
| Finding people who can understand your experience and are willing to talk about it | 7 | 100% |
| Discussion boards | 6 | 86% |
| 24-hour, 7-days a week access | 6 | 86% |
| Humor of fellow users | 6 | 86% |
| Hope | 6 | 86% |
| Expressions gallery (art work, poetry, biographies, etc.) | 5 | 71% |
| Advice about treatment options from fellow cancer survivors and caregivers | 5 | 71% |
| Chat rooms | 5 | 71% |
| Social support | 4 | 57% |
| Information about national and international cancer specific resources | 4 | 57% |
| CSN newsletter and announcements | 3 | 43% |
| Site Accessibility | 3 | 43% |
| Meeting people with different cultural and/or racial backgrounds | 3 | 43% |
| Access to treatment technologies and techniques in different states and countries | 3 | 43% |
| Information about local cancer specific resources | 2 | 29% |
| Anonymity | 2 | 29% |
| As a substitute to therapy | 2 | 29% |
| Treatment support (non-online support like through phone calls and mail) | 2 | 29% |
| Research updates | 2 | 29% |
| CSN e-mail | 2 | 29% |
| Recommendations of resources (film, books, articles, etc.) | 1 | 14% |
| Advice about treatment options from medical professionals | 0 | (0%) |

How do participants describe the meaning of giving and receiving support on the online cancer support group?

The act of giving and receiving support online with other cancer patients, survivors and caregivers holds a lot of meaning for these seven participants. The themes that emerged from the data include feeling normal, belonging to a community, hope, safety, honest and open place to talk about fears, feelings and possibility of death, acknowledging that one is still alive, and that experiencing and recovering or dealing with cancer is a process.

Feeling normal

The theme of feeling normal arose in different ways from three participants, and three times by one of those participants, but it is P3 who mentions a need to feel normal first. As P3 is talking about what she hoped to get from the online support group, she is describing feelings of fear and being “scared out of my wits”, and she is describing the emotional torture of waiting for biopsy results:

I knew I had cancer, but we just had to wait to get the biopsy results back to determine the specific type. I have never been through such torture in my entire life. Emotional torture is so completely overwhelming that your mind can simply convince you that you are dying.

It is at this point, when she is going through such anguish, that she turns to the online cancer support group, CSN. At this point, she starts to feel normal about her feelings and experiences in her cancer journey:

This is where the chatroom began to save my life and my mind. The people that I met helped me to understand that everything I was going through was perfectly normal. They helped me to really comprehend that cancer is scary stuff. They helped me to express my fear. When I saw firsthand the words these people were using it felt like they were taking the words from my gut and they were appearing on screen. This type of camaraderie amazed me.

P8 writes about the role online support has played in his facing and recovering from cancer, addressing the non-cancer issues that participants discuss on the site:

What is odd is that the talk is not always about cancer, in fact is typically not about cancer. Most of the time, people are talking about food, about children and grandchildren, about jobs, about the latest events in their lives, and, yes, about sex. There is quite a bit of sexual innuendo, and there is lots of joking.

This ability to talk about things other than cancer, or as well as cancer, seems to be a powerful part of online cancer support. P8 goes on to talk about a normal life after diagnosis:

You come away from it thinking, not only am I not alone, but these people are talking about food and sex and the pain in the ass that is taking Johnny to soccer practice just after a chemo-therapy session! There IS life after cancer diagnosis, and it may even be more or less normal.

P1’s account of the role of online support in cancer treatment and recovery, includes the topics that members discuss on the site: “... it is also a place to share our good moments like birthdays, last chemo-therapy days, wedding anniversaries, and grandchildren. Occasionally we even share a recipe or two.”

CSN members are focus not just on cancer, but also about remembering to live. P8 discusses a “sense of normalcy” that members can get and how important this is, as well as how the site helps members adjust to cancer. P8 writes: “The site lets people know that this new, this new normal, life, can be a good new normal life.”

For these participants feeling normal by talking about events to celebrate, or talking about children, grandchildren, recipes and life, feels normal, and it feels important and helpful when dealing with cancer. It lets them know they are not alone. This sense of normalcy found online at the CSN seems to be a part of their treatment and recovery from cancer.

Belonging to a community

Belonging to a community was a theme that appeared in many of the participant’s written accounts. In particular, when the participants wrote about what they get from the online CSN, as

opposed to other means of support, the theme of community was the strongest. P1 referred to the site as the “CSN community”, and also as a “community of survivors who each have his or her own experiences.” P2 describes a time when he “turned to my online family and they pulled me up from the depths.” P3 wrote about the caring for one another and the friendships that develop on the site: “I have developed friendships with strangers that have lasted.” P7 and P8 addressed acceptance from others because they have been through what the member has been through. P7: “If you’re in a bad mood, good mood these people just accept it. They’ve been through it” and P2 adds, “It was comforting to know I was not alone in my feelings and fears.” Being able to share feelings with people who know what the participants is going through helps in the process of accepting, dealing, healing and treating/recovering from cancer. P8 states:

Everyone in the network has experienced what I have experienced, or they are providing care for someone who is experiencing what I have experienced. NO ONE can know what I have experienced in the way that these people know.... Understand that when you are first told you have cancer it is a death sentence: You have not studied it, you don't know any better - you think of cancer and death. Only these people, other survivors, know what that feeling is like.

This ability to engage with people who share similar fears, understand “ups and downs”, giving and receiving support and care, all work toward creating a sense of community. In fact, as P4 talked about the uniqueness of the online CSN, she felt that “being able to speak with someone that has been or is currently on the same journey you are, [and] being able to UNDERSTAND your concerns, emotions, fears, [and] tears” is essential. Through this shared and terrifying experience, people develop friendships, a sense of family or community and a place to turn when it feels as tough no one else could possibly understand.

Hope

As participants discussed the role that online support played in their treatment and recovery I noticed a theme of hope. By speaking with survivors who share similar experiences and out lived a cancer diagnosis, participants found hope. P7 stated, “You read about Hope all the time. Just read on the discussion pages what the others have experienced and are surviving now and have been for years.” As P8 talks about what role CSN membership can play in treatment and recovery, he considers the help to people who are newly diagnosed, and equate cancer to death, in talking to people who are 10-year, 20-year, or even 5, 6, or 7 year survivors. P8 calls that hope; he thinks hope is found by talking to “someone who can honestly say, “I’ve been there, I’ve done that, and I’m still here.” When P4 talked about a specific time when turning to this online support group was useful she specifically mentioned hope; seeing others hold hope helped P4 in her own cancer journey.

