"IT'S A MICROCOSM OF LIFE":
WEAVING A WEB OF INFORMATION AND SUPPORT
IN AN ONLINE BREAST CANCER COMMUNITY

BY

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DISSERTATION

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ABSTRACT

In this ethnographic study, I examined the interactions of an online breast cancer community to understand participants' information behavior, the role of social support in participants' lives, how being part of this community influences health decisions and practices, and how the community is integrated into participants' everyday lives.

Using archives analysis, participant-observation, and interviews, I learned that this community is a microcosm of daily life, comprising a complex culture that has a significant impact on many participants' lives. Members of the community help each other as they deal with breast cancer, but the community also incorporates diverse interactions that exceed the boundaries of breast cancer, reaching into other health conditions as well as the challenges and joys of everyday life. Many participants noted strong emotional ties to others in the community, enhancing these ties through email, phone conversations, and face-to-face meetings. An important finding of this study is the social integration of participants beyond the scope of the online space through their communication practices as well as the lengths they go to when assisting each other.

I also found that exchanges of information and social support in this community are interwoven, inextricably linked in such a way that most conversations are suffused with both, occurring in conjunction with each other. My analysis showed that interactions that initially appeared to be either information exchange or expressions of social support actually comprised elements of both, threaded together in such a way as to make it difficult to distinguish one from the other.

This study offers insights about the richness and complexity of relationships that occur in this particular online forum as well as insights into the potential of online health communities. Community participants have built a web of relationships through conversations interwoven with information and social support, constructing an atmosphere that is helpful, supportive, and meaningful, and which often expands beyond the scope of an online community.

To my kids

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CHAPTER 1

INTRODUCTION

> It was the only place—it was the only place that I could speak my mind and talk about the things that bothered me. Where I was Number One—truly listened to, where I was understood….I still feel like this is the only place I'm really understood.

Jenny, a delightful middle-aged woman who has had several health scares in her life, is speaking about an online breast cancer forum that she found just after having had radiation for breast cancer. One of her first posts relates the burning side effects she suffered from radiation and how she dealt with them. In this same post, she asks questions about the side effects of tamoxifen, a hormonal drug used in treating breast cancer; lymphedema, a swelling, numbness and discomfort of the arm or hand that may occur after breast cancer surgery; and chemobrain, which refers to memory loss and problems of concentration brought on by chemotherapy (Breastcancer.org, 2011a, 2011b; Mayfield, 2009; U. S. Department of Health and Human Services, 2008). Jenny has been a member of this forum, which participants refer to as "the List," for 11 years. The purpose of her early visits to the List was to find information and social support to help her cope with breast cancer treatment. Over the years she has also provided information and social support to new breast cancer patients who found the List. Jenny's conversations with List participants include discussions about other health issues as well as the daily life problems and joys that occur for most of us. Through her association with individuals on the List, Jenny's interactions have evolved to encompass face-to-face meetings, involvement in List-related administrative activities, and the formation of close friendships. Jenny's story is only one of many stories of individuals who have accessed the List because of breast cancer, but it offers a glimpse into how being involved with this particular online forum can impact participants' lives. This study examines the intersections of information and social support as they weave through

and interact with each other in the lives of individuals who have been drawn together as a result of their breast cancer experiences.

1.1 Impact of a Breast Cancer Diagnosis

The American Cancer Society (2009) predicted the diagnosis of 192,370 new cases of invasive breast cancer in 2009, with an additional 62,280 cases of *in situ* (precancerous cells that remain in one location rather than invading other tissue) breast cancer. Worldwide, breast cancer cases number approximately 1.3 million each year. Breast cancer is the most frequently diagnosed cancer in women, and over the past 25 years, incidence rates have risen approximately 30% in western countries, likely due to changes in reproductive patterns, but also due to increased levels of screening (Garcia et al., 2007).

