A DESCRIPTIVE STUDY ON COMMUNICATING ABOUT CANCER ONLINE: UTILIZING COMMUNICATION FOR INFORMATION AND SUPPORT IN AN ONLINE ENVIRONMENT

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Abstract

THESIS: A Descriptive Study on Communicating about Cancer Online: Utilizing Communication for Information and Support in an Online Environment

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People with a chronic illness like cancer often use the Internet to participate in online health discussions and connect with people with similar medical conditions through an online community. The purpose of this study was to explore how people affected by cancer utilize communication in an online community to access information, advice, and support. This research examines the messages of a discussion forum within an online cancer community using content and thematic analyses. This study finds that people within an online cancer community (1) give/seek information more often than they give/seek emotional support, (2) give information and emotional support more than they seek them, and (3) utilize storytelling within a majority of messages.

Keywords: cancer, online community, online cancer community, cancer-related online community
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CHAPTER ONE: INTRODUCTION

Most people do not imagine that cancer will ever become a part of their lives. Yet, cancer remains the leading cause of death worldwide, accounting for 7.6 million deaths (13% of all deaths) in 2008. Cancer-related problems will continue to rise, as the total number of cancer deaths per year is projected to hit 13.1 million by 2030 (World Health Organization [WHO], 2012a).

In the United States alone, nearly 12 million people have a history with cancer. Over 1.6 million more are expected to be diagnosed with cancer in 2012, while more than half a million will die (American Cancer Society, 2012). However, having access to health information and support online can be used for cancer prevention and management. According to the WHO (2012a), 30% of all cancer-related deaths could be prevented by changing or stopping key risk factors, including tobacco and alcohol use, diet, and air pollution. How do people gain access to this information?

Doctors, nurses, and other healthcare providers remain the top source of health information in the United States, but doctors are not always available to answer questions. A rising number of people rely heavily on the Internet. Eight out of every 10 Internet (59% of all American adults) users look up health information online (Fox, 2011c). People use the Internet for a variety of health-related reasons, including reading personal commentary about a health issue; watching videos about a medical issue;
searching for people with a similar medical condition; reading reviews about medical treatments and drugs; and reading rankings of doctors and hospitals. In fact, searching the Internet for health information has become the third most common Internet activity, other than checking e-mail and using a search engine (Fox, 2011c).

![Figure 1: Estimated number of new cancer cases per state in 2012. American Cancer Society, Cancer Facts & Figures 2012.](image)

Even doctors and other healthcare providers feel the pressure to go digital. Switching from paper to electronic medical records is expected to save the healthcare industry billions of dollars by reducing administrative workload and unnecessary medical tests. The government has offered billions in funding to encourage medical institutions to switch to electronic records (Lohr, 2012). With information and medical records moving
online, many doctors assume that patients have access to the Internet. That assumption can be dangerous to the 25% of American adults who do not have access to the Internet. Dolan (2011) has stated, “That assumption could lead to patients missing out on important information, or being unable to access certain tools. So experts and analysts recommend that doctors start asking their patients whether they have Internet access -- or whether a loved one or advocate does,” (para. 5).

Going online for health information can be especially useful to people with a chronic disease like cancer. People who access health information online often become more involved in the management of their disease, which can lead to many health benefits. According to Hibbard and Cunningham (2008), “These include maintaining good diet and exercise practices; self-management behaviors, such as monitoring their condition and adherence to treatment protocols; and health information seeking behaviors, such as asking questions in the medical encounter and using quality information to select a provider,” (p. 2). The Center for Studying Health System Change has found that people who have cancer are more likely to be actively engaged in their healthcare than people with other chronic illnesses (Hibbard & Cunningham, 2008).

**Statement of the Problem**

Time is often a problem for people who rely on healthcare providers as their primary source of health information. Cancer can enter a person’s life and take over their family in ways they cannot even imagine. Harter (2012) has said, “Living with cancer and its treatment requires sustained and coordinated efforts to handle myriad demands that are physical, relational, and financial in nature. Family members, in particular, are swept up in a maelstrom of chaotic life events and role changes,” (p. 3). In order to
handle these hectic and time-consuming changes, people affected by cancer often turn to the Internet because of its convenient nature, especially when doctors and nurses are not available to answer questions. According to Fox (2010), “These resources allow an Internet user to dive deeply into a health topic, using the Internet as a communications tool, not simply an information vending machine,” (The social life of health information is robust section, para. 4). Communication between peers is especially important to cancer patients and caregivers, because they are more likely to participate in online communication with other people affected by cancer. The Pew Internet & American Life Project found that people with a chronic illness are more likely to participate in an online health discussion or work on a blog (Fox, 2010). They are also 8% more likely to go online to find someone with a similar health condition (Fox, 2011b).

Even though the Internet can serve as a useful tool to those affected by cancer, there are also many problems associated with accessing health information online. Adams (2010) found that people are often concerned with the reliability, quality, and accuracy of health information found online. Furthermore, the amount of information available can overwhelm users. This can lead to “information overload,” where users “become lost in the extra layers of information,” (Adams, 2010, p. 394).

The unpredictable nature of cancer can be frightening. The ability to access accurate and manageable health information on the Internet would serve as a great advantage to the millions of people affected by cancer every year. Since many people with cancer participate in online discussions and blogging, it is useful to study this communication to understand what people are doing online and the ways in which online health information can be made more manageable. According to Fox (2010), “The online
conversation cannot be controlled, but trusted sources can contribute by making it easy for internet users to find and share up-to-date information,” (The social life of health information is robust section, para. 5).

**Purpose of the Study**

The purpose of this study was to explore how people affected by cancer utilize communication in a cancer-related online community to access information and support. The way in which people access health information, records, and support is going digital. Cancer patients and caregivers need a way to search large amounts of information to quickly access the resources and support necessary to battle cancer. This research is necessary to understand how health communication is changing in an online environment and what people are attempting to find in these online communities.

In this study, the researcher will use a thematic analysis to determine the major themes of communication within a cancer-related online community. Then, a qualitative content analysis will be employed to discover why people participate in an online cancer community, particularly whether they are looking primarily for information or emotional support. Furthermore, the content analysis will also be used to examine the differences in how men and women communicate within these communities. This research is expected to confirm that people do use cancer-related online communities mainly to find information and emotional support. Another goal of this study is to determine how men communicate differently from women in this online environment.

**Research Questions**

**RQ1:** What are the major themes of online communication between people affected by cancer in an online cancer community?
RQ2: Do people affected by cancer use an online cancer community primarily to seek/give health-related information or emotional support?

RQ3: What are the primary, gender-based differences and similarities in the communication of people affected by cancer in an online cancer community?

Definitions

It is necessary to define certain terms that will be used frequently throughout this study. First, an online community is a type of virtual community. Howard Rheingold is credited with coining the term virtual community in 1993. He defined it as, “a group of people who may or may not meet one another face to face, and who exchange words and ideas through the mediation of computer bulletin boards and networks,” (Rheingold, 1996, p. 414). The key elements of Rheingold’s definition of virtual community are that people communicate through electronic means. However, his definition does not address the length of time or the frequency in which one participates in a virtual community.

Would a person who posts one message in an online community have the same clout as a member who posted everyday for years? Ridings, Gefen, and Arinze (2002) addressed this time factor, when they defined virtual community as “groups of people with common interests and practices that communicate regularly and for some duration in an organized way over the Internet through a common location or mechanism,” (p. 273). They emphasized that people who become members of an online community do so by communicating over time through the Internet. A more specific type of online community is one that focuses on health issues. This is commonly known as an online health community or a health-related online community. Neal et al. (2006) said online health communities, “provide a means for patients and their families to learn about an
illness, seek and offer support, and connect with others in similar circumstances,” (p. 1).

Furthermore, there are online health communities that deal with chronic illnesses (or chronic diseases), which are persistent, long lasting, and progress at a slow rate (World Health Organization, 2012b). An online community that focuses specifically on cancer is referred to as an online cancer community or a cancer-related online community. In addition, an online cancer community that includes an online support group or discussion forum can be identified as an Internet cancer support group or an online cancer support community.

Significance to the Field

As the world grows more dependent on digital technologies, the need for health information, advice, and support will become essential to maintaining healthy lifestyles and managing chronic illnesses like cancer. However, people utilizing online resources face an insurmountable amount of information that can be unreliable and difficult to organize. The benefits of a health-related online community lie in its ability to quickly and conveniently connect people to important information and people that understand their specific health situation. Many cancer patients and caregivers are transitioning from relying solely on resources provided in person to resources found virtually on the Internet. As people transition from in person to digital resources, communication researchers need to understand how people utilize health-related online communities in order to provide the information, advice, and support that people need while facing cancer.
Ethical Considerations

Since this study explored the online communication of people affected by cancer, the biggest ethical issues were ensuring the privacy of the authors. The Institutional Review Board considers cancer patients to be a vulnerable population, leaving ethical concerns about approaching this group of people for the purposes of research. Therefore, the researcher chose to study messages left in the website’s public discussion forum in lieu of contacting people for this study. The researcher chose to remain in a purely observational mode, and did not comment on or post any messages, or contact any of the message authors in any way. As such, this study did not constitute the study of human subjects. The researcher is unaware of the message authors’ identities, and all measures were taken to ensure the confidentiality of the authors. All names and points of contact were removed from the messages before the analysis began. Only relevant quotations used to answer the research questions were included.

Organization of Research

The first chapter examines the content and implications of communication within a cancer-related online communities. The next chapter will review literature describing the major themes of communication within an online community, whether people utilize those communities for the purposes of information or emotional support, and how gender affects communication within online cancer communities. The third chapter explains the methodology employed in this research and details the procedures used to investigate the research questions. The fourth chapter lists the results of the study of the online communication within a cancer-related online community. Meanwhile, the final chapter will delve deeper by interpreting the results for explanations and future implications.
CHAPTER TWO: LITERATURE REVIEW

An overemphasis on patient-provider communication has led to a lack of research in patient-to-patient communication in health communication research, especially communication through an electronic medium. The Internet offers a forum for researchers to study naturally occurring communication between cancer patients. As a communication medium without normal boundaries, the Internet also represents a fundamental change to how cancer patients communicate with each other, since they are no longer bound by institutional, time, or geographic limits.

The literature review addresses one area concerning the use of support groups among cancer patients and three areas related to research concerning the communication of online cancer communities. The first section, “Social Support Among Cancer Patients,” reviews why cancer patients join support groups and why they seek support from outside their friends, family, and healthcare providers. The next section, “Themes of Online Cancer Communities,” examines studies identifying the major themes of communication within online cancer communities. In the third section, “Cancer Patients Seeking Information or Emotional Support Within Online Communities,” there is a discussion on studies comparing and contrasting gender-based differences and similarities in the online communication amongst cancer patients. Finally, the last section, “Gender-Based Communication Within Online Cancer Communities,” addresses
research on what cancer patients are seeking the most when they enter online communities: cancer-related information or emotional support.

The literature review demonstrates that cancer patients often seek support from groups outside their network of friends, family, and healthcare providers, regardless of how much support they receive. People with cancer often feel that their friends and family members do not understand what they are going through, and they join a support group to connect with those who do. As a result, emotional support is commonly one of the top two things people are looking for in an online cancer community, followed by cancer-related information. This does differ between genders, as men seem to favor an information-based online discussion group, while women seem more emotionally invested in forming an online community.

The aim of this research is to study all people affected by cancer as members of one online community and one communication system, so that an overall view of the meaning of cancer as a disease emerges. In order to achieve this, the researcher chose to study an online cancer community that is open to everyone affected by this disease, including cancer patients, survivors, caregivers, friends, and family members. The website’s discussion forum hosts discussions on a diverse range of topics, from specific types of cancers to helping children understand cancer to living with a death caused by cancer. As such, the messages analyzed include representations of all views, regardless of type of cancer, gender, and specific communication purposes. Most studies of online cancer communities concentrate on those that focus on a specific type of cancer, often breast cancer for women and prostate cancer for men. As a result, this research often
cannot be applied to the general population of people affected by cancer, thereby making it difficult to study online cancer communities on a broad level.

**Social Support Among Cancer Patients**

Cancer patients and their loved ones have been attending support groups in person long before the Internet allowed the groups to take place online. But these physical groups did not always meet the needs of their members. Holding support groups in a virtual environment has allowed for some of these problems to be solved, while others continue to persist, despite advancements in technology. One of the most important questions to consider is why cancer patients choose to participate in a support group.

It has long been suggested that cancer patients turn to support groups, when they are not receiving enough support from their friends, family, and healthcare providers (Lieberman & Borman, 1979). However, Taylor, Falke, Shoptaw, and Lichtman (1986) found that cancer patients who take part in a support group report adequate amounts of social support from friends and family. Their survey of 667 California residents with cancer found that “inadequate or unavailable social support from family, friends, and medical caregivers may be only modestly related to joining a support group,” (Taylor et al., 1986, p. 612). Those that reported difficulties with receiving social support from friends and family were not more likely to join a support group. Yet, those that reported negative incidents with medical personnel were more likely to join a support group, perhaps motivated by a need to vent frustrations caused by their healthcare providers (Taylor et al., 1986). Since cancer patients often do receive enough support from their loved ones, why do they turn to a support group?