Safe, honest and open place to talk about fears and feelings around cancer diagnosis

This theme seems to be connected with many of the themes identified. Without a safe place to speak openly, experiences of hope, community, and normalcy may not be possible. This theme is captured in the stories told by participants, from breast reconstruction and being able to talk about loss of identity attached with losing hair to realities about being face-to-face with death and sharing fears. Many of the research participants talk about understanding their journey or experiences with cancer based on stories shared by other members. P3 shared a specific time when turning to the CSN was useful in “making sense of the chaos. Sharing their experience with me one on one is what I needed and the friends I made stepped up to the plate every single time.” P2 shared his experience of receiving a second diagnosis:

When I was told about my last diagnosis I felt all was lost and my life was over for I was sure I was going to die from this one. I felt I had beat it once and I was not sure I had the strength to fight it again. Again I turned to my online family and they pulled me up from the depths, some with humor, some with a well needed kick in the butt to get me fighting again.

The trust in his online community allowed him to share this situation with his online support group. He turned to the online community and they motivated him to find the strength to fight again.

The participants described scary moments when they turned on their computer and logged on to a website to share their fears and concerns as well as other feelings, and each learned that this community would be there for them, time and time again. In fact, P3 described times when the CSN community was “there anytime the fear would take over, night or day.” Another participant, P1, writes about her breast reconstruction thoughts and concerns with many women who had it done after their mastectomies. Other women logged on and shared their experiences of intimacy, identity and cleavage. Without safety these women might not have been inclined to share such intimate details. P4 found safety, shared her fears and felt like the CSN community listened and understood. Many of the participants address sharing their own stories and suggestions with others. P8 stated that the “most useful times have been when I have provided some sort of support to someone and they have indicated that it had a positive impact.” This reciprocal sharing helps to continue fostering a sense of safety.

Experiencing and recovering or dealing with cancer is a process

As the research participants shared their stories and experiences of cancer and the CSN, the theme emerged that a cancer diagnosis with treatment and movement towards normalcy and recovery is a process. Many participants noticed the shock and fear they experienced during the initial diagnosis of cancer, but they also recalled the CSN members help in accepting their diagnosis and learning how to live better, through shared coping strategies, shared experiences, discussions around living with cancer, not dying from cancer and in many other ways. In describing the crucial role online support can play in treatment and recovery, P3 stated:

I truly believe that every cancer patient be advised about this site by their doctors from the very first visit. I think this part of cancer is the very best way to get through moment by moment. It is a critical part of recovery to help ease the terror of cancer.

This participant is sharing the different parts of a cancer diagnosis and some of the feelings of terror that can come with diagnosis; but she also talks about recovery. In their narratives, the participants talk about diagnosis, but also about other aspects of treatment and recovery. It is not just that cancer survivors receive a diagnosis and then treatment; it is a journey towards healthy living and acceptance of cancer in one's life.

P2 was “still in shock from my diagnosis, I was just looking for information. My wife found the site and the chat area and thought it might be helpful for me to discuss my feelings with others.” P3 also described post-diagnosis shock, stating, “I don't really know that I knew what I was looking for. I was scared out of my wits. I found this group before I got my final diagnosis, which was a complete God-send.” In the beginning of his process towards recovery, P2 found comfort in knowing he “was not alone in my feelings and fears”, and P1 found it beneficial “to be able to open a conversation and express” herself. By turning to the online CSN the participants received support, understanding, humor, hope and honesty, many of which played a role in their battle with cancer. P8 stated that “just to talk to people that have had any

type of cancer helps”, and P4 wrote, “The online support group at [CSN] played a big part in my cancer journey by providing answers to questions, providing encouraging support, listening to my fears and understanding them as well.” P3 discussed the part that CSN has played in her dealing with and recovering from cancer. P3 stated:

“I can’t tell you how many days I was typing through tears. They could tell by the way I wrote. Then they could tell when I was starting the process of healing and acceptance of the disease. They knew before I did.”

As participants shared their accounts of their experiences with the CSN, they started to unfold a story of change. These stories are not only about change due to receiving support and understanding, but also from giving. P8 feels that through CSN membership, he has been useful in a way he had not been in years, which has “made me stronger and happier.” He has learned to “ask questions”, and he states that has made him “more educated in my own battle.” P7 addresses being helpful to others in recovery: “later on after I was better, I wanted to help the ‘newbies’ with their questions and concerns.” This speaks to the process of moving from needing help toward being able to provide help. Table four lists CSN participant recommendations. The three groups of people all seven participants selected represent three different stages of the cancer journey: diagnosis, treatment and post-treatment. This suggests the idea that cancer is a journey that participants believe does not have to be taken alone.

Table 4- Participant Recommendations
Participants would recommend this site to:

| | | |
|--|----------|--------|
| Those fearful of recent diagnosis | <u>7</u> | (100%) |
| Those in treatment | <u>7</u> | (100%) |
| Those in post treatment | <u>7</u> | (100%) |
| Long term survivors | <u>5</u> | (71%) |
| Caregivers | <u>6</u> | (86%) |
| other: “Those fearful of impending results, not yet diagnosed” | <u>1</u> | (14%) |

How do the participants describe the benefits they are getting from the forum or mode of communicating?

There were several benefits that the research participants report from the online forum of communication. The themes that emerged in the participant’s stories were: understanding/acceptance/support, information/first-hand knowledge, better well being related to hope and humor, feeling helpful, no time constraints, and anonymity. The following section will explore each theme through the voice of the participant.

Understanding/Support/Acceptance

The theme around understanding, support and acceptance was in a part of each participant’s account of their online cancer experience. Out of eight responses to the second survey research questions, six included responses about the importance of feeling supported, feeling understood and/or accepted. As participants talk about what they hoped to get from the CSN, one participant (P3) reported she sought only information; she found support in a way she never imagined, a network that showed understanding of her fears and feelings around her cancer

diagnosis. Another participant, P1, found support while grieving the death of her sister to pancreatic cancer, stating:

Last December the women in the breast cancer boards were very helpful as I dealt with the first anniversary of the loss of my sister to pancreatic cancer. It was good to be able to open a conversation and express myself.

This act of support was important to this participant and one that is not implied through membership, it just one of the many ways members in this community support each other. Another way P3 shared her feelings of support was to state, “Without the support of the group I do not believe that I would be comfortable in my own skin.”

P2 also talked about the part CSN has played in his recovery from cancer. He said that receiving support from others in the same situation was comforting. As mentioned earlier, P4 stated that support and understanding from CSN members played an important role in her “cancer journey.” In fact P6 feels like “people with cancer understand others with cancer and you can laugh, cry, get mad and they understand the reason”; this speaks to understanding and acceptance. When discussing the uniqueness of CSN, P7 talks about the understanding she gets from the site members: “these people understand the pain, frustration, not knowing elements of cancer.” P1 has found “in the breast cancer board that the women there depend greatly on the support, humor and love we get from one another.” This support, humor and love helps them to adjust to living with cancer. P1 explained that through this support they help each other with questions about treatment, intimacy and hair loss.