Despite its prevalence and visibility, receiving a diagnosis of breast cancer is a frightening experience for everyone involved (Manne et al., 2003; Radin, 2001, 2006; Sales, Schulz, & Biegel, 1992). Those diagnosed immediately face multiple treatment options, prognoses, and future life choices. They are likely to become confused, anxious, and uncertain about how to navigate treatment and prepare themselves and loved ones for the ensuing experience of breast cancer. Numerous quality of life issues arise, including physical responses such as fatigue, hair loss, and weight gain; emotional responses such as depression, social withdrawal, uncertainty, and anxiety; and concerns about lifestyle and careers (Beatty, Oxlad, Koczwara, & Wade, 2008; Gustafson et al., 2001; Leydon et al., 2000; Shaw, Hawkins et al., 2006).

A diagnosis of breast cancer elicits feelings of isolation and loneliness, often causing close relationships to become strained due to fear and reluctance to engage in conversations

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about outcome possibilities (Shaw, McTavish, Hawkins, Gustafson, & Pingree, 2000). Coping with the multitude of associated emotional and physical challenges in addition to the illness brings questions that friends and family might not be able to answer, and which medical providers might not have time or availability to answer (Fogel, Albert, Schnabel, Ditkoff, & Neugut, 2002). Additionally, although some concerns disappear or subside over time, breast cancer also comprises characteristics of chronic illness due to several factors, including recurrence, fear, and being aware of the amount of time one has been cancer-free. Survivors also have ongoing concerns necessitating access to information and social support long after undergoing treatment (Allen, Savadatti, & Levy, 2009; American Cancer Society, 2009).

Several years ago in an article in *Newsweek,* the author stated, "Unfortunately, many hospitals still do little or nothing to connect newly diagnosed [cancer] patients with those who have survived the same disease for several years, though this is what we crave" (Alter, 2007). Though this statement is not specifically referencing breast cancer, its sentiments are applicable to individuals affected by breast cancer. Patients who are diagnosed want to talk with others who have had the experience—they want to know what to expect, and they may not know anyone else who has had breast cancer, despite its ubiquity.

1.2 Connecting Online

Within the last 10-to-15 years, the Internet has created new options for people seeking to find information about health issues and illness, including numerous informational websites addressing any health condition imaginable, as well as online support groups for people interested in learning more from others undergoing similar conditions. In 2001, the Pew Internet and American Life Project reported that 90 million Americans (84% of Internet users) contact

online groups for information, and 56% of these users decide to join the groups with whom they have communicated (Horrigan, 2001). Online communities offer people the ability to transcend geography and find people like themselves, especially in instances of illness or disability (Kraut et al., 2002; Warschauer, 2003). At the same time that the Internet offers a venue for far-reaching interactions and relationships, it also creates ways for individuals to maintain and build on existing relationships, allowing people to maintain connections that have already formed offline (Kendall, 2002; Kraut et al., 2002). Online communities provide opportunities for friendship and expanded social connections, often resulting in relationships that complement and influence both online and offline life (Baym, 2000; Haythornthwaite & Hagar, 2005; Kendall, 2002). Online communities also have the potential to enhance local engagement (Horrigan, 2001; Soukup, 2006). Although there is a tendency to think about the online world in opposition to the offline world, both worlds are integrated, evolving spaces where people's lives intersect on an ongoing basis through multiple media (Haythornthwaite, 2005; Preece & Maloney-Krichmar, 2005).

1.3 Sharing Health Experiences Online

A Pew Internet and American Life Project report on peer-to-peer health care states that 18% of all Internet users have sought health information from peers online, and 23% of Internet users with chronic health conditions such as cancer, lung and heart conditions, diabetes, and high blood pressure have done so as well (Fox, 2011b). Other health-related concerns for which people seek similar others include weight loss, pregnancy, quitting smoking, and caring for loved ones with serious health problems. Online health support groups are valuable venues for people seeking help with a variety of issues related to coping with illness. They offer specific opportunities for people to meet others with similar conditions, promoting interactions that socialize patients into the discourse and language of particular health issues while at the same

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time fostering a positive environment where individuals can develop trusting relationships (Mittman & Cain, 2001; Orgad, 2005b). In addition to information, patients can access personal and professional support, share their experiences with others, and obtain patient advocacy (Klemm et al., 2003; Shaw et al., 2000). Participants are able to enhance their understanding of their health issues by reading about others' experiences, as well as by writing about their own experiences with the prospect of receiving support and information from knowledgeable peers (Lieberman & Goldstein, 2006).