Half of the participants wished they could speak more openly with their loved
ones, while more than a third agreed that their loved ones do not understand what they are going through (Taylor et al., 1986). Even though friends and family members do support them, cancer patients seek support groups to connect with people who better understand what it’s like to have cancer. A study of breast cancer patients found that members experience a sense of empowerment and belonging from joining a support group. According to Ussher, Kirsten, Butow, and Sandoval (2006), “Support groups were positioned by participants as providing a unique sense of community, unconditional acceptance, and information about cancer and its treatment, in contrast to the isolation, rejection, and lack of knowledge about cancer frequently experienced outside the group,” (p. 2565). Specifically, van Uden-Kraan et al. (2009) found that “being better informed” and “enhanced social well-being” were the top two empowerment outcomes reported by members of online support groups.

This study also highlighted some of the demographic factors that prevent people from joining cancer support groups. Men, minority groups, and those with low socioeconomic status are usually underrepresented in cancer support groups, while white women in the middle-to-upper-class range are overrepresented (Taylor et al., 1986). Eakin and Strycker (2001) also identified common barriers that prevent people from accessing cancer support groups, including having an adequate support system, a lack of awareness of support groups, and a lack of referral from a healthcare provider.

The availability of the Internet has breached some of these problems. After all, an online support group offers access to people who cannot travel, live in a remote location, and suffer from social anxiety (Winzelberg et al., 2003). However, socioeconomic status is still very much a problem, as three-quarters of American adults who do not graduate
high school do not access health information online (Fox, 2011a). Since white women are the most likely to join a support group, this also explains why studies among breast cancer patients are so prevalent. Davison, Pennebaker, and Dickerson (2000) evaluated health-related online support groups, and found that breast cancer support groups came in third in the frequency of postings, just after alcoholism and AIDS.

Participating in a support group can lead to many physical, psychological, and social benefits for cancer patients. Gottlieb and Wachala (2007) found that support group members report have a high morale. They “felt less alone, more understood, and more hopeful following their group experience,” (Gottlieb & Wachala, 2007, p. 396).

In addition, Grande, Myers, and Sutton (2006) found that cancer patients who join support groups cope better than those who do not. However, support group member also have higher levels of anxiety concerning their cancer (Grande et al., 2006).

**Themes of Online Cancer Communities**

Articles studying online communities for those with cancer have often researched the communication between patients and healthcare providers or the factors driving people online. Yet, few have focused on the actual communication between the people within the online communities. What are these people saying to each other about their illnesses and their common experiences? What are they seeking when they talk with other members of an online community: health information, emotional support, a place to tell their story, an outlet to vent their frustration, or simply a place to connect with other people with cancer? There are certain, discernable themes that run through the messages within online cancer communities that need further investigation.
Klemm, Reppert, and Visich (1998) wrote one of the first studies to analyze the content of messages in an online community for cancer patients, which clearly identifies seven major themes of communication. The purpose of this study was to determine the themes of information shared during communication in an online cancer support group. First, the researchers analyzed the messages of an online support group for people with colorectal cancer. Next, they ran a content analysis of a total of 300 messages: 150 messages from a four-day period in June and 150 messages over a five-day period seven months later in January. A total of 97 people posted messages: 48 men, 46 women, and three unknown. The initial analysis resulted in 29 themes, which was later reduced to eight major categories: information giving/seeking, personal opinions, encouragement/support, personal experience, thanks, humor, prayer, and miscellaneous. If a message was identified as containing multiple themes, then each theme was placed as an individual response in a separate category. Out of 300 total messages, this resulted in a total of 436 responses. The analysis yielded the total percentage of responses per category: information giving/seeking, 25.4%; personal opinions, 22%; encouragement/support, 17.4%; personal experience, 16.4%; thanks, 7.7%; humor, 4.5%; prayer, 2.9%; and miscellaneous, 3.2%.

This leads to the conclusion that there are a number of themes running through an online community for cancer patients, but the most common theme seems to be the seeking and giving of cancer-related information. With over one-quarter of the total messages in this category, cancer patients sought information on treatment options, clinical trials, side effects, alternative therapies, and other cancer-related information. Another common theme was the participants giving their personal opinions and advice on
a wide variety of subjects regarding cancer, including cancer statistics, experimental chemotherapy, medical insurance, research studies, even the mind-body connection. The other two most commonly used themes are patients offering messages of encouragement and emotional support, and patients telling narratives of their personal experiences with cancer.

The main limitation of this study is the small time periods of the two analyses. Messages were collected over one four-day period and a second five-day period. The research team completed two separate analyses to verify the results of each study, but they resulted in a couple of noticeable differences. In the case of the information seeking/giving category, the June messages accounted for 28.1% of the messages, while they only accounted for 22.8% in the January messages. Also, the number of messages in the encouragement/support category rose from 10.5% in June to 23.7% in January. Perhaps future studies that include a larger data collection period and a larger sample would yield more stable results between comparative studies.

While Klemm et al. focused on the communication within an online community for one type of cancer, Ginossar compared the communication between two online cancer communities, one for a common type of cancer and the second for a rarer form of cancer. The researchers studied computer-mediated communication between cancer patients in a virtual community, also referred to as an Internet Cancer Support Group [ICSG]. The study examines the ICSG members’ e-mail messages to explore communication needs that were not met through other communication channels and how members used the ICSG to meet different communication needs. The researchers hoped to identify the patterns in the content of the e-mail messages they studied. By comparing two different
online communities, this study helps to determine if the themes of online cancer communication are common among ICSGs for different types of cancer.

Researchers conducted a content analysis consisting of 1,424 e-mail messages from two ICSGs. The sample was selected through a three-step process. First, the authors chose the ACOR (Association of Cancer Online Resources) server because of the website’s popularity with cancer patients and long-term presence on the Internet. Next, the author identified a lung ISCG and CLL (chronic lymphocytic leukemia) ICSG. The authors chose to study an ICSG for lung cancer patients because lung cancer is the most prevalent type of cancer, and there is a lack of research concerning lung cancer patients. Both ICSGs chosen to study were popular and had over 400 members at the time of the study, providing a large sample of messages to analyze. Lastly, the author chose to study the messages from the month of May, because the month has no major holidays to interfere with communication and was deemed to be a typical example of communication within the groups.

Two independent coders who were not familiar with the goals of the study analyzed each of the 1,424 sample e-mail messages. Prior to the study, the coders practiced coding similar messages in an ICSG for patients with non-small cell lung cancer. By the time of the study, the coders’ intercoder reliability was assessed at 92%.

The researchers identified the uses of ICSGs from previous research as (a) exchange of informational support, (b) exchange of emotional support, and (c) political and advocacy-related purposes and on concerns regarding uses of ICSGs for conflicts. Based on this information, the researchers further divided the themes into seven categories: information seeking, information reply, unsolicited information, emotional support only,
political/advocacy, conflict, and other. Out of the 1,424 e-mail messages analyzed, 756 came from the CLL ICSG, while 612 came from the lung cancer ISCG.

The results indicated that information exchange was the most frequent use of the communication between members of the two ICSGs examined. The three categories used most often consisted of information reply (31%), information seeking (18%), and unsolicited information (15%). A total of 15% of the messages were classified as seeking emotional support only, while conflict messages had 5% and political/advocacy messages consisted of 4%. Fifteen percent of the messages were classified as other. The researchers found two differences between the messages of the support group that were of statistical significance. The significant differences comprised of the frequency of political/advocacy and conflict-related e-mails. Six percent of the lung ICSG messages pertained to the political/advocacy category, compared with three percent in the CLL ICGS. Second, nine percent of the lung ICSG messages pertained to the conflict category, compared to only two percent in the CLL ICGS.

Several conclusions can be made based on the results of the study. First, these cancer patients used the two support groups mainly to seek information. Although healthcare officials are still a person’s primary source of health information, more and more people are using the Internet to seek health information. A recent poll shows that doctors, nurses, and other healthcare professionals are the first choice of information for people with health concerns, yet 80% of Internet users have looked for health information online (Fox, 2011c). After all, the variety of information and endless resources of the Internet can lead to a decentralization of the doctor as the patient’s only source of reliable information. This conclusion could represent a fundamental shift from a patient’s
healthcare provider to the Internet as a patient’s primary source of health information. Next, many articles have shown the ICSG as a valuable source of emotional support and empowerment (Barak, Boniel-Nissim, & Suler, 2008; Shim, Cappella, and Han, 2011). Yet, in this study, more than half of the messages constituted some form of information seeking while only 15 percent sought emotional support from other members.

Finally, it can be assumed from the results of this study that the major themes of online cancer communication apply to online communities supporting different types of cancer. The two major statistical differences between the two groups showed that the online community for lung cancer held more political/advocacy and conflict-related messages, both minor themes. Ginossar did not know why these statistical differences occurred. Lung cancer is more prevalent than CLL, which means there is more information available about the disease, more people who have the disease, and more fundraisers held to raise money to battle the disease. Perhaps, since lung cancer is more common than CLL, the number of political/advocacy and conflict messages from this group is consistent with the communication of people who have more common types of cancer.

This study had several limitations that weaken the results of the findings. First, the researchers chose to study the e-mail messages of only two forms of cancer. Studying only two ICSGs limits the scope of the study, as does the selection of ICSGS that cater to specific types of cancer. Lung cancer is the most prevalent form of cancer, while CLL, which accounts for one-third of all leukemia, is more rare (American Cancer Society, 2010a). The differences in the two forms of cancer would lead to different issues being faced by the members of the two ICSGs. Perhaps the only way to ensure fair
representation would be to choose ICSGs that were open to patients with all forms of cancer.

Anderson (2011) conducted a study that concentrates on determining the typologies of the content of communication for an online health community for all people facing a serious illness. CaringBridge is a website established in 1997 that provides webpages for people experiencing hospitalization, childbirth, military deployment, and other type of care situations. The purpose is to “keep loved ones informed during a significant health challenge” (CaringBridge, n.d.) by hosting webpages that feature blogs, guestbooks, and photo galleries. People interested in accessing the webpages for individuals they know simply go to www.caringbridge.org and then type in the name of the individual’s website. CaringBridge offers a unique way for loved ones to keep updated on friends and family members who are suffering from a long-term medical condition. The purpose of the study is to show that typologies of Internet gratifications cannot be generalized to all online activities, specifically those with a healthcare context. Anderson chose to study a rather large online health community that does not focus on a specific type of cancer. A majority (67%) of responders created websites because of a serious illness, mainly cancer. The results of this study can show whether the major themes are applicable to all online cancer communities, not generalized to a community for a specific type of cancer.

The author uses the eight dimensions of gratifications obtained by Internet use established by Charney and Greenberg as a base to compare the uses and gratifications of CaringBridge pages that focus on individuals with a long-term health issue. The eight dimensions are: keep informed, diversion/entertainment, peer identity, good feelings,
communications, sights and sounds, careers, and coolness. Anderson argues that these eight dimensions cannot all be applied to the health-related online communities, because people have more specific gratifications when establishing one of these websites. Anderson (2011) has said, “For a person experiencing a health crisis, gratifications such as keeping informed and convenience might be more important than career or coolness. Indeed, people experiencing health problems may well seek different gratifications altogether than those identified in general typologies of Internet gratifications,” (p. 3).

The study consisted of two surveys of authors of CaringBridge pages. A total of 1,646 survey invitations were sent to all new CaringBridge authors between January to March 2006 with 378 people (22.4%) answering the survey in the pilot study. The survey included 14 provisional categories of uses and gratifications. The author adapted the provisional categories of entertainment, pass time, surveillance, information gathering, personal insight, social interaction, and status from previous research on the uses and gratifications of the Internet. Meanwhile, questions for a social support category were developed based on previous research of online communities, and a spirituality category was developed based on the author’s previous content analysis of a CaringBridge guestbook. The remaining five provisional categories of helping others, learning about others, gaining fame, creative outlet, and convenience were developed from phone interviews with CaringBridge administrators and authors. Based on the results of the first study, a second study was prepared and sent to all new CaringBridge authors who created a website between April and November 2006. A total of 4,497 invitations were sent with 1,035 (22.1%) responses over a two-week period. A majority (67%) of responders created websites because of a serious illness, mainly cancer. The
author modified the pilot study so that the second study was refined to 45 hypothetical gratifications. Fifty-eight percent (26 items) of the gratifications were originally on the pilot study, while 29% (13 items) were changed from the pilot study’s typologies. Only 13 percent of the questions (six items) that were derived from previous research on the uses and gratifications of Internet use appeared in the second study under modified forms: getting information from others, becoming a part of a larger group, passing time, meeting new people, and participating in discussion. The 45 hypothetical gratifications were labeled as “benefits” on the survey and were measured on a five-point scale with 5 indicating high importance of benefit and 1 indicating low importance. The data was analyzed using an exploratory factor analysis. Anderson (2011) took into consideration that 87 percent of the gratification benefits were modified from prior research or original to the study. The author extracted four factors that explained 49% of the total variance: networking, convenience, spiritual support, and psychological support.

The study shows that the top four benefits for CaringBridge authors were to provide others with information, encouragement upon reading the words of so many, the convenience factor, and psychological support factor. These findings are consistent were other studies that show two of the top reasons for participating in health-related online communities are to seek or provide information and for emotional support. This indicates that seeking or providing health information and emotional support are major themes of the communication in online health communities, including those that focus on cancer. However, two of these categories are unique and do not appear in previous typologies of the uses and gratifications of Internet use. According to Anderson (2011), “Encouragement upon reading the words of so many is a benefit unique to guestbooks. It
refers to an emotional outcome based on reading specific, accumulated messages. Psychological support (factor) is received from general awareness of others’ caring,” (pgs. 6-7). This leads to the conclusion that CaringBridge authors use these online health communities for gratifications outside the normal Internet use gratification typologies. However, these gratifications may be common themes of online health communities. As two of the top four benefits do not appear in previous Internet gratification typologies, these benefits could represent new media gratifications that are specific to a health-related context.