Others found support that they lacked from other people in their lives, even doctors. P3 could not “imagine living through this experience without it. I got the kind of support that I was missing from some of my doctors.” The theme of understanding, support and acceptance extended to understanding the needs and concerns of fellow members. P6 found it supportive when “you can vent when you need to and also lurk when you need to. Others on the discussion board understand what you are going through.” Support reportedly comes in various forms: from giving and receiving advice, to sharing sadness or anger, or information.

Acceptance includes being accepted by the group as well as finding acceptance for the disease; P3 stated: “they could tell when I was starting the process of healing and acceptance of the disease.” P3 shared that this move toward acceptance on her journey towards healing was due to “a beautiful lady really helped me to understand that it's just hair and when it was appropriate to just shave it off.” Acceptance also refers to feeling accepted to be one’s self; P6 talks about receiving acceptance from the CSN members: “If you're in a bad mood, good mood these people just accept it.” Online cancer support is a place to share any gamut of emotion of feelings due to a diagnosis or treatment without judgment. P2 recalls his wife’s inability to know his experiences: “as much as she tried to help there were feelings she just could not understand.”

Information/first-hand knowledge

Many participants identified information and first-hand knowledge as important benefits to online cancer support. This was a theme in five of the seven participants’ responses. Five hoped to find information when they first joined the CSN, and the other two hoped to share their knowledge. P2, P3, P4, P6, and P7 all wanted information about their specific cancer. P7 described one of her first encounters on the site, when she sought information, and how she now shares this information with others:

The reason I went to CSN was to find out about a chemo-therapy drug I was taking. The skin, on my hands, was beginning to peel off and very sore. My feet started to do the same thing. I found a person that was taking the same drug and suggested a type of cream to put on both the hands and feet. I tried that and it worked. I now suggest that to others that have the same problem.

P6 found it helpful to receive “information from other survivors” and P4 felt that fellow members “played a big part in my cancer journey by providing answers to questions.” In later discussions, P4 adds, “CSN helped me deal with my situation better because of the available resource and information. I knew I could turn to their support to find my answers or relieve my concerns.” The fear of not knowing is relieved for participants when they find answers and resources in their battle against cancer. P1 and P8 also acknowledge learning from other people’s experiences and knowledge. P8 states:

My hope initially was to help others who were going through the same thing I had gone through. Frankly, I had no idea that I needed any help until I came to the site, where I learned that there was much I did not know, that there was much I needed to know.

P1 provides examples of some common questions that she found useful and supportive when addressed among the breast cancer board:

They are able to ask questions like "what can I expect to feel when my hair starts to fall out", "how long till it will grow back", "what is radiation like", "how do you get back to being intimate when you feel marred", "when will I stop being tired", "when will I stop being scared" and [voila] within moments others will start penning notes of support and information that will help to ease their concerns and/or help them to see a different view point.

Participants suggested that many others can be a resource to cancer patients; intimate details such as hair loss, intimacy and when the fear will stop, are not things that someone without cancer can answer with firsthand knowledge and advice. As P8 said at one point:

You do not talk to a therapist, generally, about who is going to win the World Series; you do not speak to your doctors about what you or they are cooking tonight; [and] you do not make lewd insinuations to family members or friends.

P1 mentions in response to the question about CSN uniqueness, that “since there are so many of us to bounce ideas or thoughts off of we can brainstorm and get several suggestions to help us as we battle cancer.” P4 did just that stating that “when I was first diagnosed in 2006, I had sooooo many questions, concerns, etc., going through my mind, but no answers, so finding the CSN was a god send.” The participants address a variety of experiences sharing information and knowledge, an important part of online support.

Better well-being related to hope and humor

Based on previous research, hope and humor are often large themes and components in online cancer support. Humor and hope can lead to a sense of better well-being. P7 notes a sense of better well-being as she talks about the part of CSN that has been useful in her recovery. She reportedly derives a sense of better well-being from the connections she has made on the site. It is this “connection” to other survivors that others claim is responsible for their hope. P3 talks about “camaraderie”, P2 talks about hope from fellow members after another cancer diagnosis,

and P8 states that “humor matters” as he talks about the role online support can play in treatment and recovery. P8 states: “Some people when they come to CSN, in particular, and, most particular, to the Chat Room, are delighted that there is humor being slung around, even amazed.”

P2 also feels it is “humor [that] can help dispel the feelings of doom and gloom that can overcome you at times,” creating a better sense of well being. As illustrated in Table 3, humor, as well as hope, were each selected by 86%, or 6 participants and as an attractive quality of online support. It is evident that they are each important themes to the research participants as they each mentioned hope or humor in many of their responses.

Feeling helpful

Feeling helpful is another theme that can be found throughout the research data. P4 captures this theme of a need to feel and be helpful by stating, “Having answers and providing support is what makes this journey bearable.” P8 follows this up by saying, “The site has served two fundamental purposes for me...it made me feel useful and contributory in the way I have been able to help others over the last few year...[this] made me stronger and happier.” Other participants supported this notion as well. In fact, all seven participants selected ‘helping others’ as an attractive quality to online cancer support (Table 3). P1 stated that it was not about what she hoped to get, but rather hoped to give, by becoming a CSN member. She said, “It is my desire to use that knowledge to help others who may be struggling or who can benefit from the knowledge I have.” P8 also stated that his initial “hope was to help others who were going through the same thing I had gone through.”

This theme of helping is strong in the data. Being able to share and give back is what makes the site useful to users. It gives members a sense of being needed and useful, during a time, or after a time, when they have been needy and helpless. It also adds to the sense of community through sharing firsthand experiences.

No time constraints

On Table 2, six participants selected the ‘24 hour, 7 day a week, 365 days a year’ availability as an attractive quality of online support. In fact P4 felt that being “able to turn to this support group on a 24/7, 365 basis is great for anyone taking the cancer journey.” P3 describes a time when she turned to the site over twenty times a day, at all hours. This is a quality that other forms of support cannot match. Many support groups have time constraints and large lag times between meetings. These participants found the lack of time constraints a strength to online cancer support.

Anonymity

The theme of anonymity was selected by two research participants in Table 3. This is not a prevalent theme, but it is a unique quality of online cancer support. P6 found the anonymity very valuable. She stated, “You are anonymous. If I ask a personal or embarrassing question, no one is going to know it's me asking.” P6 also found “lurking” useful. Lurking in online forums, refers to reading only, rather than actively participating. P3 has found that she has “developed friendships with strangers that have lasted.” She and many others are friends with people even if they may not know their real names, which may be helpful. There is not enough data to thoroughly address the appeal of being anonymous.

How do participants say online cancer support groups affect their day-to-day relationships in their family life, as well as other relationships?