Research has shown that having social support networks impacts health and coping in beneficial ways (Cohen, Gottlieb, & Underwood, 2000; Wellman & Gulia, 1999). Studies of online breast cancer support groups have reported positive emotional outcomes for participants, citing both social support and exchanges of information as explanations (Klemm et al., 2003; Lieberman et al., 2003; Shaw et al., 2000). These studies suggest that exchanging information with caring and supportive peers can aid patients by reducing depression, stress, and social isolation as well as increasing their ability to deal with physical pain (Gustafson et al., 2001; Høybe et al., 2005; Lieberman et al., 2003; Weinberg, Schmale, Uken, & Wessel, 1996; Winzelberg et al., 2003). Because seeking information and social support is often a collaborative activity among participants who are engaged in similar goals (Brashers, Goldsmith, & Hsieh, 2002), online health communities are often able to satisfy people better than individual communication. For example, patient-physician relationships are not peer relationships, making it more difficult for patients to acquire the kinds of information and support they may need to cope with an illness (Brashers et al., 2002). Furthermore, the activity of coping with others in the same position places people in a social, communal coping environment that is associated with

positive emotional outcomes (Dunahoo, Hobfoll, Monnier, Hulsizer, & Johnson, 1998; Folkman & Moskowitz, 2004; Lyons, Mickelson, Sullivan, & Coyne, 1998; Wells & Hobfoll, 1997).

1.4 Description of the List

The List is an online community that has been in existence since 1994. It is an unmoderated forum that serves "women and men who have breast cancer, their families and friends, medical and other caregivers, researchers, students and other concerned people" (What is the List? para. 1, n.d.). The List was founded in 1994 by a molecular biologist on faculty at a Canadian university who had an interest in telemedicine and who was a member of a breast cancer information project (Sharf, 1997). The List operates both as a listserv and website—members have the option to read messages through their email, a digest, or through the List's online archives, which can be accessed through the website. The website has other information available about the site and some links to a few other resources, but its primary function is as a placeholder for the listserv. The archives are freely available on the Internet, making it possible for non-members to lurk and gain benefit by reading messages. However, if someone wants to post a message to the List, she needs to be a subscriber (or member), which is accomplished by signing up through the website. The website states that there are 500-600 members; however, in February 2010 there were only 122 registered subscribers and in October 2010 there were 131 (J. Church, personal communications, February 26 and October 4, 2010). The vast majority of members are based in the United States, but the List also has registered members in other countries, including Canada, the U.K., The Netherlands, South Africa, and Australia.

In addition to posts specifically about breast cancer, participants discuss other health problems, including health concerns about relatives and friends. Discussions also include non-

health related topics such as social events, news stories, pets, and family news. Between July 2009 and August 2010, the number of postings ranged from 586 to 1140 per month, for an average of 865, and between 67 and 85 participants posted each month. According to Google Analytics, a program designed to track website visits, the List also draws approximately 200 visitors per month to its web-based archives. Most of these visitors are likely not registered members due to members' primary use of email for List interaction, and, thus, are over and above the amount of people contributing. Although there is some overlap between the numbers of visitors to the archives and actual members, the overlap is probably small.

Participants interact with the List in several ways, using it to provide and obtain both information and social support. There are participants who check it habitually, as much as several times a day, or perhaps every few days. Others read it or check in only occasionally, when they think of it or have a specific reason for doing so. Some participants are extremely active, contributing to conversations whenever they are there, whereas others are quieter, reading but not contributing, or contributing when they have particular questions or answers to offer. The List functions as a second home to many participants, and even those for whom it is not quite a second home, it is a place where they exchange information and social support related to breast cancer, other health concerns, and everyday life occurrences.