The major limitation of the study was the fact that it studied authors from only one website. There are millions of other people who use the Internet for support in health-related illnesses through blogs, support groups, and online communities. Given that the sample was limited to CaringBridge authors, it is unknown if the results of the survey are applicable to the general population. Although, Anderson (2011) points out that the demographics of the CaringBridge survey responders are similar to the demographics of online support groups and informal caregivers. However, the questions of the second study were modified greatly by the results of the pilot study, further limiting the likeliness that Anderson’s (2011) results are unique to CaringBridge.

In conclusion, computer-mediated messages through online communities are a popular method of support for those with cancer. Defining the themes of these messages can be tricky for researchers. Research identifies the most common themes for communication within online cancer community as being seeking and giving information, emotional support, and encouragement. The less common themes are not always agreed upon, although most include humor, prayer, and advocacy. The obvious
question is how many themes are needed to properly identify the major themes of online discussion between cancer patients.

In Klemm et al.’s (1998) article studying the communication within an online community for those with colorectal cancer, the major themes cover most of the messages, with only a little over 3% of the messages are classified as miscellaneous. However, it may not be necessary to have seven major themes and a miscellaneous category to cover all the messages. It could be argued that some of the less common themes could be incorporated into the larger themes. For example, the prayer and thanks themes would probably fit into the encouragement/support category. Next, Ginossar’s (2005) examination of two online cancer communities shows that common themes do run between ICSGs for different types of cancer. However, the chosen themes also bring into question how many themes are necessary. Ginossar (2005) presents six major categories for messages and an other section, which accounts for 15% of the messages. The first three categories (information seeking, information reply, and unsolicited information) all refer to themes that are related to the giving and seeking of cancer-related information, which is the most common theme of online cancer communication. Perhaps, these three sections could be formed into one or two sections, and more time should be spent exploring the themes of the other category. With 15% of the messages, surely some extra themes could be discernable from that amount of information. Finally, Anderson’s (2011) study of the online messages within CaringBridge websites surveyed 45 possible gratifications, yet extracted four factors that explained 49% of the messages: networking, convenience, spiritual support, and psychological support.
Cancer Patients Seeking Information or Emotional Support Within Online Communities

Millions of Americans use the Internet to seek support when dealing with cancer through online communities. This leads to the question of what are they looking for on the Internet? What is the most important thing they are looking for: information and advice or emotional support?

LaCoursiere, Knobf, and McCorkle (2005) studied the survey results of cancer patients to discover the most important dimensions of cancer patients’ online activities. The surveys of 41 cancer patients were selected as a subsample of 265 people who participated in the Attitudes Toward Online Heath Care survey, a study developed to measure the attitudes of people who engage in online healthcare activities. The original survey comprised of 51 items on a 5-point Likert scale. The subsample was reduced to 42 questions. However, one item was omitted due to a coding error, leaving 41 items to be analyzed. Responders were recruited through e-mail discussion groups, Web-based discussion groups, and referrals from other websites. The data was collected over a two-week period in March. The survey measured five dimensions of Internet use by cancer patients: community and news, outcomes, trusted information and advice, self-efficacy in evaluating information and intention, and disclosure. Using the Likert scale, the five dimensions were rated in terms of most use: self-efficacy in evaluating information and intention 3.46 (SD = 0.65), community and news 3.22 (SD = 1.01), outcomes 3.20 (SD = 1.08), disclosure 3.15 (SD = 1.06), and trusted information and advice 2.73 (SD = 0.65).

This study leads to the conclusion that cancer patients use online activities more for information-related purposes than for emotional support. The cancer patients...
identified efficacy in evaluating information and intention as the dimension they used the most in online health activities, meaning that the knowledge they gain online helps them gain the confidence needed to take a greater hand in the treatment of their illness.

According to LaCoursiere et al. (2005), “The knowledge gained from accessing online information and support and from participating in community and news venues of health websites can enhance one’s self-efficacy and sense of empowerment,” (Self-Efficacy in Evaluating Information and Intention section).

Although, the cancer patients in this study still used online communities for various types of emotional support that cannot be filled by simply seeking health information online. The community and news dimension was the second most commonly used dimension of the study. The patients sought emotional support by sharing their stories with people who were dealing with the same disease and showed empathy to the stories of other patients. LaCoursiere et al. (2005) argued, “Patients are comfortable giving as well as receiving cancer information and support online and are comfortable evaluating it. They are interested in the experiences of other patients and derive benefit by interacting with them directly, through venues such as discussion boards and e-mail lists,” (Discussion section). As a result, the patients often benefited from the emotional support found online. The authors reported patients were better able to cope with their diseases, which resulted in less uncertainty, anxiety, and depression (LaCoursiere et al., 2005, Discussion section). One interesting note is that the cancer patients surveyed demonstrated a level of altruism while seeking emotional support. They rated the statement, “I like to give online support to other patients who have my condition,” slightly higher than the statement, “I like to participate in e-mail based
discussion about my condition,” (LaCoursiere et al., 2005). Moreover, this leads to the conclusion that those surveyed placed more value in giving others emotional support than gaining emotional support themselves.

The main limitation of this study is its sample size. With only 41 survey responders, the results of the study may not be applicable to the general population of cancer patients who seek information and support on the Internet. Furthermore, since a large portion or the responders were highly educated, 14.6% held bachelor’s degrees while 43.9% held graduate degrees, the results of the survey most likely do not represent the population segment without access to the Internet. Future studies could seek to include a more accurate educational demographic sample.

Next, the Health eCommunities study is a multi-method project collaboration between the Association of Cancer Online Resources (ACOR) and the University of North Carolina at Chapel Hill designed to study the impact of cancer patients’ and caregivers’ participation in ACOR’s mailing lists (Meier, Lyons, Frydman, Forlenza, & Rimer, 2007). ACOR is a non-profit organization with a partnership of more than 150 mailing lists for cancer patients and survivors. Memberships range between less than 10 to more than 2,000 members per mailing list. This study focuses on the qualitative analyses of the study, which resulted in content and thematic analyses of 9% of the messages sent to 10 cancer mailing lists. One researcher conducted a pilot study of a colon cancer mailing list, which resulted in estimates that more than 12,000 messages would be sent during the five-month time frame. Due to limited resources, the researchers sampled 9% of the archived messages by using an automated system to capture every eleventh e-mail message. However, the sample size yielded 50% more
messages than researchers estimated, resulting in a sample of 2,755 messages. Next, the researchers completed a content analysis on each message using Atlas.ti, a qualitative analysis program. Also, researcher used theory-based and grounded theory approaches to complete the thematic analyses. Coding categories were first developed based on the project’s simplified Stress and Coping Model and from items used in the project’s online surveys. Researchers refined the codes after researching the e-mail messages and developed new codes and subcodes as new themes emerged (Meier et al., 2007).

The analyses provided several major themes to the messages of the cancer mailing list. First, the most dominant theme was information and advice. The researchers identified four major categories within the information and advice theme: specific treatments, communication with health care providers to find the best treatment, problem management strategies, and coping with cancer recurrence. The second common theme was emotional support, which was divided into six major categories: emotional coping strategies, empathy, encouragement, prayers, esteem support, and solidarity. Encouragement was the most used category of emotional support, with around one-quarter of the messages expressing some form of encouragement, such as wishes for continued recovery, perseverance, and sustaining hope that the cancer is treatable (Meier et al., 2007).

The results were consistent with hypotheses that a majority of the messages sent by members of the cancer mailing lists would be in the category of information and advice. Many of the members consistently sought and provided information rather than emotional support. The researchers found that cancer patients and survivors offered informational support far more than explicit emotional support. However, researchers
were surprised that so many more people offered support than explicitly requested support. It could be that offering others support is a more rewarding experience than seeking support for oneself. Being a rock for another cancer patient also brings up a sense of empowerment that is often seen as necessary in the battle against cancer.

According to Meier et al. 2007, “Being able to offer help is a more empowered position than being a supplicant. List members who have more personal experience with cancer and have learned a lot about cancer from participating on the list can find rewarding roles as ‘elders,’ sharing both what they have learned and how they have coped (Dominance of Offers Over Requests section).

The main limitations of this study were the problems with the data set. First, due to time restraints, they chose every eleventh message for analysis over a five-month period. Second, they underestimated their expected number of messages, resulting in a sample size more than twice as big as their original estimate. Perhaps, they would have gained more accurate results if they had used a smaller time frame for data collection. Also, ACOR does not collect background information for the members of its mailing lists, meaning that the researchers identified the members as cancer patients or cancer caregivers based on the content of the messages. They estimated that they correctly identified 87% of the contributors as patients or caregivers. Caregivers are more likely to seek support rather than information (Meier et al, 2007). However, given that patients and caregivers may use the mailing lists for different purposes, the 13% of unidentified contributors could skew the results.

Last, Chung and Kim (2008) concluded that cancer patients who write and read blogs use the online communities more for emotional support than to find or give
information on cancer. They performed biweekly Google searches for blogs with the word “cancer” in the title for a period of two months. Invitations were sent to 153 of the bloggers, 113 of which chose to participate in the online survey. Participants were all 18 or older and wrote blogs in English. The purpose of the study is to use uses and gratification theory to determine the gratifications received by cancer patients who participate in blogging and online communities. The survey included questions about the participants’ background and interest in cancer, blog use, effects of using cancer blogs, factors limiting blog activity, and demographic information. Chung and Kim factor analyzed 16 blog perception items using a principal components analysis, which resulted in four main gratifications that account for 69% of the variance. The four gratifications that cancer patients use through their blogs and online communities are emotion management (M = 4.16, SD = 0.76), information sharing (M = 3.85, SD = 0.80), problem solving (M = 2.92, SD = 0.83), and prevention and care (M = 2.40, SD = 0.83).

The study indicates that that the cancer patients use blogs and online communities for the four major gratifications. Emotion management is the most widely used gratification of the cancer patients, followed by information sharing. This is consistent with previous studies that show emotional support and seeking health information are the most common reasons that cancer patients participate in online communities. The three statements that the bloggers rated the highest were: “Blogs have helped me express my frustration in dealing with cancer,” “Blogs have helped me cope with my cancer-related situation,” and “I have learned new information through reading cancer blogs,” (Chung & Kim, 2008). Furthermore, participation was a major factor in receiving all the benefits associated with the blogs. The results indicated that bloggers who hosted their own blogs
were more likely to obtain the emotion management gratification, and those who posted comments on other blogs were more likely to obtain the information-sharing gratification. Therefore, cancer patients who hosted a blog, read other blogs, and posted messages were more likely to benefit from emotional support and information sharing, compared to a cancer patient who only hosted a blog or read other cancer blogs.

This study was somewhat limited by the scope of the sample. Blogs were chosen solely through the Google Blog Search function, and the author also targeted well-established blogs. Given that there are a much greater number of cancer-related blogs on the Internet, the results of a survey of 113 bloggers may not be applicable to the population of cancer patient bloggers at large. Next, it should also be noted that the four major gratifications defined by Chung only account for 69% of the variance. That leaves 31% of gratifications undefined for this study. Future studies should identify more gratifications if researchers want to get a complete sense of what the cancer patients are communicating about online.

In conclusion, the research shows that cancer patients are often looking for cancer-related information and advice the most while participating in online communities, instead of emotional support. LaCoursiere et al.’s (2005) analyses of surveys indicated that gaining knowledge to help fight cancer was the most used online activity by cancer patients. Also, Meier et al.’s (2007) word analyses of the messages of a cancer patient mailing list revealed that a majority of the messages were categorized as information and advice, followed by emotional support. Only Chung and Kim’s (2008) survey study of bloggers indicated that cancer patients are seeking emotional support more than information while online. Chung and Kim (2008) reported that emotion
management was the most used gratification among the bloggers surveyed, followed by information sharing.

**Gender-Based Communication Within Online Cancer Communities**

The manner in which men and women communicate is often different, especially when dealing with a serious illness and life-altering event like cancer. When men and women go online, what are the similarities and differences between their communication, the way they deal with their diseases, and the way they offer support and connect to other cancer patients?

Sullivan (2003) conducted a phenomenological thematic analysis of the messages posted by two online cancer mailing lists. With the goal of analyzing gender-specific cancer groups, the author chose to study two online support groups for cancers affecting reproductivity, the Ovarian Problems Mailing List and the Prostrate Problems Mailing List. At the time of the study, the ovarian cancer mailing list had 1,213 subscribers and the prostate cancer support group had 1,711 subscribers. A total of 170 subscribers posted messages to the ovarian cancer mailing list, with nearly 79% of the subscribers women who have or have had ovarian cancer. The author found that a core group of 12 women posted 42% of the messages. A total of 213 subscribers posted messages to the prostate cancer mailing list, with nearly 83 percent of the subscribers men who have or had have prostate cancer. The author did not find a core group of subscribers within the prostate cancer mailing list. Most subscribers posted only one message during the month the messages were analyzed. Sullivan (2003) analyzed messages over one-week periods to determine themes. She analyzed 1,487 messages from the ovarian cancer mailing list and 1,902 messages from the prostate cancer mailing list (Sullivan, 2003).
Sullivan (2003) found that the thematic messages received in the ovarian cancer mailing list were often optimistic and empathetic in nature. Many of the messages offer positive support for fellow cancer patients. The online support group was described by some subscribers as a “cyber tea party,” referring to postings that describe the empathic understanding only another woman suffering from ovarian cancer could elicit. Another frequent theme was seeking health information and advice. Numerous messages gave advice and suggestions on how patients can become more active in their own health care. Sullivan (2003) has found, “Many of the women stated that they were initially ‘naïve’ and that the information provided on the List and elsewhere helped them to become better informed and able to ask their doctors appropriate questions. These women educated each other, preparing each other to face health care professionals and the medical system. Getting copies of one's medical records was frequently advised,” (p. 12).