Relationship with spouse

Participants told stories and described situations where the relationship with their spouse was affected in both positive and negative ways, noting more positive effects than negatives due to their online support group use. Participants also shared many stories about how the cancer diagnosis affected their relationship with family members, friends and coworkers, but they did not talk about how online support affected those relationships. The themes that emerged when looking at the partner relationships were: feelings of jealousy at first/sharing online community with partner, and partners becoming caregivers. A few of the participants did however, talk about the use of the CSN impacted the relationship they had with their doctors. The theme that was noticed in this relationship was fear from doctors about patient use and the usefulness of online support on the doctor-patient relationship.

Feelings of jealousy at first/Sharing online community with partner

The theme of jealousy appears in the data as participants address in more detail how their online use has affected their marriage. When participants log onto the site, they are not turning to their partner. P7 found that as she first started turning to online cancer support, her husband was hesitant about her use. She wrote:

I think at first, he wondered who I was chatting with. I think he knew that talking with other people with cancer helped but he may have been guarded at first. I believe that a spouse can feel left out if they haven't had cancer. They don't know what you are going through while the chat support people do.

P7 was not the only participant to mention jealousy as having a negative effect on their relationship. In fact P3 found that there was a "little jealousy I think. I was constantly on the chat room and this bit into our alone time." P1 did not report that online cancer support use had a negative effect on her relationship with her husband. She stated:

Well I suppose in the beginning my husband was surprised at my desire to go to CSN, however he understands it and fully supports it. I of course do not choose to go to CSN rather than spend time with him so it does not directly affect him.

P3 later added that two negative effects of the site on relationships are jealousy and that it is time consuming. P3 also states that "at the same time" logging onto the site "helped because these folks had the ability to raise my attitude and I always felt better for it and then that would spread over to our time together." P7 writes about her husband being guarded:

At first he was guarded because my husband and I met through a chat room. He knows how that can work. I know he knows I love him very much but when I was chatting more often than I do now, he might have not liked it at first. He never told me that, though.

It is interesting to note that, while she is not really sure if her husband was guarded, P7 addressed it over two years later, suggesting that perhaps he was guarded. Both P3 and P7 felt like their partners became less jealous as the participants started to feel better, and started including their partner in chat room banter. As time went on, P7 found that she would:

...discuss all the people in the chat room to him and told him what cancers they had or how funny they were, etc. And, I would mention my husband in the chat room. Now, it isn't a problem at all. I'm very open with him and he is comfortable now.

P8 also comments on how much time he is spending on the site, which is then time he is not spending with his family. He notes this can take a toll on his marriage, stating:

In my case, I was there [on the CSN], I am there, to help. That means that I spend a lot of time there, and that has a negative impact at times, because it takes away from time with family. Most people though, do not spend that kind of time on the site.

However, P8 also shares the chat room with his wife: “I think my wife would agree it has been a positive thing. These other people, my site friends, have become true friends, a number of them, and my wife even knows who they are, a number of them.” P6 has not noticed a negative impact of online use on her marriage relationship, but she did state that she shares “things people have posted about with my spouse.” Perhaps it is sharing with one’s spouse that alleviates the unknown, and shows the CSN member’s partner that their cancer patient is getting help and support.

P8 reported an estimated 28 hours per week online, and refers to it as an addiction of sorts. He writes:

You can develop what I can only describe as an addiction, depending on your needs. In my case, I was there, I am there, to help. That means that I spend a lot of time there, and that has a negative impact at times... Maybe the one extra thing, in my case, is that it disrupted my sleep cycle. I began to sleep during the day and go online at night, not unlike some weirdo seeking porno sites. Except that my addiction was the cancer support site. I wanted to help.

The time P8 spends online not only takes away from his family, but feels like an addiction to helping, a need to be useful; this can take a toll on a relationship. While P2’s wife encouraged him to go to the site to express his feelings, P2 talks about the negative impact online cancer support has had on his relationship with his wife. He does not address sharing the site with his wife, nor does he discuss the decrease of negative impacts with time or sharing with his spouse. P2 writes:

I got yelled at a lot for the time I was spending in the chat room and talking to the people in there. I think my wife at times felt left out because she felt I should be talking to her about these things and not spending so much time in chat. But as much as she tried to help there were feelings she just could not understand.

Jealousy may be another issue. The majority of users online are women, as represented in this study. P8 talks about potential jealousy due to the opposite sex, as well as time spent online:

I will say this: there is some jealousy, or potential jealousy, that you are spending time with other people online, some of the opposite sex, and in any event, taking up time you could be spending with spouse and family. That potential is always there.

Most of the participants noted the theme of jealousy in the beginning of their membership, as it related to their marriage partners. The participants seemed aware of the time it takes to be an active member of the site, and many addressed this time away from their partner by sharing the stories of other members with their partners.

Partners becoming caregivers

A couple of the participants mention the idea of their partners becoming caregivers, as they discussed the impact of diagnosis and online support group membership. It appears that through online support the CSN members began to reconceptualize their partners as caregivers.

This theme is noticeable when participants addressed that ways their partners were helpful and caring in their battle with cancer. P3 wrote:

My diagnosis brought me closest to my husband. He was terrific and did his very best to study NHL and help me make sense of things... I ALWAYS knew when he was worried. He would make arrangements from out of town to make sure I was eating... My husband did get on the ACS site to help me find information as the questions arose. He researched diet, and rest, cleanliness. We made all kinds of changes to our routines to make sure I stayed healthy.

P3's husband took an active role in her treatment and recovery by becoming informed, making changes and turning to the CSN site himself. Similarly, P7's account of how diagnosis and online support group use affected her relationship with her husband, she wrote:

My husband (I have no kids) was my best caregiver. He would gather information for me. Tell me what to read or what not to read on the internet. Go with me to my appointments. Remember the things I couldn't or ask the questions I'd forget. Hug me even if I'd get mad or upset.

Support and attention from their husbands gave them a sense of being cared for during treatment and recovery. They both suggest that online resources helped their husbands better support them.

Relationships with other family members

While many of the participants focused mainly on their spouses, those that did talk about their family members give stories of support and closeness. P2 talks about turning to his online family for support and being able to depend on them. P8 attributes his learned patients from the site as having an impact on his relationships off of the site.

Doctor-patient relationship

One participant addressed the impact of CSN use on her doctor-patient relationship. One negative aspect or drawback of online cancer support is concern that patients will rely too heavily on information online instead of from their doctors and this could affect their treatment and recovery. P3 wrote:

My doctor I think was a little skeptical because he worried that I was looking too much to the internet for information, however with time he began to understand that I was getting good vibes. If something came up where I had questions that came up from someone in chat I always confirmed with him the next visit.