1.4.1 Choosing the List

Prior to deciding which online breast cancer support group I would use as the focus for my research, I spent time observing several groups' structure and interactions. I did not know initially which aspects would interest me—all I knew was that I was interested in the exchange of health information in online support groups. Some groups comprised multiple forums with

particular topics for each. For example, there would be threads specifically about receiving a diagnosis, or about chemotherapy, or about other aspects of the illness, with each set of postings strictly about these particular topics. There were no "off-topic" postings within these threads, although some groups had particular threads for off-topic discussions. These groups seemed very well organized, and it was easy to follow the discussions. When I examined the List's archives, my initial reaction was that they seemed chaotic. There are no separate forums for various topics—conversations are woven together, with posts sometimes related to several topics at one time and great variety in the kinds of topics participants discussed. I did not see how one could track what people were talking about or figure out how the conversations were evolving.

My interest in the List became piqued, however, after I spent time more closely reading the archives—I saw things in this group that seemed to be different from other forums. Several aspects that drew me in included sincere expressions of emotion, humor, and caring that went beyond what I saw in other places. Most interesting to me was that despite the difficulty in following the various threads because they are all lumped together, after a while it all seemed to make sense. It did not matter that there were intersecting subjects. The variety of conversations was similar to what occurs in real life in that life is not organized in a particular way—it meanders and changes direction, and we may not have control over it. I also discovered that participants met face-to-face at an annual Gathering, and that they had other points of contact as well. Taking all of this into consideration led me to discern a sense of community that was not evident in the other forums that I looked at. It was this sense of community that inspired me to investigate what was happening in this group. It was obvious that there was health information exchange and social support occurring, but it was also obvious that other things were happening as well.

1.5 This Study and its Significance

In my introduction of Jenny at the beginning of this chapter, I note the multiple ways that she has engaged with the List. For Jenny the List is more than an information and social support forum—it is a space for her to be herself and holds a special place in her life. Most studies of online health support groups concentrate on the health and psychological benefits participants gain through either social support or information access, or both. They do not delve into what group interactions mean for the long-term, nor do they examine the integration of these groups into individuals' lives. Moreover, they primarily focus on a single health issue, which is not surprising because health support groups primarily form for the purpose of helping patients navigate through specific conditions. However, the List comprises myriad types of interactions related to every aspect of life, opening up additional avenues of investigation.

The goal of this study was to obtain insight into the ways that the List functions to provide information, social support, and community to people dealing with breast cancer. I was interested in several aspects of List interactions, including the information behavior of participants, the role of social support for people dealing with illness, how participation influenced health decisions and practices, why participants sought online help for breast cancer, and what kinds of meaning the group has for its participants. Because of the structure of the List and its integration of multiple types of conversations, this study takes into account other factors as well. In addition to examining the health concerns of breast cancer patients and survivors and how the List helps them navigate through the complex issues associated with breast cancer, this study also strives to learn more about the integration of this community into participants' everyday lives. Although the List is an online community formed to help patients deal with breast cancer, it also is a community that incorporates diverse interactions that exceed the

boundaries of breast cancer, reaching into other health conditions as well as the challenges and joys of everyday life. In order to gain an in-depth understanding of the processes occurring on the List, I undertook an ethnographic study comprising archives analysis, participant-observation, and interviews. I draw on theories and models of information behavior, social capital, social networks, and social support to obtain a multi-faceted understanding of the dynamics of participation on the List as well to gain insights into individuals' perspectives about the List's meaning in their lives.

CHAPTER 2

METHODOLOGY

The goal of qualitative methodology is to aid in interpreting the complex dimensions of

human experience, allowing the researcher to translate the situated meanings behind people's

words and actions (Corbin & Strauss, 2008; Strauss, 1987). Corbin and Strauss (2008) write, "It

is not distance that qualitative researchers want between themselves and their participants, but

the opportunity to connect with them at a human level" (p. 13). In doing this research I hoped to

gain a multi-faceted understanding of how the group facilitates information exchange, how it

meets the diverse needs of participants, what kinds of interactions occur and are most valuable,

and, most importantly, what the meaning of the group is for its members. What I strove for in

this research was to be able to interact as completely as possible with the people whose lives

intersected with the List. To be able to do this in a way that would allow me to best obtain the

information I wished to learn as well as understand the community as well as possible, I

designed an ethnographic study that would offer me the experience of being a member of this

group as well as allow me to gain the personal perspectives of individuals who were both

intimately and peripherally involved in the community.