The major conclusions drawn from this study indicate that men communicate in a hierarchal fashion while seeking cancer-related information, while women are more concerned with the emotional well being of group members (Sullivan, 2003). The types of online communities formed by men and women highlight the major differences in gender-based communication. First, women in the ovarian cancer list were likely to communicate with each other as equals about a variety of information. According to Sullivan (2003), “Women logged on, wrote messages, read messages and responded to others in ways that created a community of similar others. This community provided a variety of benefits to its members that appeared to aid in the coping process,” (p. 22). The author reported several major themes dealing with emotional support running through the ovarian cancer online community: including venting feelings and expressing
negative emotions; building relationships and sharing personal information to those in a similar situation, and helping others to cope with their cancer experience (Sullivan, 2003).

The men in the prostate cancer list, however, were more likely to communicate under a hierarchal structure, with the medical professionals at the top of the food chain. According to Sullivan (2003), “These physicians were recruited by the prostate cancer patients themselves, lending support for the perceived importance of obtaining quick, accurate, up-to-date medical information online,” (p. 21). The author points out that the women responders experienced a variety of benefits from the online community, while the men did not share the same everyman mentality. The prostate cancer list was of the most benefit to the “well-educated, analytically minded prostate cancer patient,” as the online community is a “medically oriented group, serving educational and informational functions,” (Sullivan, 2003, p. 22).

Women in the ovarian cancer list did seek health-related information and advice through the online community. However, they were more likely to seek that information through other members, while the men sought professional advice from physicians. Many of the women joked that they became, “honorary health care professionals automatically after becoming diagnosed with ovarian cancer by doing lots of research as though they were in nursing or medical school,” (Sullivan, 2003, p. 12). Some subscribers even offered to “interpret” medical reports for newer subscribers. One subscriber went so far as to diagnose what stage of ovarian cancer a new subscriber was in (Sullivan, 2003).
Next, the men invited several doctors to join their online community and provide medical expertise, which actually led the community to become more health-information based. Many of the doctors would not respond to messages, unless the patients provided detailed case histories and medical reports. Sullivan (2003) stated, “These posts sent the message that participants of this List must ‘do their homework,’ by reading the same articles, becoming familiar with the medical terminology and statistics relevant to their case,” (p. 21). In return, patients who sought the advice of medical professionals became skilled in reading their medical reports, so that they could provide accurate information to the doctors and often read the articles and medical reports that the doctors suggested.

Another difference found on the prostate cancer mailing list is the idea that new members were not automatically included in the online community. Some new members felt it apparent to read the messages for a month to learn the ropes, and new members were told to be well informed and prepared before participating in posting and responding to messages (Sullivan, 2003).

Both men and women experienced similar benefits within their online cancer communities. A common theme between both men and women was that the support communities provided empowerment, information, and support to take a greater hand in the patient’s treatment (Sullivan, 2003). Armed with information found through or suggested by other members of the online community, patients would often confront their doctors to seek more information or alternative treatment options. For example, one member of the prostate cancer mailing list convinced his urologist to continue with a surgery, even though the cancer had spread to his lymph nodes and the doctor would normally not continue with the surgery. The patient convinced his doctor to continue the
surgery after preparing a paper with 20 references from books and articles supporting the
continuation of the surgery after lymph node invasion (Sullivan, 2003).

The major limitation of this study is that the author studied Internet support
groups for people suffering from specific cancers. While prostate cancer is the second
most common form of cancer in American men, ovarian cancer is the ninth most
common cancer in women (American Cancer Society, 2010b; American Cancer Society,
2010c). The author chose two cancers that specifically affect reproductivity in an effort
to isolate and compare an online cancer community for women and another for men.
Since prostrate cancer is more common among men than ovarian cancer is among
women, the results of this study are more likely to be typical of men who have cancer and
less likely to be typical of women with cancer. Perhaps future studies could be conducted
analyzing online cancer communities with a gender-based membership to ensure an equal
representation of men and women with more common types of cancer.

In a second, gender-based analysis of the communication within online cancer
communities, Owen, Klapow, Roth, and Tucker (2004) analyzed the online messages left
by a group for breast cancer and a second for prostate cancer. Research assistants, who
disregarded messages that were not posted by cancer patients, first analyzed messages
from a two-month period. The researchers analyzed messages from 325 people in the
Breast Cancer List and 162 people in the Prostate Problems Mailing List. The use of
words related to emotional expressing and cognitive processing in the online messages
were analyzed using Linguistic Inquiry and Word Count (LIWC), which compares each
word in a text file to words or word stems in 74 categories and calculates the percentage
of the total number of words included in the 74 categories. Since the LIWC dictionary
only held 2,290 words, the researchers analyzed the remaining words using a programming language called Using Practical Extraction and Report Language (PERL), which resulted in 23,376 unique words or word fragments (Owen et al., 2004).

Next, three trained raters reviewed the words and deemed 2,229 words as being cancer-related. These words were subdivided into seven word categories: outcomes of cancer treatment, disease status and processes associated with the cancer, health care facilities and personnel, medical tests and procedures, cancer treatment, physical symptoms and side-effects, and descriptions of cancer. The researchers found a total of 7,670 unique words, abbreviations, and misspellings of cancer-related terms. Finally, these words and subcategories were used to form a cancer information library, which was uploaded into LIWC to analyze terms not previously held in the LIWC dictionary. After the LIWC analysis, the researchers performed t tests to determine the average levels of words use between breast cancer and prostate cancer patients (Owen et al., 2004).

The LIWC analysis showed that members of the breast cancer community posted more messages per day and posted more messages altogether than members of the prostate cancer community, whose messages were much shorter. The breast cancer patients posted a mean of 37.9 messages per day, compared with 6.4 messages for the prostate cancer patients. The breast cancer patients posted a mean of 7 messages per participant with a mean of 180.6 words per post; the prostate cancer patients, 2.9 messages per participant with a mean of 160.4 words. Next, prostate cancer patients used nearly twice as many words about cancer information when compared to the breast cancer patients, including a higher word use concerning disease status, \( t(484) = 3.56, p=0.0004 \), healthcare facilities and personnel, \( t(484)=3.47, p=0.0006 \), medical tests and
procedures, \( t(484) = 7.48, p < 0.0001 \), cancer treatment, \( t(484) = 3.95, p < 0.0001 \),
description of cancer in the body, \( t(484) = 3.49, p = 0.0005 \), complementary and
alternative treatments, \( t(484) = 4.85, p < 0.0001 \), all FDA-approved drugs, \( t(484) = 3.25, p \\
= 0.001 \), and FDA-approved oncology medications, \( t(484) = 2.38, p = 0.018 \). However,
the breast cancer patients posted messages with a higher number of words related to
emotion, \( t(484) = 2.79, p = 0.006 \), including positive emotion, \( t(484) = 4.95, p < 0.0001 \),
and negative emotion, \( t(484) = 2.79, p = 0.006 \). While both breast and prostate cancer
patients used words related to anger and sadness evenly, breast cancer patients, \( t(484) \\
= 2.91, p = 0.004 \), expressed anxiety more often than prostate cancer patients (Owen et al.,
2004).

The study leads also lends credibility to the conclusion that men in the prostate
cancer group use the online community more for informational purposes, while the
women in the breast cancer group are more emotionally vested in the online community
(Owen et al., 2004). The word analyses clearly show that men in the prostate cancer
community used almost twice as many words related to cancer information, while the
women used more words relating to emotion. Also, the women in the breast cancer
group posted a far greater number of messages per day, both as a group and as individual
participants, as well as longer messages when compared to the men in the prostate cancer
group (Owen et al., 2004).

This study contained several limitations. First, the researchers make several
conclusions based on the assumption that a majority of the breast cancer patients are
women, but the researchers did not collect any demographic information from the authors
of the online messages. While it is rare, some men do get breast cancer (American
Cancer Society, 2011). Without demographic information, there is no way to verify the assumed genders of the cancer patients. Furthermore, the accuracy of the LIWC analysis is reduced by the lack of a library of cancer-related words. The authors report that capability of LIWC to classify words in medical populations is reduced from 83.3% to 73-77% (Owen et al., 2004).

Instead of comparing and contrasting online cancer communities, Orgad (2006) studied the communication of breast cancer patients across many online communities and interviewed participants in an effort to discover the cultural elements that contribute to the participation and design of their online communication. In doing so, Orgad (2006) discovered many common themes that are prevalent in online discussions between breast cancer patients, which highlights some of the differences between the communication of men and women cancer patients online.

The study is based on 41 offline and online interviews with breast cancer patients and a textual analysis of related websites and online forums. Orgad (2006) spent several months exploring online communities of breast cancer patients that she found through searches of the keywords “cancer” and “experience” on Google and Yahoo search engines. She then posted invitations on message boards seeking participants and e-mailed people who had posted their personal e-mail addresses on messages. Orgad received 83 replies, 29 of which were used for data analysis. Next, she contacted 15 participants to see if they would also complete face-to-face, follow-up interviews. Of those 15, Orgad conducted 10 face-to-face interviews and one telephone interview. All of the participants were white women between the ages of 32 to 76, with the exception of one man.
Orgad (2006) noted that there is an “overwhelming presence of English, especially American English, in breast cancer online environments,” indicating that the non-native English-speaking cancer patients were often highly educated to be able to participate in the online communities (p. 887). She postulates two explanations for this phenomenon. First, Americans have greater access to the Internet than many other countries. Second, Americans have a cultural tendency to disclose personal experiences, meaning that the online cancer communities could be heavily dominant with communication from Americans simply because they are more willing to share than participants from other countries. This tendency to over share information online is sometimes known as digital disinhibition. According to Deffenbaugh (2010), “Psychologists call it the ‘disinhibition effect.’” Many people—young and old alike—are emboldened by the ability to be anonymous, feeling as if they will never get caught, even though we all leave digital traces behind. And many people… experience greater difficulty curbing their impulses online,” (p. 91). Orgad (2006) also sees this sharing of personal information as a common tendency in online cancer communities, with many women viewing information sharing as an essential part of their cancer treatment.

Two major items of conversation were the offering of emotional support and seeking medical information and advice, though this usually was done in a positive context. The online community gave cancer patients the advantage of discussing medical treatment and information on a global scale. Communication with a negative context was often rejected or discouraged among the hopeful atmosphere of the online community for breast cancer patients. For example, Orgad (2006) refers to the religious dimension, especially Christianity, as a common discourse among cancer patients across cultures.
Cancer patients will often post empathic messages of emotional support to fellow members of their online communities that hold a religious context, such as a reference to God, prayer, or a blessing (Orgad, 2006). Another example of the religious dimension is when patients participate in online prayer boards, where patients focus their collective prayers on other patients.

The members also viewed participation in the online community as a sign of their fight against cancer. According to Orgad (2006), “Some patients equate explicitly between active online participation, which involves sharing experience and information, and the positive and empowered attitude necessary to be cured,” (p. 891). One interviewee equated a patient’s participation in the online cancer community to their battle with cancer. Those who actively participated in online communities were “fighters,” while those who were “passive” in their online communities were “surrendering” to their illness (Orgad, 2006, p. 891). In fact, negative information seems to be rejected in the online communication of cancer patients. Orgad (2006) completed a textual analysis of 553 messages on the forum of online cancer community Shared Experience and found that only 6% of the messages included the words “death” or “die”, with less than 2% mentioning death in a negative context (p. 892). Furthermore, messages posted about painful experiences while dealing with the treatment of cancer are often posted in connotations of humor and hope. New members of the online communities who expressed despair and shock over a recent diagnosis to cancer are often encouraged to have a positive attitude by the veteran members of the community (Orgad, 2006).
The main limitation of this study is that most of the participants interviewed were American women, meaning the results may not be applicable on a global basis. The author searched for website and posted messages in English and gained responders mostly from the United States. However, after recruiting only from global domain websites (.com, .org, .net), Orgad (2006) attempted to recruit from country-specific websites to overcome a bias of American responders. However, she received very few replies from her attempt to recruit participants at online cancer communities for people living in the United Kingdom. Future studies should include a larger sample of participants from other countries.

In conclusion, these studies have shown that men and women do communicate differently in online cancer communities. Both genders often seek cancer-related information and emotional support, yet their priorities are different. Men seem to favor an information-based online discussion group, while women seem more emotionally invested in forming an online community. Sullivan (2003) has shown that men and women share similar goals while communicating with other cancer patients online. Both groups sought information and advice and emotional support, yet they retrieved that information in different ways. The women in the ovarian cancer mailing list formed a more complete community by offering more forms of emotional support, including everyone equally in the discussions, and by using other members as a base when seeking advice. However, the men in the prostate cancer mailing list sought information about cancer as their primary interest in the online community (Sullivan, 2003). Offering emotional support to other members was not as common as with the ovarian cancer mailing list. Not all members were automatically included in the discussion, as
evidenced by members who felt the need to lurk in the group for a month before joining the discussion. Also, men sought information from outside sources by inviting medical professionals to join the mailing list, while the women stuck primarily to information provided by other members (Sullivan, 2003).