It seems for some, at least, the online resource can add to their relationship with their doctor, treatment and recovery. P6 also used information she learned online to discuss treatment options with her doctor. P6 wrote:

Someone mentioned she didn't need chemo-therapy because she had a low Oncotype score. I'd never heard about it, I asked in a post and several people explained it to me, as they had understood it from their doctors. I asked my doctor, she sent my tumor to be tested, and I also have a low score and will not need chemo-therapy.

These participants of online cancer support groups did turn to other forms of support. Participants in this study ranked types of support they have used in addition to CSN. They were asked to rank these other supports in order of importance to them, 1 being most important and 9 being least important. Five participants completed this survey question. Their answers are as follows:

Table 5-Non-CSN support ranked in order of importance (per the participants' actual responses)**P1**

- 1-Family support
- 2-Friends
- 3-Church
- 4-Charities

P3

- 1- CSN
- 5- "in person friends"
- 8- NHL email group

P4

- 1- Church and fellowship
- 2-Cancer specific support group(s)
- 3-Turning to family for support
- 9-Face-to-face support group(s) run by a professional facilitator

P7

- 1-Family support
- 2-Cancer specific support
- 3-Friends
- 4-Taking advantage local/national charities

P8

- 1- Family support
- 2- Friends' support
- 3- Therapy
- 4- Magazines

CHAPTER V: DISCUSSION

Introduction

This qualitative research study was intended to explore the meaning of giving and receiving support for online cancer support group members, the benefits of using this mode of communication and to understand the effects of online use on day-to-day relationships of users. This study endeavored to identify themes and construct a story of the participants' experiences. The following chapter will compare findings from the research on online cancer support groups to the findings in this study's data.

Summary of Findings

The themes identified in this study tell a story. They tell a story of cancer as a journey that does not have to be walked alone; one filled with support, honesty, hope and humor. The themes herein describe a community that is understanding and accepting of fears and concerns, as well as loving and caring in a way that only fellow cancer survivors can relate to. These participants represent the voice that has been missing from the research of online cancer support.

Links to the Current Research

Aside from the goal of representing the voice of the online cancer support group member, another goal is to compare this data to the current research on online cancer support groups. When the results of this study are compared with the studies referenced in the literature review, there are interesting differences and similarities that become apparent.

As stated in chapter two herein there is no disagreement about the fact that a cancer diagnosis is extremely stressful for people and their families, nor is there disagreement around the difficulty and complexity of treatment options which can be confusing for patients and families to understand (Anderson & Klemm, 2008). However there is disparity about whether internet cancer support groups can address the needs of patients and alleviate the confusion caused by a cancer diagnosis. Before professionals make a decision they need to be mindful of the discrepancies between the two groups in Klemm and Hardie's (2002) study. In fact, the six of the seven participants in this study stated that their needs were met and surpassed. The participants talked about a sense of community, friendships that are dependable and a connection that is strong and uncommon. P3 said it best:

I truly believe that every cancer patient be advised about this site by their doctors from the very first visit. I think this part of cancer is the very best way to get through moment by moment. It is a critical part of recovery to help ease the terror of cancer. I think every member of the families need to be involved here too. I cannot imagine living through this experience without it. I got the kind of support that I was missing from some of my doctors.

The current research lacks the voice of these users, who are turning to online cancer support at growing rates.

Advantages of Online Cancer Support Groups

The research literature describes many reasons people turn to online cancer support such as 24-hour availability, convenience, up-to-date information, patient friendly formats and anonymity, better coping, lower rates of depression due to connection with others (Anderson & Klemm, 2008; Blank & Adams-Blodnieks, 2007; Beaudoin & Tao, 2007). Others have found that this mode of connecting with other people can be empowering for patients (Anderson & Klemm, 2008; Radin & Landzelius, 2006). As participants told their stories and themes were identified, all of these "reasons" mentioned in current research were also discussed by this

study's participants.

A prominent researcher in the field of online cancer support talks about nine themes that she finds repeatedly in her research: information giving/seeking, personal opinions, encouragement/support, personal experience, thanks, humor, prayer and miscellaneous (Klemm, et al. 1998; Klemm, et al., 1999; & Klemm, et al., 2003). This study found some of these themes as well, such as information giving/seeking, personal opinions, encouragement/support, personal experience and humor, as well as hope, a sense of community, normalcy, connection, safety, being helpful and honesty.

There are also themes related to the users' interpersonal relationships that do not seem to be represented in the literature. These would include partners' feelings of jealousy, sharing the online community with the partner, and partners becoming caregivers. This data does not address the impact of online cancer support on other family members, friends and coworker relationships.

The literature has found that anonymity makes online support groups attractive to those less inclined to turn to traditional support groups. This study supports this finding. In fact, when asked whether or not the participant tried face-to-face support group(s) run by a professional facilitator, six out of seven never tried one and the one that did try face-to-face support didn't find it useful (Table 2). This suggests that online cancer support group members may not be inclined to use face-to-face support groups.

The current research does not address charities, magazines, or church and fellowship as cancer patient resources. These may be important factors to consider as forms of support for cancer patients and their families.

The current literature considers the act of typing one's thoughts, feelings and comments as being therapeutic (Finfgeld, 2000). The research in this study supports this finding. As members communicate via email and online chat about the process of their cancer journey, a healing process emerges. These participants address feeling terrified and fearful, and demonstrate movement towards acceptance and information gathering, then eventually to treatment options and effects, and for many recovery and living afterwards. The online mode of communicating seems emotionally healing. White and Dorman (2001) found that "online communication allows members to think carefully and deliberately before sending messages or responding to postings" (p. 702), findings supported by this study. In addition to these advantages, the possibility for online support groups to have endless numbers of members is an advantage over face-to-face support groups which are limited in their numbers (White and Dorman, 2001). This was supported by one of the current participants as a benefit, as she felt that the large number of online users led to more brainstorming and collaboration.

The current study supports past research that found benefits for caregivers, family members and friends as well as patients and survivors who join online cancer support groups (White & Dorman, 2001). Many of the participants talked about their partners logging on and finding support and information for them, and that they found this helpful. Perhaps these partners gained perspective of what it is like for the patient, and perhaps they too needed to gain perspective and information in order to face a cancer diagnosis. The participants found this act of logging on by their partners to be supportive in their journey.

Disadvantages of Online Cancer Support Groups

Researchers disagree about whether online groups run without professional facilitators are safe (Anderson & Klemm, 2008). When the consumers in the current study were asked, a

theme of safety emerged, safety to discuss feelings and fears openly, safety to ask embarrassing questions and safety to be vulnerable and honest.