2.1 Ethnography

Ethnographic research constitutes the study of a culture's social settings and behavior as

its members interact in their daily lives (Creswell, 2007; Emerson, Fretz, & Shaw, 1995).

Ethnographers immerse themselves in a community by participating, observing, and having

conversations, using these activities to understand and analyze the interactions and

interconnections among community members (Emerson et al., 1995; Hammersley & Atkinson,

2007). Originally a method used by anthropologists to become immersed in little-known, sometimes exotic, cultures, ethnography is now also used in other settings where researchers want to learn about and explain the lives and cultures of people in everyday life (Fetterman, 2008, 2010; Hine, 2000). Ethnographers are interested in meaningful, enduring practices as they are understood by communities. Using "thick description," an ethnographer seeks to understand the import of "a multiplicity of complex conceptual structures, many of them superimposed upon or knotted into one another" (Geertz, 1973, p. 10). Hine (2000) describes ethnography as an approach through which the researcher sees through participants' eyes, "that aims for a deep understanding of the cultural foundations of the group" (p. 21). Through online ethnography it becomes possible to understand how these spaces are both "socially constructed" and "social conduits" at the same time in ways that lurking cannot accomplish (Hine, 2009, p. 11).

An aspect of ethnography that is important to be aware of is that it is rarely possible to enter a field site without having some sensitizing concepts of what might be found (Charmaz, 2006; Hammersley & Atkinson, 2007). Hammersley and Atkinson (2007) also note that sensitizing concepts can "suggest potential lines of inquiry" (p. 124). Due to my past observation of the List as well as extensive reading about other similar sites and online communities in general, there were certain ideas that informed my thoughts upon commencing research. My earlier work analyzing a small portion of the List's archives revealed cultural, informational, and social support processes indicating multiple areas worthy of ethnographic exploration (Rubenstein, 2009). For instance, although individuals initially contact the List for informational or social support purposes, their continued contact with the List appeared to indicate a complex culture where participants engage with each other on a regular basis for a variety of purposes. Numerous group-related traditions, meanings, and norms pointed to a strong community based in

shared experiences and understanding. Additional sensitizing concepts that informed my questions and analysis were based on my interests in research related to information behavior, social support, coping, social informatics, social networks and social capital.

An ethnographer must be open to whatever may be occurring in the research setting (Charmaz, 2006). Despite my preexisting interests and concepts, I approached the List with the idea of discovery and the understanding that my research might reveal interactions and processes that had not yet occurred to me. In addition, several things were not at all clear from my early analysis of the archives. I could not tell from that analysis why people participated in the group, how participation meshed with their "offline" lives, and what benefits, both medical and otherwise, occurred through continued interaction with others in this group. Ethnography encompasses the use of data from multiple sources to gain an understanding of the lives of a community (Charmaz, 2006; Hammersley & Atkinson, 2007). In order to incorporate multiple sources and acquire as much insight as possible into the List community, I used methodological triangulation (Denzin, 1989; Flick, 2006) comprising archives analysis, participant-observation, and interviews. The data accessed through each of these elements allowed me to be able to harness a rich picture of the lived experience of breast cancer patients, survivors, and other members of the List as they interacted with each other and navigated through the various stages of the trajectory of the breast cancer journey.