The word analyses completed by Owen et al. (2004) have given us a picture into the communication between women in a breast cancer online community and men in a prostate cancer online community. The results clearly indicate that men use more words related to cancer information, while women use more words related to emotion. These results can be explained by differences in gender communication. Owen et al. (2004) notes that several studies show that men are more reluctant to express emotion than women, which could explain the breast cancer patients’ tendency to use more emotion-related words than men (Owen et al., 2004). Also, women are more likely to seek emotional support and engage in social relationships while dealing with stressful situations than men (Taylor et al., 2000).

**Summary**

When cancer patients join an online community, they are most often looking for information or advice about their disease or emotional support to deal with their disease. Yet, there is more complex communication happening beneath the surface. These people are dealing with an illness that threatens their lives. Studies have identified major and minor themes that encompass humor, altruism, faith, empowerment, storytelling, and so many other ways that cancer patients deal with this life-changing event. Research studies have shown that men and women communicate differently within online cancer communities. While they do often seek the same information and support, they go about
different ways to achieve these goals. Men participate in information-heavy discussions and post shorter messages, while women post more often and seek emotional support by forming complex, online relationships. However, these studies were often limited by the sample. Messages were often analyzed within one online cancer community or by comparing and contrasting two communities for specific types of cancer. An analysis of messages within an online cancer community for all types of cancer will yield results that can be applied to the general population of cancer patients participating in an online community. The current study will contribute to the existing research literature by identifying the major and minor themes of communication within an online community for all types of cancer and also compare and contrast gender-based communication.
CHAPTER THREE: METHODS

The online communication between cancer patients, survivors, caregivers, and friends and family members of those with cancer requires a mixed qualitative analysis that is capable of properly evaluating the complex communication within this community. The members of this online community participate in the online discussion forum for various reasons, and rich themes have developed from those messages. Some members have recently been diagnosed with cancer and are looking for answers. Others are facing the prospect of dying and looking for emotional support. Some survivors have beat cancer and, though ecstatic about their good health, are now questioning how to live their lives without the constant battle against cancer that previously dominated their lives. Caregivers want to know how to talk to their family members about the disease, and friends want to know how to support their loved ones throughout this experience. Some people experience cancer as a constant battle to maintain any control of their lives, while others view cancer as an existential journey that has changed their lives for the better. Within this rich variety of experiences, one wonders what is happening within these messages. What types of messages are being sent? How are men and women communicating? This study implemented multiple qualitative analyses consisting of a thematic analysis and a content analysis to answer the following questions:
RQ1: What are the major themes of online communication between people affected by cancer in an online cancer community?

RQ2: Do people affected by cancer use an online cancer community primarily to seek/give health-related information or emotional support?

RQ3: What are the primary, gender-based differences and similarities in the online communication of people affected by cancer in an online cancer community?

This study explores the major themes of the messages within an online community for people affected by cancer. First, five months of messages were collected from the Cancer Support Community from January 2011 to May 2011. The 286 messages were analyzed blind. All names and possible contact information were removed. The messages were only identified by numbers. Then, the messages were analyzed to identify the major themes expressed by members of the public forum. These themes were largely identified and developed inductively from the messages by examining the most common types of messages written. However, a few themes were influenced using previous research articles that studied online communication of cancer patients and are discussed within the literature review (Ginossar, 2005; Anderson, 2011). First, Ginossar (2005) detailed a political/advocacy theme that resembles the “Join Together” theme. Next, Anderson’s theme of “encouragement upon reading the words of so many,” influenced the “You are not alone,” theme. Last, messages were selected to highlight examples of these specific themes.

Studies have shown that seeking/giving information about cancer and seeking/giving emotional support to other people affected by cancer are two of the
primary reasons people communicate within an online cancer community (LaCoursiere et al., 2005; Meier et al., 2007; Chung & Kim, 2008). However, previous research has also shown that there are differences in the way men and women communicate about cancer online. Men are more likely to primarily seek information and engage in information-heavy language within an online support group for cancer patients, while women are more likely to seek, offer, and give emotional support more readily than their male counterparts (Sullivan, 2003; Owen et al., 2004).

To answer the second research question, a content analysis of the messages was conducted to determine whether people primarily use the online cancer support community to give and seek information or to give and seek emotional support. A preliminary analysis yielded 13 categorical codes developed from previous studies (Klemm, Reppert, & Visich, 1998; Anderson, 2011; Ginossar, 2005) and inductively from the data. Combinations and exclusions of the categories resulted in 10 major categories and two sub-categories.

1. Giving Information
   
   Sub-category 1: Personal Experience

   Sub-category 2: Advice/Opinion

2. Seeking Information

3. Giving Emotional Support

4. Seeking Emotional Support

5. Prayer/Spiritual

6. Gratitude

7. Administrative
8. Advocacy

9. Humor

10. Miscellaneous

First, each message was analyzed and coded blindly to determine which categories were used most often. The first analysis determined what percentage of messages contained each major category. For example, 3.5% of the messages contained Humor. Furthermore, the messages were analyzed again to determine the percentage of each category in comparison to the total amount of codes found during the analysis. To illustrate, 10 instances of humor were found among 654 total codes, which amounts to 1.5% of the major codes. Finally, the third research question is investigated by comparing and contrasting the similarities and differences in message content between men and women.

**Thematic Analysis**

Thematic analysis is a widely used, qualitative method that offers the flexibility to quickly identify similarities and differences within a data set (Braun & Clarke, 2006). Braun and Clarke (2006) have identified thematic analysis as a “method for identifying, analyzing and reporting patterns (themes) within data,” (p. 79) which involves, “the searching across a data set to find repeated patterns of meaning,” (p. 86). A thematic analysis is an ideal way to study the communication within an online cancer community. It allows for social and psychological interpretations of the messages within the online community, and the ability to generate insights into the complicated narratives between community members (Braun & Clarke, 2006).
One of the advantages of using thematic analysis is its ability to summarize important features of a large data set, which is useful in identifying themes within communication. Braun and Clarke (2006) said that, “a theme captures something important about the data in relation to the research question, and represents some level of patterned response or meaning within the data set,” (p. 82). The importance of a theme is not necessarily captured by quantifying the number of times the theme appears within a data set. Even if the theme appears only a few times within your data, it’s overall importance may be measured by the depth of knowledge it adds in answering adding the research question (Braun & Clarke, 2006).

Content Analysis

Content analysis is a widely used method in both quantitative and qualitative research. Berelson (1954) defined it as a, “research technique for the objective, systematic, and quantitative description of the manifest content of communication,” (p. 485). As content analysis is considered the equivalent of survey research when studying texts, it is ideal to analyzing a large sample of messages (Bailey, 1994). Over the years, content analysis has been adjusted to reflect the inductive needs of qualitative research. According to Krippendorff (2004), “One could say that content analysis has evolved into a repertoire of methods of research that promise to yield inferences from all kinds of verbal, pictoral, symbolic, and communication data,” (p. 17). A content analysis is also a good way to study the online communication of cancer patients, because it can be used to study patterns of communication and describe trends within the content of communication (Bailey, 1994).
Setting

The study came from a sample of messages collected from an online community for people affected by cancer. The Cancer Support Community is an international, non-profit organization that provides emotional support and educational information to people with cancer and people who know someone with cancer. The Cancer Support Community was formed in 2009, when two well-known, non-profit organizations (The Wellness Community and Gilda’s Club Worldwide) dealing with cancer joined together. The Cancer Support Community provides support to millions of people affected by cancer through its website, global network of 50 affiliates, and 100 satellite locations (Cancer Support Community, 2011). The online discussion group has been operating since 2000, where more than 7,500 members have left nearly 13,000 posts in over 4,000 topics (Cancer Support Community, 2011).

![Figure 2: Screenshot of Cancer Support Community’s homepage.](image)

CSC’s website offers information for people affected by cancer in four main areas: newly diagnosed, learn about your cancer, cancer survivorship, and caring for your
loved ones. CSC also provides an online community that members can access at any time. The online community consists of three areas: online support groups that meet 90 minutes once a week; mylifeline.org, where members can create a website to document and share their experiences with cancer; and the online discussion group. The time frame chosen to collect messages from the online discussion was from January to May 2011, which resulted in a total of 286 messages. The discussion group area is open to all CSC members. The online group had 13 active topic areas during the sample collection: breast cancer; living with cancer in your 20s and 30s; living with loss; returning to work; advanced breast cancer; colorectal cancer; kidney cancer; lung cancer; lymphoma; managing cancer treatment side effects; ovarian cancer; parents with cancer who have young children; and prostate cancer.

**Sample/Participants**

The selection followed a multi-stage process. First, the primary researcher entered several search strings into commonly used search engines, including www.google.com and www.yahoo.com, to find appropriate online communities for cancer patients. Among the search strings used were “online cancer support community,” “Internet cancer support community,” and “cancer” in combination with “online community.” Next, the researcher gathered a short list of 10 online cancer communities, and then compared them to a list of criteria assembled to fit the analysis. One of the limitations common to most thematic analyses of online cancer communities is that the results would probably not be applied to the general population. The results are
Figure 3: Screenshot of Cancer Support Community’s online discussion forum

Figure 4: Screenshot of Cancer Support Community’s options for online support
weakened by limiting the data to communities that only cater to a certain type of cancer or to cancer patients only, not the caregivers, friends, and relatives of cancer patients. Since the researcher wanted the analysis to be applicable to the general population, the online cancer community chosen needed to be international, open to cancer patients and people affected by cancer, and not limited by a certain type of cancer. Since the researcher was looking for a sample that was representative of people with and affected by cancer, the researcher also searched for an all-inclusive online cancer community that was well known and well established. Finally, the researcher utilized an online community that was open to the public.

The top result for most of these searches was the Cancer Support Community. This non-profit organization also fit the previously mentioned criteria the best with the 10 online communities on the short list. The Cancer Support Community has online support groups for people and their loved ones with specific types of cancer. Since those support groups are for private members, the researcher limited data collection to the organization’s online message forum, where people are only required to have an account with the Cancer Support Community in order to view and/or write messages. The researcher remained in a strictly observational mode during the data collection process, and collected all of the messages left in the public forum over a five-month period from January 2011 through May 2011. The researcher never commented on or posted any messages in the forum or contacted any of the participants in any way.

The researcher collected a total of 286 messages from 125 contributors, of which 108 were female and 17 male. Out of the Cancer Support Community participants, 95 (83 female, 12 male) were people who currently have or previously had cancer; 25 (20
female, 5 male) were caregivers of people with cancer; and 5 (all female) were friends, relatives, or romantic partners of people with cancer. Two of the female participants who are former cancer patients served as administrators for Cancer Support Community, while two other female participants who previously had cancer seemed to be representatives of a different non-profit organization for people with cancer. The ages and geographic locations of the participants are unknown. However, most of the messages are written in English with American slang, so most of the participants are presumably from the United States. Fifty-three out of the 125 contributors posted multiple messages, including 40 (32 female, 8 male) cancer patients and/or survivors and 13 caregivers (12 female, 1 male).

The multiple contributors also included the two female Cancer Support Community administrators and the two female former cancer patients who were associated with an additional cancer-related, non-profit organization. Out of the total 286 messages, 221 (77.27%) were sent by females and 65 (22.72%) were sent by males. Out of the total 211 messages sent by multiple contributors, 155 (73.46%) were sent by females and 56 (26.54%) were sent by males. Messages sent by multiple contributors accounted for 211 (73.78%) of the total messages.1

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1 People who lurk in online communities can also gain benefits by reading comments without joining the conversation. However, this study analyzed the messages left by members, and did not measure the possible effects on lurkers. See Preece, Nonnecke, and Andrews (2004) for information on why lurkers lurk in online communities.
<table>
<thead>
<tr>
<th>Table 1: Breakdown of Messages</th>
<th>By Number</th>
<th>By Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total Number of Messages</strong></td>
<td>286</td>
<td>100%</td>
</tr>
<tr>
<td><strong>Written by Women</strong></td>
<td>221</td>
<td>77.27%</td>
</tr>
<tr>
<td><strong>Written by Men</strong></td>
<td>65</td>
<td>22.73%</td>
</tr>
<tr>
<td><strong>Written by Administrators</strong></td>
<td>21</td>
<td>7.34%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Table 2: Breakdown of Message Authors</th>
<th>By Number</th>
<th>By Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Authors</strong></td>
<td>125</td>
<td>100%</td>
</tr>
<tr>
<td><strong>Women</strong></td>
<td>108</td>
<td>86.4%</td>
</tr>
<tr>
<td><strong>Men</strong></td>
<td>17</td>
<td>13.6%</td>
</tr>
<tr>
<td><strong>Cancer Patients/Survivors</strong></td>
<td>95</td>
<td>76%</td>
</tr>
<tr>
<td><strong>Caregivers</strong></td>
<td>25</td>
<td>20%</td>
</tr>
<tr>
<td><strong>Friends/Family/Romantic Partners</strong></td>
<td>5</td>
<td>4%</td>
</tr>
<tr>
<td><strong>Administrators</strong></td>
<td>2</td>
<td>1.6%</td>
</tr>
<tr>
<td><strong>Representatives of other cancer-related, non-profits</strong></td>
<td>2</td>
<td>1.6%</td>
</tr>
</tbody>
</table>

Data Analysis

The unit of analysis was each message in the current sample. Each message was read and analyzed by the primary researcher. In order to ensure the accuracy of the analysis, a second researcher was enlisted to code 25% of the messages. The coders’
intercoder reliability was assessed at 87%. The researcher was chosen because she is knowledgeable in the area of online communication and has a good relationship with the researcher. She was blind to the conditions of the study. The coding schema was used to train the second researcher. Prior to coding the sample messages, the coders practiced coding messages from the online discussion area from a different time period. The coders were blind to the genders of the message authors during the content and thematic analyses. After the first analysis, the primary researcher examined the message content in relation to the gender of the authors.