Other disadvantages named in previous research, were not mentioned at all by the current study. Previous research noted disadvantages in the cost of the equipment, high volume of electronic mail, lack of professional facilitator, one-on-one personal contact that discourage participation for some, unreliable information, lack of a phone line for modem connection, limited access for the illiterate and the visually impaired (Klemm, et al., 1998). All of the current participants had access to the internet, a computer and could type and read. This study's participant selection may have naturally excluded illiterate and visually impaired. Other studies cited the lack of nonverbal and visual cues, highly active postings which require a great deal of attention, possibility of poor or inaccurate information, postings that criticize health care professionals which could delay users from seeking medical help, lack of guidelines and professional facilitation, exacerbating internet addiction problems, increased social isolation and lag time between posting and receiving a response as disadvantages of online cancer support groups (Finfgeld, 2000; van Uden-Krann, et al., 2008a).

When the current participants were asked about the negative results of their online cancer support group membership, many addressed the issue of the amount of time it requires to be an active member and how it can take a toll on their relationships offline. The factor of internet addiction was mentioned as a concern by one of the current participants. P8 stated:

Maybe the one extra thing, in my case, is that it disrupted my sleep cycle. I began to sleep during the day and go online at night, not unlike some weirdo seeking porno sites. Except that my addiction was the cancer support site. I wanted to help. I am sure there is a name for that.

However, as for isolation, the current participants addressed feeling more connected to their cyber community and their spouses than ever. None of the other disadvantages mentioned in previous research were specifically addressed, nor were they mentioned by any of the current study's participants.

Depression

The issue of depression as discussed in the literature review was not directly addressed in this study. However, participants stated that they felt better, felt connected, found hope, found understanding, normalcy, acceptance, started to heal and felt helpful and needed. These are not characteristics of depression. The research exploring depression and online cancer support suggested that traditional support groups could help people function with their disease better than those who primarily turned to online support (Klemm & Hardie, 2005); this study does not support that finding.

In fact White and Dorman (2001) found that writing reduces symptoms of depression, and that the act of group members sharing their experience of cancer and diagnosis through poetry, drawing and storytelling can increase self-esteem and be helpful towards recovery. Five out of seven of current study participants noted the helpfulness of the CSN expression galleries, including art work, poetry, and biographies. These finding support past research.

Effects on Doctor-Patient Relationship

The two participants that addressed using the site to communicate with their doctor support the past research that explored benefits to the doctor-patient relationship. van Uden-Krann, et al. (2008b) found that online cancer support groups users report feeling more informed and confident about their physicians, treatment and social interactions.

Study Limitations

There are a number of factors that limit this study. One of these limitations was that by using an online survey as opposed to face-to-face interviews the researcher was unable to explore ideas in greater depth. Gathering data in person or over the telephone might have led to a greater depth of information.

The limitation of only recruiting from the CSN left out hundreds of other sites, and access to hundreds of other online cancer support users. Having a more diverse online environment might have provided a more diverse and rich story.

Another limitation to this study is the sample size. A larger participant group, might have added to the data, or continued to strengthen the data already provided by the first seven participants. It also might have provided some diversity in the form of race and sex. Five of the participants are Caucasian and two are unknown; five are female and two are male. A greater variety of information might have emerged from having a more diverse group of participants.

A disappointing limitation is a missed opportunity. Due to the screening criteria of 'being in a relationship', this study missed the opportunity to talk to CSN members whose spouses left due to their cancer diagnosis or died due to their own cancer. It may have been helpful and interesting to include the meaning of giving and receiving support and benefits of the use of online support for this "missed" population. Lack of communication with the spouses of these seven participants is also a limitation. Comparing the caregiver's perspective of online support group use for the current participants could have really enriched the data. It would be helpful and interesting to explore how caregivers describe the benefits of online support for their cancer patient and how they would describe the effects of their patient's online support group use on their relationship. This would add to the current literature, the caregivers may have a different experience than the CSN member.

Clinical Implications

The findings in this study are significant to the field of Marriage and Family Therapy. With the large number of people affected by cancer in America each year, it is a safe assumption that therapists will have clients who are affected, either directly or indirectly. Clients diagnosed with cancer, or who have family members diagnosed with cancer will benefit from online resources. Having a therapist work through the extremely volatile emotions can be useful, but cannot take the place of talking with someone who has that shared cancer experience. Family members may also be struggling with the diagnosis of their family member and therapists can work with this population in order to ease the confusion and stress of a cancer diagnosis. Therapists can also refer these family members to online cancer support groups for information, support and understanding. In fact, some of the current participants stated that the online cancer support groups is a cheap form of therapy, or acts in place of therapy for them, but online support may be more effective in conjunction with therapy.

This study suggests that clinicians may not know or understand the cancer patient's experience. To keep this perspective could be useful for therapists when working with this population, so to avoid minimizing their experiences or feelings, and being mindful to remain empathic and curious. Clinicians tasked with helping clients feel supported, normal and connected; referring them to an online site is one of many options for doing so. Realizing that they were not alone in their cancer journey was an important theme from the participants' stories that could be useful when working with these clients.

It would also be important for clinicians to realize that cancer happens to a family, not just a family member. Helping the family cope with the effects of this disease could also be a

step toward healing. Working with family members to understand the disease's effects, as well as the fears and worries and other feelings that can accompany a cancer diagnosis would also be a supportive intervention.

Research Implications

It is obvious that the work in exploring online cancer support groups is far from exhausted. While this study brought up themes that support existing data, it also brought up themes that support and do not support past findings. Further studies that explore the benefits to clients who are in therapy to deal with the aspects of cancer (as patients or caregivers) and are accessing online support as well are needed.

Further studies that explore the effects of online cancer support for those who lost their partners to cancer or who left because of cancer would also be an addition to the current research. A richer story and deeper understanding of the meanings attributed to online cancer support are needed. This should include a more diverse research population.

The third implication is to explore the benefit of online cancer support on the caregivers, from a qualitative perspective. Considering the impact of a cancer diagnosis on the entire family system, how could family members benefit from seeking online support for themselves as well as their relative.

Self of the Researcher

This writer is a member of the CSN site as a caregiver, as well as the daughter of a CSN active member. These relationships helped develop the interest in this phenomenon of online support as intriguing due to the personal connection to CSN and cancer. Being mindful of this while reading and coding the data, this researcher took steps to distance herself from both her father and the CSN site as a member. These steps included: not speaking with her father during the data collection process, aside from sending him the recruitment letter via email and not logging on to the CSN site during the data collection after posting the recruitment letter. Though distance was created, it is impossible to say that this personal connection did not influence coding or theme development. However there were some surprising themes that emerged from the current data: stronger partner relationships due to online cancer support group membership; the enormity of needing to feel helpful to others; the positive effect membership had on some of the doctor-patient relationships; the sense of community current participants addressed; that many participants felt that the membership was a good substitute for therapy and their descriptions of their experience of cancer as a journey.

As the participants stated, I cannot know what having a cancer diagnosis is like, I do know how to access support for family, friends or myself if need be. That is a comforting thought. I do not claim to understand the true feelings or fears of cancer survivors, but I am mindful of that and that leaves room for curiosity when working with this population.

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Appendix A: Recruitment/Consent Letter**Online cancer support groups: What the consumer has to say**

Eric McCollum-Primary Investigator

Erin Rapach-Co-Investigator

My interest in conducting this study is twofold. As I read through the current literature and research exploring online cancer support, it is evident that the voice of the user is missing. I would like the opportunity to share your voice and your thoughts, as active members in an online cancer support group. I am trying to recruit eight to ten active online cancer support users.

I also have a personal connection with this study; my dad is a cancer survivor and active member in the Cancer Survivor's Network. I am also a caregiver user on the site. As my dad rode the roller coaster of emotion that often comes with cancer diagnosis, treatment and recovery, he turned to his online community.

I know how the use of the online Cancer Survivors Network affected my dad, but professionals are still unclear about what the meaning of giving and receiving support has for users, how use affects partners and family members of users, and how use affects the day-to-day lives of users. I turn to you as experts in the area of online cancer support group members.

In order to participate in this study you must be at least eighteen years old, must be living with a significant partner, must have been diagnosed with any type of cancer and can be in any stage of treatment or recovery, and must consider yourself an active member of the online group.

If you are interested in sharing your voice, please contact me at vt.research@hotmail.com I have an online 7-question screening questionnaire, this will take ten to fifteen minutes, and a link to an online research survey, this will take thirty to forty-five minutes, that I would like to share with you.

Potential risks include writing about difficult issues in your life and the sharing of personal information. At the end of the survey, if you are invited to contact the researcher if responding to the survey upset you in any way. A list of local resources will be provided. Neither the researchers nor the University have funds to pay for such services, and the costs of such services must be paid by the participants.

The benefits of conducting this study will add to the current research providing the voice of the user as well as adding new knowledge about a widely used, but little understood way to provide online social support to cancer patients.

No promise or guarantee of benefits have been made to encourage you to participate. There will be no compensation for participating.

To guarantee the utmost confidentiality, you will be protected by a coding system for your email address, which will be locked away separately from surveys and will only be accessible by the researcher, as the researcher I promise not to divulge that information.

It is possible that the Institutional Review Board (IRB) may view this study's collected data for auditing purposes. The IRB is responsible for the oversight of the protection of human subjects involved in research.

You are free to withdraw from the study at any time without penalty. You are free not to answer any questions or respond to experimental situations that you choose without penalty.

I look forward to hearing from you.

Sincerely,
Erin Rapach

Appendix B: 7-question Screening Questionnaire

Please answer the following as they apply to you:

Are you at least 18-years of age?

- yes
- no

Do you live with a significant other?

- yes
- no

if yes, for how many years:

What type(s) of cancer have you been diagnosed with?

How long ago were you first diagnosed with cancer?

When was your last diagnosis?

How would you describe your current stage of treatment?

Do you consider yourself an active member of the Cancer Support Network?

- Yes
- No

Appendix C: Research Survey Questions

1. When you first joined this online support group, what did you hope to get from it?

Those expectations were:

- Not Met
- Partially met
- Met
- Surpassed
- Not sure yet

Comments:

2. What part, if any, has the online support group played in your dealing with and/or recovering from cancer?

3. Please check other forms of supports you have used or tried during your treatment and/or recovery and indicate its usefulness:

Face-to-face support group(s) run by a professional facilitator

- Tried it, it wasn't useful
- Tried it, it was useful
- Currently using it
- Didn't try

Face-to-face support group(s) not facilitated by a professional

- Tried it, it wasn't useful
- Tried it, it was useful
- Currently using it
- Didn't try

Cancer specific support group(s)

- Tried it, it wasn't useful
- Tried it, it was useful
- Currently using it
- Didn't try

Turning to family for support

- Tried it, it wasn't useful
- Tried it, it was useful
- Currently using it
- Didn't try

Turning to friends for support

- Tried it, it wasn't useful
- Tried it, it was useful
- Currently using it
- Didn't try

Church and fellowship

- Tried it, it wasn't useful
- Tried it, it was useful
- Currently using it
- Didn't try

Taking advantage local and/or national charities and/or services

- Tried it, it wasn't useful
- Tried it, it was useful
- Currently using it
- Didn't try

Therapy

- Tried it, it wasn't useful
- Tried it, it was useful
- Currently using it
- Didn't try

Please list any others not previously mentioned:

4. Of these additional support types you used, rank them in order of importance to you (1 being most important, 9 being least important).

5. Compared to these supports what is unique about the online support group, Cancer Survivor's Network?

6. What qualities of online support do you find most attractive?

- 24-hour, 7-days a week access
- Anonymity
- Humor of fellow users
- Hope
- Site Accessibility
- As a substitute to therapy
- Meeting people with different cultural and/or racial backgrounds
- Access to treatment technologies and techniques in different states and countries
- Finding people who can understand your experience and are willing to talk about it
- Social support
- Assisting others
- Expressions gallery (art work, poetry, biographies, etc.)
- Treatment support (non-online support like through phone calls and mail)
- Advice about treatment options from medical professionals
- Advice about treatment options from fellow cancer survivors and caregivers
- Recommendations of resources (film, books, articles, etc.)
- Research updates
- Discussion boards
- Chat rooms
- CSN newsletter and announcements
- CSN e-mail
- Information about local cancer specific resources
- Information about national and international cancer specific resources

other:

7. Would you recommend this use of online support to others?

- Yes
- No

8. If so, to whom would you recommend this site to? (please check all that apply)

- Those fearful of recent diagnosis
- Those in treatment
- Those in post treatment
- Long term survivors
- Caregivers

other:

9. How would you describe the role online support can play in their treatment/recovery?

10. Tell me about a specific time when turning to the online support group was useful to you; what was the situation and how was online support useful?

11. How did your initial cancer diagnosis affect your relationship with your spouse? Other family members? Friends? Co-workers?

12. To what extent, if any, did the use of online support help or hurt you and your spouse's dealing with the initial reaction to your diagnosis? Other family members? Friends? Co-workers?

13. To what effect did it help or hurt your relationships as you continued using online support?

14. Some online users describe how the use of online support has affected their family life in both positive and negative ways. In what ways has your use influenced your relationship with your spouse in positive and negative ways? (please list those that you have not previously mentioned) With other family members?

15. Please answer the following demographics:

Age:

- 18-29 30-39 40-49 50-59 60-69 70-79 80-older

Sex:

- Female Male

Race:

In what state do you live in?

Length of online Cancer survivor's Network (CSN) membership:

Estimated number of hours you log onto the CSN weekly:

Since you have become involved with the CSN have you used the internet

- more the same less, than you did before?