**Conclusion**

This study employed multiple qualitative approaches to answer the three research questions. A thematic analysis and content analysis of messages from an online cancer community was used to identify the major themes of communication within online cancer communities, explore whether those people are seeking cancer-related information or emotional support the most within the online community, and compare and contrast gender-based, online communication by people affected by cancer.
CHAPTER FOUR: RESULTS

This research utilized a qualitative study with limited quantitative methods\(^2\) to (1) identify the major themes of communication within an online cancer community, (2) determine whether people use an online cancer community to seek/give health-related information or emotional support, and (3) analyze difference and similarities in communication between men and women in an online cancer community. First, the major themes of communication within the online cancer community are determined using a thematic analysis of five months’ worth of messages from an online cancer discussion forum. Next, the messages are analyzed blind using a qualitative content analysis, followed by an analysis comparing and contrasting the messages written by men and those written by women.

**RQ1: What are the major themes of online communication between people affected by cancer in an online cancer community?**

The analysis of messages yielded seven major themes of communication in an online cancer community. The first theme seems to serve as a method of introduction or an opportunity to vent as members relate the story of how they or a loved one was

\(^2\) Limited quantitative methods refers to the fact that this analysis can be aptly perceived as descriptive (as the title of this thesis says) in a social science sense, and that medium calculations are employed to highlight the significance of some of the observations being made.
diagnosed with cancer. Next, two recount how people interpret their feelings about having cancer. They may feel alone once, or optimistic about what life will be like after cancer. The next theme appears to be a direct response to people who said they feel alone. Other members will write to them and offer encouragement and support. Out of the three remaining themes, one concentrates on people who believe God had some direct impact on their cancer. Another focuses on people who are trying to get back to the normal life they can before cancer. Finally, the last theme encompasses people who are advocating for cancer-related causes. The themes include:

1. I was diagnosed.
2. I feel so alone.
3. You are not alone.
4. I am alive!
5. God has other plans for me.
6. There is no back to normal.

1. **I was diagnosed.**

   New members often introduce themselves to the online discussion group or introduce themselves to other members with a post that describes their initial diagnosis and subsequent medical and personal history with cancer. Friends and family members often introduced themselves with the story of how their loved one was diagnosed with cancer. Storytelling is an important function of the authors’ messages. The posts in this theme are often personal narratives that describe a person’s complex medical history and
personal feelings about cancer. The “I was diagnosed” theme also gives authors a chance to express what they want out of the online discussion group. The messages often end by asking a question, a request to hear from someone in a similar situation, or a plea or help or advice. The following message was written by a female cancer patient:

I was diagnosed in Feb 2010 with 2 lumps stage 2A breast cancer, Her2 +, estrogen +, progesterone +. I had lumpectomy, reexcision (to get clear margins), 6 rounds of chemo (TCH), 33 radiation, and continue with Herceptin infusions every 3 weeks until April. In Nov 2010, I had my ovaries removed (they produce estrogen, so that was the recommendation). Beginning 11/30/10, I started taking Arimidex. YUK! I feel awful. I am soooo stiff it is hard to do things. Even my fingers ache. Every joint in my body is locked up. The only relief I feel is when I lay down in bed. Even then, it's hard to roll over. Doctor said it takes up to 6 months for the effects to be more manageable. Anyone have any experience with Arimidex? I would like to hear what you've been through and if you found anything that works to help lessen the effects. I really don't want to stop taking it because I feel like if I have a recurrence in the future, I would kick myself for not sticking with it. Thanks!

2. I feel so alone.

These messages are often written by people who are overwhelmed in their experience with cancer. They feel alone, desperate, and sometimes have no hope left. People question why this is happening to them and their families. They don’t want to die.

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3 All of the messages from the Cancer Support Community are quoted verbatim, with the exception of the names being removed to protect the identity of the authors. As such, the messages contain spelling and grammatical errors.
Some express hope, while others shout cynicism and hatred about doctors and the cruelty of modern medicine. People often ask for emotional support in the form of a person to talk to. These people are looking for a connection to anyone who understands what they are going through, just like this message written by a 37-year-old woman with cancer:

They are calling it Bronchial Adenocarcinoma, which is also a NSCC. They did a fluid biopsy and have staged it at 3/4. It is extremely diffuse and they say it is non-operable. I am 37 yrs old. That was the hardest thing in the world to hear. They tell me if I take aggressive, then palliative chemo and radiation, I can possibly have 3 yrs. Without it, 9 to 13 months. I have 5 kids, ages 21, 19, 17, 15, and 13. So, I can relate to how it feels to have to tell your family that you may die. My kids are taking it in various ways, but I don't think any of them fully want to comprehend. My Mother just cries and tells me she feels helpless and my brother and sister just kind of ignore it. I know how hard it is to pretend to be in a good mood, to try to make everyone feel normal. It gets so tough to not have anyone to tell how I really feel. How scared I am. I am afraid to complain about the treatments, or how I'm feeling. I want to keep my family safe.

3. You are not alone.

Cancer patients and caregivers often feel overwhelmed when dealing with this disease. They are facing complicated medical decisions, overwhelming emotions, and a new life that is dominated by cancer. They seek information and advice from people who have already experienced cancer and emotional support from people who are going through the same situation. Members often reach out to make a connection with
members who feel alone. The messages are often filled with words of understanding, reassurance, and advice. Members make offers of friendship and let the other person know that they are not alone, as did this male member with leukemia:

Hi Im (Name) and also an APL patient, was diagnosed of February 2010. Let me tell you something new friend, you're not alone there is actually 5 of us and now 6 with you. Im the only male until recently I located another guy by the name of Jason, I still havent heard from him yet. All 5 of us are from Texas. (Name) you can email me directly to (Name)@email.com, I will be your new friend with some advice that will get you through this.

4. I am alive!

These messages are usually written by people who have had cancer, but came away from the experience with an optimistic outlook on life. They may contain detailed descriptions of their symptoms, medical treatments, or worst moments from their battle with cancer. However, having a serious illness like cancer has helped them to focus on the positive things in life. The authors focus on lessons they have learned. One woman, whose husband had an affair, described how she positively dealt with the loss of her hair. “I actually learned to LOVE being bald, I drew Homer Simpson hair on my head,” she said. Overall, the messages tend to carry optimistic, joyful, thankful, and humorous overtones. The following message was written by a 43-year-old mother with breast cancer:

For me, I had a couple of exhausting days around chemo, lost all my hair (traumatic!), weakness, white lines on my fingernails and fingertips were sore, and just last week (yes, 7 months after chemo!) I lost my entire big toenail. I deal
with the Arimidex severe stiffness everyday. But, you know what? I am alive! I am 43 yrs old and I'm able to enjoy every day with my husband and teenagers. I am thankful that the medical world was able to get me more time on this Earth! Did I look like a refugee? Not even close! And honestly, I haven't seen anyone who's been through this, who does. If there is one thing I know for sure....you really need to battle this with a positive attitude! My advice would be to take everything they offer so you don't have any regrets in the future. Good luck!

5. God has other plans for me.

These messages are characterized by people who believe that God had a direct influence on their life with cancer. The stories contain highly religious or spiritual tones. The authors believe they had cancer because it was part of God’s plan for them; that God saved them from dying from cancer; or that God gave them the strength to battle cancer. The following message was written by a female breast cancer survivor:

I was in pain, lost and didn't know where to turn. My only hope was being in church and those that prayed for me. On may6.2009 the doctors said I had 48 hours. I was very very sick. But God has other plans for me. I had to pull myself up--it wasn't easy. I involved myself in others that are walking these steps, and my church. Most understand if I have to bow out on a meeting but I really try to be where I csn. My advice is write down just one thing to do each day--even if it is a shower---- then the following week write down 2 things each day. It isn't easy but it can be done. As long as I have a breth to breathe then I will do something with my life. Sometimes the best thing to do when I was depressed was to help someone else. There is always others that need help.
Due to their optimistic nature and tendency to focus on lessons learned from cancer, these messages can be similar to the “I am alive!” theme. Survivors often describe a “higher understanding” that allows them to gain meaning or a new purpose from their experience with cancer. However, these messages can also refer to people who have accepted that they will ultimately die from cancer and believe that God is watching over them. They have made peace with their impending deaths, and find comfort in the personal knowledge that God will be with them when they die. The following message was written by a male member with prostate cancer:

I have no family, or friends. I retreated when I started going thru treatments. Its funny but, the only thing that I wanted to happen before I died was to go to Disneyland and spend a few days there, soaking up the sun, and having my last fling with fun. I don't have the money or means to do that, so, when I get ready to meet my maker, I will close my eyes and pretend that I am at Disneyland, and then slip into death. I know GOD will watch over me....I am HIS child, and I know he wants the best for me. I just wanted to respond to your message here, and congradulate you....GOD be with you and your husband...I pray for all of mankind, and the patients of cancer.

6. **There is no back to normal.**

These messages are written by people who have survived cancer and are now looking for a way to move on with their lives. When someone gets cancer, their lives and the lives of their loved ones are often dominated by the battle with cancer for an extended period of time. When the battle is over and seemingly won, survivors and caregivers can
have a hard time readjusting to a life that is not focused on cancer and find that they cannot return to the “normal life” they had before cancer. They wonder if the cancer will return. Authors also describe feeling “lost,” and ask existential questions about how they should live their lives and define their history with cancer. The following message was written by a female member who is in remission from breast cancer:

I agree with you there is no back to normal-as they say, THIS is the 'new normal'. I hate that term but it is so true. I've asked myself the same question about whether I should live life like I conquered cancer or wonder if it'll come back. In my opinion, I think it's healthier to think 'conquered, done' than to keep your mind occupied with whether it will come back-because maybe it won't, then you've wasted all that energy worrying for nothing.


These messages consist of invitations to join or seek more information concerning a cancer-related cause. People are often asked to “join together” or “join the cause” by participating in a fundraising event like a walk or cookbook; sharing their stories; joining a research project; visiting a website for more information; or attending a conference. People who share these messages are often organizers of fundraising events, or those who have found information useful and want to share it with others:

For the first time ever, breast cancer survivors have the opportunity to join together to help answer a critical question: What are the emotional and social needs of breast cancer survivors? By joining the Cancer Survivor Registry's M.A.P. (Mind Affects the Physical) Project, you can help change the breast
cancer experience for the millions of women who live it every day (more than 2.5 million to be exact). Joining The Breast Cancer M.A.P. Project is easy: Register in less than 10 minutes by answering some simple background questions (we’ll even give you a peak at how your fellow survivors have answered) Once a year, answer questions about your experience with breast cancer. Enjoy access to M.A.P. Project updates, breast cancer news, existing support resources for breast cancer survivors and opportunities to take part in other studies throughout the year.

RQ2: Do people affected by cancer use an online cancer community primarily to seek/give health-related information or emotional support?

A total of 286 messages were collected from the non-profit website Cancer Support Communities (CSC) during a five-month period from January 2011 to May 2011. CSC’s online discussion forum consisted of 13 active topic areas during the time of collection. These areas ranged from cancer-specific discussions (breast, advanced breast, lung, colorectal, ovarian, prostate, lymphoma) to topics that dealt with cancer-related lifestyle issues (returning to work, parents with young children), medical treatments (managing cancer treatment side effects), and survivors (living with loss).

An initial analysis yielded a categorical scheme of 13 categories developed from previous studies (Klemm et al., 1998; Ginossar, 2005; Anderson, 2011; Sullivan, 2003) and inductively from the data. Further analyses led to the combination and exclusion of certain categories, which resulted in 10 major categories of: Giving Information, Seeking Information, Giving Emotional Support, Seeking Emotional Support, Prayer/Spiritual,
Gratitude, Administrative, Advocacy, Humor, and Miscellaneous. The first category of Giving Information was further divided into two sub-categories: Personal Experience and Advice/Opinion.

**Table 3: Classification of Messages Within an Online Cancer Community**

<table>
<thead>
<tr>
<th>Categories</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Giving Information</td>
<td>“My Oncologist had to change my chemo from Taxol/Carboplatin to Gemzar/Carbo, because the cancer became resistant to Taxol. The Gemzar seemed to work, but it wipes out most of your WBC, Platelets, and gives a very low Hemoglobin.”</td>
</tr>
<tr>
<td>1A. Personal Experience</td>
<td>“I had robotic surgery, which is amazing in terms of recovery--no up and down incision, but 4 small ones. If one can have robotic surgery, I highly recommend it.”</td>
</tr>
<tr>
<td>1B. Advice/Opinion</td>
<td>“My advice...contact your local hospice staff asap (ask hospital social worker for references).”</td>
</tr>
<tr>
<td>2. Giving Emotional Support</td>
<td>“reading your entries really makes me happy for you. You have come a long way and the strength you have displayed is amazing! Go after your dreams...”</td>
</tr>
<tr>
<td>3. Seeking Information</td>
<td>“Is there anyone on this site that is currently experiencing or a survivor of stage 3C endometrial cancer and is young? I am 38 with a rare type of aggressive grade 3 cancer and just want to hear if anyone out there has survived this and how they did it.”</td>
</tr>
<tr>
<td>4. Seeking Emotional Support</td>
<td>“I have been reluctant to seek support groups until now due to a bit of survivor's guilt and fear of hearing too much bad news. Lately however, I have come to realize that I need to talk to more people who understand without 10 minutes of explanation.”</td>
</tr>
<tr>
<td>5. Prayer/Spiritual</td>
<td>“I know GOD will watch over me....I am HIS child, and I know he wants the best for me. I just wanted to respond to your message here, and congratulate you...GOD be with you and your husband...I pray for all of mankind, and the patients of cancer.”</td>
</tr>
<tr>
<td>6. Gratitude</td>
<td>“Thank you for adding this post.”</td>
</tr>
<tr>
<td>-----------------------</td>
<td>----------------------------------</td>
</tr>
<tr>
<td>7. Administrative</td>
<td>“Welcome to this new forum for people impacted by prostate cancer. We hope you will find this discussion group helpful and you share with and support each other.”</td>
</tr>
<tr>
<td>8. Advocacy</td>
<td>“The Undy 5000 is a family-friendly 5K run/walk that is unique because participants are encouraged to run in their boxers to bring attention to the area affected by colon cancer. We have found that by getting people talking about this disease, we can save lives!”</td>
</tr>
<tr>
<td>9. Humor</td>
<td>“I actually learned to LOVE being bald, I drew Homer Simpson hair on my head, I made jokes of all the horrible side effects I went through, I made it through with flying colors.”</td>
</tr>
<tr>
<td>10. Miscellaneous</td>
<td>“i edited &amp; moved the original message.”</td>
</tr>
</tbody>
</table>

The following are descriptions of the categories:

1. **Giving Information**: Giving Information consists of giving factual information, advice, opinions, and sharing personal stories. Many authors shared stories of personal experiences with cancer, gave advice on medical treatments, and shared information like medical statistics, news stories, and drug trials. This category was divided into two sub-categories: Personal Experience and Advice/Opinion. Personal Experience pertains to information that is shared through a personal narrative or story, while Advice/Opinion refers to advice that one author gave and opinions on topics like alternative medicine, doctors, and cancer treatments.