Appendix D: Thematic Mapping

Stage one of thematic mapping: Identifying codes

- 1 When you first joined this online support group, what did you hope to get from it?
 - hoped to be able to help
 - information/answers
 - unlimited availability
 - Was unsure what to expect
 - Support
- 2 What part if any, has the inline support group played in your dealing with and/or recovering from cancer?
 - understanding from those with a shared experience
 - feeling helpful towards others
 - feeling normal
 - better well being
 - healing
 - receiving support
 - relief from nightmare
- 3 Compared to these supports what is unique about the online support group, Cancer Survivors Network?
 - understanding from other members
 - support from caregivers
 - anonymity
 - honesty
 - ability to talk openly about death
 - sense of community
 - acceptance from members
 - unlimited availability of contact
 - information and knowledge provided
 - helping others
- 4 How would you describe the role OCSG can play in treatment and recovery?
 - you are not alone
 - there is humor
 - feelings of normalcy
 - honesty
 - hope
 - helps with cancer journey
 - information
 - understanding
 - support/shared experience
 - love
 - safety
- 5 Tell me about a specific time when turning to the online support group was useful to you; what was the situation and how was online support useful?
 - see specific stories for themes
- 6 How did your initial cancer diagnosis affect your relationship with your spouse? Other family members? Friends? Co-workers?
 - intimate relations were negatively affected
 - relationship is stronger
 - partner became caregiver
 - family was supportive
 - grew closer to some family members
 - other family members cutoff
 - had to help mom feel better about guilt
 - some feel sorry for you
 - relationships were good
 - some friends took an active role in treatment
 - supportive
 - did not lose friends due to cancer
 - developed stronger friendships
 - some feel sorry for you
 - wanted to help but didn't know how
 - distant
 - lost golf buddy with second diagnosis
 - some feel sorry for you
 - great immediate support
 - no change in relationships
 - negative, non-supportive reactions
 - To what extent, if any, did the use of online support help or hurt you and your spouse's dealing with the initial reaction to your diagnosis?
- 7 Other family members? Friends? Co-workers?
 - some didn't use it at first
 - some stated that it didn't help the initial reaction
 - some stated that it didn't hurt the initial reaction
 - partner was jealous at times

spouse turned to online support
improved the relationship
spouse sent me to site

shared about other group members with partner
improved the relationship
improved the relationship
improved the relationship

family
friends
coworkers

8 To what effect did it help or hurt your relationships as you continued using online support?

helped
served as conversation starters
shared postings with partner
didn't hurt at all
wife just couldn't understand feelings, chat group does
didn't help
negative effects on relationship with spouse
turned to wife
doctor was skeptical of use but came around

Some online users describe how the use of online support has affected their family life in both positive and negative ways. In what ways has your use influenced your

9 relationship with your spouse in positive and negative ways? (please list those that you have not previously mentioned) With other family members?

spouse

balance has occurred over time between time online and time with partner
no affect
sharing experiences with partners has been useful
partner has been supportive
internet has disrupted sleep cycle and feels like an addiction
partner has been jealous of time spent online
spouse was surprised at partner's desire to log on
partner was guarded at first
boost in attitudes has been positive
camaraderie has been positive
knowledge/information has been positive

Stage two of thematic mapping: Noticing themes

| | | | | | |
|--------|---|--|---|---|-------------|
| themes | feeling helpful towards others unlimited availability of contact information/answers understanding from those with a shared experience Support feeling normal better well being support from online caregivers anonymity honesty sense of community acceptance from members humor hope important part of cancer journey | helping others unlimited availability information and knowledge provided understanding from other members receiving support feelings of normalcy boost in attitudes has been positive ability to talk openly about death you are not alone ability to share fears healing partner was jealous at times intimate relations were negatively affected improved the | hoped to be able to help information understanding support/shared experience a lot of non cancer talk honesty camaraderie has been positive ability to share feelings relief from nightmare some stated that it didn't help the initial reaction internet has disrupted sleep cycle and feels like an addiction some stated that it | knowledge/information has been positive love partner was guarded at first spouse was surprised at partner's desire to log on helped | didn't help |
| spouse | negative effects on relationship with spouse relationship is stronger | | wife just couldn't understand feelings, chat group does partner has been jealous of time spent online didn't hurt at all | | |

| | | | | |
|-----------|---|--|--------------------------------------|---|
| | | relationship | didn't hurt the initial reaction | |
| | | balance has occurred over time between time online and time with partner | no affect | partner has been supportive |
| | partner became caregiver shared about other group members with partner spouse turned to online support spouse sent me to site | turned to wife shared postings with partner | served as conversation starters | sharing experiences with partners has been useful |
| family | family was supportive | grew closer to some family members | online use improved the relationship | |
| | other family members cutoff had to help mom feel better about guilt some feel sorry for you | | | |
| friends | some friends took an active role in treatment | relationships were good wanted to help but didn't know how some feel sorry for you | did not lose friends due to cancer | developed stronger friendships |
| | supportive lost golf buddy with second diagnosis online use improved the relationship | | distant | |
| coworkers | great immediate support no change in relationships negative, non-supportive reactions online use improved the relationship | | | |
| Doctors | doctor was skeptical of use but came around | | | |

Stage three of thematic mapping: Grouping the themes

1) How do participants describe the meaning of giving and receiving support on the online cancer support group?

it means you are not alone
 it means what you are feeling and experiencing is normal, and there is a lot of non cancer talk
 honesty: you could be honest and receive honesty around cancer, fears and death
 it means there is hope, by talking to survivors who have "walked the walk"
 It means there is a process in this cancer, so there are fears, healing and relief from the "emotional nightmare"
 It is a life saver to be able to help others by providing support, understanding and acceptance and also in receiving these things
 It means that there are people in this community that love you
 It means that this is a safe place to be angry, scared, sad, happy and to laugh

2) How do the participants describe the benefits they are getting from the forum or mode of communicating?

understanding/acceptance
 support from other patient's caregivers
 better well being due to hope and humor
 feeling helpful/ability to receive and give support, purpose, needed
 no time constraints
 information, answers, first-hand knowledge
 anonymity

3) How do participants say online cancer support groups affect their day-to-day relationships in their family life, as well as other relationships?

spouse negative effects on relationship with spouse
 relationship is stronger
 spouse turned to online support
 partner became caregiver
 shared about other group members with partner
 spouse sent me to site

family Data was directed towards the affects of a cancer diagnosis, not online use, on this relationship

| | |
|-----------|---|
| friends | Data was directed towards the affects of a cancer diagnosis, not online use, on this relationship |
| coworkers | Data was directed towards the affects of a cancer diagnosis, not online use, on this relationship |
| doctors | doctor was skeptical of use but came around |