2. **Giving Emotional Support**: Giving Emotional Support consists of messages that offer caring, support, and encouragement (“I wish you well,”), or express sympathy (“I’m
really sorry to hear about your husband having an affair when you are dealing with cancer,”) and empathy (“I know how hard it is to pretend to be in a good mood.”).

3. Seeking Information: These messages contain a large variety of requests for information. Members often ask for information about cancer treatment centers, doctors, pharmaceutical trials, alternative medicine, etc. Furthermore, members often ask to speak to people who currently or previously had the same type of cancer and make personal inquiries about a person’s experience with cancer.

4. Seeking Emotional Support: People who seek emotional support often “feel alone.” They often look for help and people to talk to.

5. Prayer/Spiritual: These messages consist of references to prayer, religious, and spiritual issues. Members would often pray for themselves and other members and speak about God or a higher power.

6. Gratitude: This category involves any messages that express thanks or gratitude. Members often thank other members for responding to a message, giving comfort, offering prayers, giving advice, etc.

7. Administrative: These messages are authored by the Cancer Support Community administrators who monitor the online discussions, welcome new members, respond to questions, and invite members to join other areas of the website like the weekly support meetings.

8. Advocacy: This category consists of messages where the authors are supporting or recommending a cancer-related cause or event. These include announcements of fundraising events, invitations to join research trials, and pleas for cancer survivors to “share their stories.”
9. **Humor:** Some messages use jokes and humor phrases like “lol” (Laughing Out Loud) to describe certain experiences with cancer or to make a particularly serious message seem less tense.

10. **Miscellaneous:** Messages that did not fit into any of the previous categories were classified as miscellaneous.

**Analysis of Messages**

Most of the messages contained multiple categories and were coded appropriately. The analysis of 286 messages yielded 654 major categorical codes, resulting in an average of 2.29 categories per message. The data was first analyzed to determine what percentage of messages contained each category. For example, 12.9% of the messages contained Gratitude. Next, the messages were analyzed a second time to determine the total percentage of each category in relation to the total amount of codes found during the analysis. For example, there were 83 codes of Seeking Information, which equals 12.7% of the 654 total categorical codes.

The analysis found that Giving Information is the primary activity of people who give messages within an online cancer support community. More than four out of every five (82.5%) messages contained some form of Giving Information. Furthermore, the analysis of the sub-categories found that 65.7% of these messages contained a Personal Experience, while 44.8% gave Advice/Opinions. Next, more than half of the messages (51.4%) also contained Giving Emotional Support, followed by Seeking Information (29%) and Seeking Emotional Support (18.5%). The second analysis found that these four categories account for 78.8% of the total amount of codes found in the messages. The messages also consisted of 14% Prayer/Spiritual, 12.9% Gratitude, 7.3%
Administrative, 5.9% Advocacy, 3.5% Humor, and 3.5% Miscellaneous. In addition to, the second analysis of the percentages of the individual categories in relation to the total amount of codes found that 36.1% of the codes were categorized as Giving Information. This category was followed by Giving Emotional Support, 22.5%; Seeking Information, 12.7%; Seeking Emotional Support, 8.1%; Prayer/Spiritual, 6.1%; Gratitude, 5.7%; Administrative, 3.2%; Advocacy, 2.6%; Humor, 1.5%; and Miscellaneous, 1.5%. The full results are described in the following table.

### Table 4: Types of Messages Within an Online Cancer Community

<table>
<thead>
<tr>
<th>Types of Messages</th>
<th>Total Messages</th>
<th>Total Percentages of Codes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Giving Information</td>
<td>82.5%</td>
<td>36.1%</td>
</tr>
<tr>
<td>Personal Experience</td>
<td>65.7%</td>
<td>X</td>
</tr>
<tr>
<td>Advice/Opinion</td>
<td>44.8%</td>
<td>X</td>
</tr>
<tr>
<td>Giving Emotional Support</td>
<td>51.4%</td>
<td>22.5%</td>
</tr>
<tr>
<td>Seeking Information</td>
<td>29%</td>
<td>12.7%</td>
</tr>
<tr>
<td>Seeking Emotional Support</td>
<td>18.5%</td>
<td>8.1%</td>
</tr>
<tr>
<td>Prayer/Spiritual</td>
<td>14%</td>
<td>6.1%</td>
</tr>
<tr>
<td>Gratitude</td>
<td>12.9%</td>
<td>5.7%</td>
</tr>
<tr>
<td>Administrative</td>
<td>7.3%</td>
<td>3.2%</td>
</tr>
<tr>
<td>Advocacy</td>
<td>5.9%</td>
<td>2.6%</td>
</tr>
<tr>
<td>Humor</td>
<td>3.5%</td>
<td>1.5%</td>
</tr>
<tr>
<td>Miscellaneous</td>
<td>3.5%</td>
<td>1.5%</td>
</tr>
</tbody>
</table>
RQ3: What are the primary, gender-based differences and similarities in the online communication of people affected by cancer in an online cancer community?

An analysis of gender-specific messages from an online cancer support community showed that men and women who are affected by cancer communicate largely the same in the major categories of giving information, giving emotional support, seeking information, and seeking emotional support. The full results are described in the following table.

<table>
<thead>
<tr>
<th>Table 5: Types of Gender-Based Messages Within an Online Cancer Community</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total Female Messages</strong></td>
</tr>
<tr>
<td>Giving Information</td>
</tr>
<tr>
<td>Personal Experience</td>
</tr>
<tr>
<td>Advice/Opinion</td>
</tr>
<tr>
<td>Giving Emotional Support</td>
</tr>
<tr>
<td>Seeking Information</td>
</tr>
<tr>
<td>Seeking Emotional Support</td>
</tr>
<tr>
<td>Prayer/Spiritual</td>
</tr>
<tr>
<td>Gratitude</td>
</tr>
<tr>
<td>Administrative</td>
</tr>
</tbody>
</table>
While a high amount of both male (83.1%) and female (82.4%) messages contained information giving, one major difference occurred in the way this information was provided in the sub-categories of personal experience and advice/opinion. Women were more likely to give information in the form of a personal experience (69.2%) than advice and opinions (43%). Even though men gave information as a personal experience (53.8%) more often than advice/opinions (50.8%), men were still more likely to give advice/opinions more than women and use personal experiences less often than women.

Next, although both men and women gave emotional support approximately 22.5% of the time, female messages contained a slightly higher amount (52.5%) of giving emotional support than male messages (47.7%). Furthermore, men and women sought information and emotional support in approximately the same amounts. Men sought information 13% of the time and sought emotional support 8.7%, while women sought information 12.6% and sought emotional support 7.9%. Similarly, the male messages (15.4%) contained slightly more references to prayer and spiritual beliefs, when compared to female messages (13.6%). Women were more likely to express gratitude (14%) in their messages than men (9.2%). Finally, the female messages contained all messages that were written by administrators of the online cancer support community and all advocacy-related messages. This is not to say that men who are affected by cancer do not write administrative or advocacy messages. In this particular instance, two female
administrators monitored the online community during the period of data collection and authored all 21 administrative messages. Similarly, the advocacy messages were in large part authored by two women who work for cancer-related, non-profit organizations.

**Conclusion**

According to this research, it is interesting to note that people who participate in an online cancer community are far more likely to give than they are to receive. One could surmise that those who join this discussion forum do so with a specific purpose in mind: to find information about a specific type of cancer, to research a doctor or medical treatment, or to find someone to talk to. Yet, members gave information and emotional support at a much higher rate than they sought information and emotional support. When people did give information and emotional support, they often did so in the form of a narrative that combined personal experience with advice. Even the major themes of communication seemed to encompass many elements of storytelling. Hoybye, Johansen, and Tjornhoj-Thomsen (2005) found that cancer patients experience therapeutic benefits by sharing their personal stories online, including gaining a place to vent frustrations and laugh about the hardships of cancer. The online community “can lead to the articulation and transformation of the individual experience of illness by offering a mode of action,” (Hoybye et al., 2005, p. 216). It seems that the people who joined this online cancer community are really just looking for a place to share their stories, and the discussion forum offers a useful medium to do so.
### Table 6: Comparison of Messages Within an Online Cancer Community

<table>
<thead>
<tr>
<th>Category</th>
<th>Total Messages</th>
<th>Total Percentages of Codes</th>
<th>Total Female Messages</th>
<th>Total Percentages of Female Messages</th>
<th>Total Percentages of Male Messages</th>
<th>Total Male Codes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Giving Information</td>
<td>82.5%</td>
<td>36.1%</td>
<td>82.4%</td>
<td>35.3%</td>
<td>83.1%</td>
<td>39.1%</td>
</tr>
<tr>
<td>Personal Experience</td>
<td>65.7%</td>
<td>X</td>
<td>69.2%</td>
<td>X</td>
<td>53.8%</td>
<td>X</td>
</tr>
<tr>
<td>Advice/Oppinion</td>
<td>44.8%</td>
<td>X</td>
<td>43%</td>
<td>X</td>
<td>50.8%</td>
<td>X</td>
</tr>
<tr>
<td>Giving Emotional Support</td>
<td>51.4%</td>
<td>22.5%</td>
<td>52.5%</td>
<td>22.5%</td>
<td>47.7%</td>
<td>22.5%</td>
</tr>
<tr>
<td>Seeking Information</td>
<td>29%</td>
<td>12.7%</td>
<td>29.4%</td>
<td>12.6%</td>
<td>27.7%</td>
<td>13%</td>
</tr>
<tr>
<td>Seeking Emotional Support</td>
<td>18.5%</td>
<td>8.1%</td>
<td>18.6%</td>
<td>7.9%</td>
<td>18.5%</td>
<td>8.7%</td>
</tr>
<tr>
<td>Prayer/Spiritual</td>
<td>14%</td>
<td>6.1%</td>
<td>13.6%</td>
<td>5.8%</td>
<td>15.4%</td>
<td>7.2%</td>
</tr>
<tr>
<td>Gratitude</td>
<td>12.9%</td>
<td>5.7%</td>
<td>14%</td>
<td>6%</td>
<td>9.2%</td>
<td>4.3%</td>
</tr>
<tr>
<td>Administrative</td>
<td>7.3%</td>
<td>3.2%</td>
<td>9.5%</td>
<td>4.1%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Advocacy</td>
<td>5.9%</td>
<td>2.6%</td>
<td>7.7%</td>
<td>3.3%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Humor</td>
<td>3.5%</td>
<td>1.5%</td>
<td>3.2%</td>
<td>1.4%</td>
<td>4.6%</td>
<td>2.2%</td>
</tr>
<tr>
<td>Miscellaneous</td>
<td>3.5%</td>
<td>1.5%</td>
<td>2.7%</td>
<td>1.2%</td>
<td>6.2%</td>
<td>2.9%</td>
</tr>
</tbody>
</table>
CHAPTER FIVE: DISCUSSION

People affected by cancer often turn to the Internet, especially if they cannot find the support they need in person. While online, they may look for information about doctors and medical treatments, or people to talk to about what they are going through. All of these things can usually be found in an online community. This thesis surmised that people use cancer-related online communities to give/seek health-related information more than they give/seek emotional support. To test this theory, the following questions were answered through qualitative content and thematic analyses of messages in a cancer-related online community:

RQ1: What are the major themes of online communication between people affected by cancer in an online cancer community?

The analysis of messages yielded seven major themes of communication in an online community for cancer. They include:

- I was diagnosed.
- I feel so alone.
- You are not alone.
- I am alive!
- God has other plans for me.
- There is no back to normal.
• Join Together.

The communication in these messages focused on different aspects of dealing with cancer. The first theme, “I was diagnosed,” primarily served as a method of introduction by sharing a member’s personal story with cancer. These were often the longest messages, as well as the shortest messages. Members might introduce themselves with nothing more than “I’m new,” or give a two-page summary of their diagnosis of cancer and corresponding medical history. Nevertheless, these represent the most common messages within the discussion forum, and the messages with the most potential for storytelling.

Out of the seven themes, two seem to focus on how people feel about having cancer. First, the “I am alive,” theme is centered around people who are thankful to be alive after having cancer. Living with a life-threatening illness has made them re-examine their choices. While cancer is still a very real part of their lives, they are grateful for the present, and many look forward to an optimistic future. As one member said, “I, too, have a fear of dying, but I am so grateful to still be here to fight after all of this time.”

Next, many of the messages within the “I feel so alone,” theme were written by people who are looking for emotional support. Many of them have just been diagnosed with cancer and do not know what to do. Others do not have strong emotional support from their friends and family and are looking for support online. The “You are not alone,” theme is often a direct response to the authors of messages within the “I feel so alone,” theme. The members feel a connection with fellow cancer patients, survivors,
and caregivers, and they want to respond. In addition to words of empathy, sympathy, and encouragement, these messages usually contain personal experiences that let the respondent know the author understands what they are going through.

An interesting phenomenon emerged within the “You are not alone,” theme. There seems to be a handful of individuals who consider themselves to be the elders of the online community. They frequently browse the discussion forum and look for messages to respond to, especially the messages of new members. In doing so, they usually post a higher-than-average number of messages than the average member. These members are often survivors of multiple bouts with cancer, who feel that it is their responsibility to monitor the group and share their experiences. They often reach out to new members and members who are particularly vulnerable and upset. These members are quick to share their contact information and are often available to speak with other members at all times. They are quick to make emotional connections with fellow members and appear to take on the role of a guide and mentor, possibly even a parental figure. This cancer survivor responded to a new member who felt nervous about their recent diagnosis:

I'm a two-time cancer survivor -- testicular in '94 and kidney in '10. After '96/'97, I did not really think much at all about ‘it’ coming back. A routine CT scan in Oct '10 found a new growth. So....I've dealt with that, back into the 3-month CT scans for a year or two, and life goes on. And, yah, I'm probably way too old to be posting in this forum. But, hey, I thought I'd share some of wisdom & experience. :-}
Barak, Boniel-Nissim, and Suler (2008) have said that members in an online support group find a sense of empowerment by sharing their knowledge and taking on the “role of a guide, instructor, and helper,” (p. 1874). Furthermore, Meier et al. (2007) have said members who share their experiences and coping methods “find rewarding roles as ‘elders,’” (Dominance of Offers Over Requests section). It is likely that these guides of the online cancer community gain a feel-good sense of achievement by responding to so many messages.

The remaining three themes involve how people accept cancer as a part of their lives. Authors of the “God has other plans for me,” theme believe that God is responsible for their cancer in some way. These messages can have a positive or negative context, and they usually deal with people explaining, understanding, or accepting their cancer. The authors believe that God gave them cancer for a specific reason, or that God saved their lives. Others have accepted that they will die and acknowledge it as God’s decision. According to Harter (2012), this type of narrative sense making is common in health stories. It seems that these strong admissions of faith give the members a certain amount of comfort and power in a situation where they are not always in control. If God is the reason why someone has cancer, then what right does anyone have to question that? By granting control to God, the members are absolved of dealing with the final responsibility of cancer. One female cancer patient explained, “Knowing in my heart of hearts that God is in full control of all circumstances and what I’m going through, so I can trust Him no matter what.”

Next, the “There is no back to normal,” theme is also about accepting cancer, but it focuses on how to accept cancer once its gone. Most of these authors want to get back
to the “normal life” they had before cancer. When they realize they cannot get “back to normal,” the life they create after cancer is often described as “the new normal.” According to Harter, Patterson, and Gerbensky-Kerber (2010), “Humans make and tell stories, both of which remain central to clinical interactions. Individuals grapple with the task of remapping their existence when corporeal exigencies threaten previously imagined life courses—they must make sense of acute or chronic illness and create ‘new normal’s,’” (p. 467). These members are often facing an identity crisis. Many of these members accepted cancer as the dominating figure in their lives for an extended period of time, and they identify themselves according to their cancer roles: a patient, a survivor, a caregiver, etc. Many of these authors described the need to act in the way that society deemed appropriate for cancer patients. One female cancer patient said, “Most people think I am the strongest person in the world because I put on a happy face in public. Privately, it is a lot different.”

Finally, authors of the “Join Together” theme have not only accepted cancer as a permanent part of their lives, but have embraced their cancer personas of cancer as a way to contribute to cancer relief. The members use their knowledge and experience of cancer to raise funds, research, counsel, and lobby for cancer-related causes.

**RQ2: Do people affected by cancer use an online cancer community primarily to seek/give health-related information or emotional support?**

Previous studies have shown that people researching cancer online are most often seeking health-related information and advice, followed by emotional support (LaCoursiere et al., 2005; Meier et al, 2007; Chung & Kim, 2008). The results of this study certainly indicate that is true. Furthermore, they indicate that people who use a
cancer-related online community give information and emotional support far more often than they seek information and emotional support. LaCoursiere et al. (2005) also found that cancer patients were more likely to give support than to talk about themselves. If people visit an online community with a specific purpose in mind, it is logical to conclude that they would seek more than they would give. So how can these results be explained? It remains a difficult question to answer due to the inherently complex nature of these messages. Nearly all of the messages coded in the study contained multiple codes and themes. Consider this message written by a female cancer patient:

I am so saddened by what I am reading here. Especially when a husband is so selfish he can't support his wife, who is sick. He obviously doesn't have the compassion or empathy you need. Can you find a support group nearby? Is there a Wellness community near you, or maybe a hospice with support groups? You need someone who can care for you and help you. When my husband was sick from the chemo, and none of the drugs they gave him helped, I finally got him to try pot; it worked. But this is California where you can get a rx for it, and it is legal to buy from certain collectives. If you are in a state where you can't get it legally, then the hell with it - go find a dealer and get some! It may be illegal, but it's worth it. It may also give you the munchies, but it didn't do that to my husband.

As for a boyfriend breaking up with you when you have a parent who is sick, my daughter's boyfriend - now fiancee - was here with her for the time when her father, my husband obviously - for the week he was dying. I don't mean to be negative, but his cancer spread to his liver and his bone marrow and there wasn't
anything left to do so we brought him home and had hospice. He was surrounded by his family and close friends when he passed away, and although it wasn't a peaceful death, I could see that he was a peace after he passed. His face smoothed out, he almost had a semi-smile on his face! But I was there for him for the entire year he was sick; we made a vow - in sickness and health, and he was there for me when I needed him. If your partner can't be there for you, it will only cause more stress and you don't need that now - you need less and more support than ever. If you can go somewhere else and get that, then go. Or make him go.

This type of multi-purposed message is common amongst the messages of the online discussion forum. This woman is responding to multiple messages. Her message is in reply to another female cancer patient who feels that her husband is not supporting her and also to the daughter of a cancer patient whose boyfriend couldn’t handle the stress of her parent’s cancer. The primary purpose of the author’s message is to offer support to both women, but the author does much more than that. She gives advice to the first woman by telling her to find a support group and seeks additional information by asking her questions. The author also gives the woman information on how to obtain marijuana to help with pain, a personal narrative on how she got it for her husband, and gave her opinion that marijuana, “may be illegal, but it’s worth it.”

The real variable that complicates the question of whether people spend more time seeking/giving information or seeking/giving emotional support while in an online cancer community is the fact that people often give information and emotional support through the use of personal narratives dealing with their own experiences with cancer. Storytelling is a major factor in almost every message given. Even when giving
information and advice, it is often completed by telling a personal story of past mistakes or triumphs. There are several explanations for this phenomenon. First, Harter (2012) explained that people affected by cancer often use narratives to cope with and make sense of the way cancer affects their lives. Harter (2012) said, “Narratives endow disruptions with meaning by organizing events in time and space, developing characters and their relations with one another, and ascertaining causality by plotting otherwise disconnected events,” (p. 5). Members who participate in an online community may do so to fulfill a specific purpose, yet they contribute more than they intended, because they feel a connection with other people affected by cancer. Orgad (2006) theorized that Americans are more likely to share personal information within an online cancer community, because they have a cultural tendency to disclose personal information. This is also known as the digital disinhibition effect (Deffenbaugh, 2010). Another explanation for this tendency can be found in the feelings of empowerment that members develop by sharing knowledge in an online support group (Barak, Boniel-Nissim, & Suler, 2008).

In conclusion, people who participate in an online cancer community do so, because they are primarily seeking and/or giving information on a cancer-related manner. However, people who join these online communities often become emotionally invested in other members. They respond to their messages, offer advice, ask how they are doing, and offer encouragement in the form of anecdotes, prayers, and well wishes. Even though they are primarily seeking information, they also spend a large amount of time offering emotional support as well. Since emotional support is often given in combination with a personal narrative that contains information and advice, members often provide information and emotional support at the same time.
RQ3: What are the primary, gender-based differences and similarities in the online communication of people affected by cancer in an online cancer community?

Previous studies have shown that women are more likely to use an online cancer community for emotional support, while men are more likely to use it for informational purposes (Sullivan, 2003; Owen et al., 2004). Yet, the results of this study indicate that men and women use online communication in more equal ways. Both men and women give/seek information and emotional support at close levels. The biggest difference is that female messages gave emotional support 4.8% more often than male messages.

Perhaps these findings can be better explained by the Giving Information subcategories of Personal Experience and Advice/Opinion, which show a much greater statistical difference between female and male messages. Women gave information in the form of a personal experience over 15% more often than men, while men gave advice and opinions nearly 8% more often than women. This would indicate that women are more comfortable sharing personal information. Taylor et al. (2000) said that women are more likely than men to engage in social relationships while dealing with stressful situations. This might also explain why women expressed gratitude 5.8% more often than men. Although men shared personal experiences 3% more often than advice, they are still more comfortable sharing advice and opinions than women. Owen et al. (2004) explained that men are more reluctant to express emotion than women.

Limitations

Although this research helped to explore how people affected by cancer utilize communication in an online community, this study had several limitations. The first limitation was related to the sample size and number of coders. This study contained a
sample of 286 messages that was coded by the primary researcher, and a second coder to ensure intercoder reliability. Although this study had significant findings, additional coders could have ensured a larger sample size and more detailed findings.

The second limitation concerns the validity of the analysis of messages based on gender. As it stands, the sample yielded a larger amount of female messages than male messages. Therefore, it is likely that the results of this analysis more accurately reflect women than men. Also, the male members contained one outlier who wrote a much larger amount of messages than the rest of the members. Research (Radin, 2006; Coulson & Knibb, 2007) has shown that these guide figures are common in health-related online support groups, so the researcher chose to leave the messages in tact. However, it is possible that leaving his messages within the data set misconstrued the results.

The next limitation concerns demographics. Although the messages were analyzed in content according to gender, this was the only demographic feature taken into consideration. Also, the fact that this is an English-speaking website means that the members were primarily from the United States. Even though there were a number of people who stated that they did live outside the United States, not enough members stated this information within their messages to gauge an accurate picture of the members’ nationalities. This particular study did not allow for the collection of more demographic information. However, the research would have been strengthened by knowing how certain demographic factors affect communication in an online cancer support community.
Recommendations for Future Research

Based on the results of this study, there are several avenues for future research. First, some of the limitations identified in the previous section could be addressed and minimized, or eliminated. Additional researchers could study a larger sample of messages to verify the accuracy of the results. Furthermore, researchers could study a sample of messages that also contains the authors’ demographic information. The Pew Internet & American Life Project found that three-quarters of American adults who did not graduate high school do not access health information online (Fox, 2011a). An analysis of the demographic background of the authors could explore this phenomenon and also how different demographic factors influence how people use communication in an online cancer support community. Some of the authors who lived outside of the United States mentioned having different experiences because of their country’s healthcare system. For example, one woman from Canada commented that she was glad she lived outside of the United States, because her country has a government healthcare plan that pays for procedures she didn’t think she could afford if she had private health insurance. It would be interesting to explore the differences in communication based on countries with different healthcare systems. Last, a larger data sample could also provide an opportunity to identify more members who act as guides within the online community. It would be interesting to explore the motivating factors behind these individuals, who seem to have a unique position as a mentor to other cancer patients.

Conclusion

Several conclusions can be made based on the results of this study. First, there is no question that people give/seek information more often than they give/seek emotional
support. Furthermore, people are much more likely to give information and emotional support, than they are to seek them. This raises questions about people’s motivations for participating in an online cancer support community. One could theorize that people join one of these online communities with a specific purpose in mind. If that is the case, why do the members give more information or emotional support than they ask for?

With 65.7% of messages containing some sort of personal experience, storytelling is obviously an important function of these posts. Participating in an online conversation holds several important differences than participating in a face-to-face conversation. The conversations held in the online discussion groups are posted in text, continuous, and long lasting, while face-to-face conversations are fleeting. If one can imagine that the messages they post in an online community are lasting, then perhaps it is desirable for someone facing a life-threatening illness to write in a place that offers the semblance of permanence.

The Internet has rapidly changed the way we live our daily lives, and it is continuing to transform the ways in which we receive health information. While visiting a healthcare provider is still the most prevalent way to receive health information, turning to the Internet is a close second option that is quickly closing the gap. For someone who is facing a serious, life-changing illness like cancer, the need for constant and consistent information and emotional support is vital. Convenience may be a motivating factor that explains why people with life-threatening illnesses turn to the Internet, but what happens once they get there is what is really unique. In a world where people cannot always connect with someone in real life, they often turn to the Internet to get the support they need. Even though they are connecting in a virtual world, those connections are very
real. People don’t form connections based on geographic boundaries. They form communities based on their personal connections with cancer.
References


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