2.2 Grounded Theory and Theoretical Sampling

My primary models for using grounded theory are Charmaz (1983, 2001, 2006), and Corbin and Strauss (2008). Grounded theory is a flexible, ongoing, and dynamic process that incorporates simultaneous data collection and analysis, and is grounded in the data (Charmaz,

1983; Glaser & Strauss, 1967). As soon as initial observations and interviews occur, the researcher immerses herself in the data, coding, writing memos, and deciding who to interview or what to observe next (Charmaz, 2001, 2006; Corbin & Strauss, 2008). Charmaz (2006) describes grounded theory as a process that is emergent as one interacts with and interprets the data. In grounded theory, theories are not imposed upon the data; concepts and themes emerge as the researcher immerses herself in the data (Charmaz, 2006; Corbin & Strauss, 2008). Grounded theory "emphasizes inductive development of theory from the 'ground up,' emerging from the accounts of those interviewed and the meanings they assign to their experiences" (Souden, 2011). Using grounded theory means looking at the processes and themes that emerge while at the same time being aware that the act of understanding social life "is itself a process" (Charmaz, 1983, p. 111). Charmaz (2001) takes a constructivist, interpretive approach to grounded theory that assumes that there are multiple realities, that the data reflect the mutual construction of both researchers and research participants, and that the researcher "is affected by participants' worlds" (p. 678). Corbin and Strauss (2008) also note that different researchers will find different things in the data depending upon their focus and perspectives.

Most central to my approach to this study was asking what was happening in the social environment, and what was happening in the data (Charmaz, 2006; Corbin & Strauss, 2008; Glaser, 1978; Strauss, 1987). Although I had identified several research areas that I was interested in based on previous observation and analyses, I was also cognizant that I might discover things that I had not thought of previously. Becker (1998) has written about researchers reformulating questions or finding phenomena that they could not have known about prior to investigation, and I was aware that this could happen to me as well. My goal in commencing study was to remain as open as possible to what I might find in the data.

I collected data through the process of theoretical sampling, which, as part of grounded theory, is an iterative process that evolves based on concepts that emerge from the data (Charmaz, 2006; Corbin & Strauss, 2008; Glaser & Strauss, 1967). Theoretical sampling progresses cyclically through data collection and analysis, which leads to concepts and questions, resulting in additional data collection until saturation is achieved (Corbin & Strauss, 2008). Charmaz (2006) describes theoretical sampling as an emergent process through which "developing ideas shape what you do, areas you tap and questions you pose" (p. 108). As I progressed through the research, theoretical sampling led me through each stage of my data collection and analysis, helping me to make decisions about where to go next in my research, who to interview, and what to look for based on the various concepts and themes that were emerging.

Coding in grounded theory analysis occurs in conjunction with data collection, helping the researcher to focus on emerging themes while also guiding choices in further data collection. Coding segments of data makes it possible for the researcher to be able to see what is happening, to be able to frame questions that assist in understanding the data, and to identify analytical categories (Charmaz, 2006). Corbin and Strauss (2008) describe "break[ing] the data into manageable pieces," looking for ideas in the data, and coding to explain what is occurring (p. 160). Charmaz (2006) suggests several ways to conduct initial coding: word-by-word, line-by-line, or incident-to-incident, depending on what can be derived from the data. Charmaz (1983) also states that coding is a "process of *categorizing* and *sorting* data" as a way "to *label, separate, compile* and *organize* data" (p. 111). Once initial coding occurs, focused coding serves to combine smaller categories into larger conceptual ideas that offer deeper theoretical clarity and meaning to the data (Charmaz, 2006). Through the process of coding, the researcher also

engages in constant comparisons (Charmaz, 2006; Corbin & Strauss, 2008), which consist of comparing incidents as a way to understand the differences and similarities between the data.

2.3 Archives Analysis

The List's archives, dating from 1995, are freely available on the Internet and update each time someone posts a new message. The archives were an essential resource in framing this research as well as a source of information throughout the research process—I consulted them continually through my participant-observation, my interviews, and the writing process. The archives aided me in understanding current interactions, past events, List participants, and the progression of interactions. They provided me with background information as well as up-to-date information on the conversations occurring among List participants—reading the archives meant I was keeping abreast of ongoing occurrences as well as gaining historical insights about emerging themes.

My study of the List began with reading the archives as a way to familiarize myself with the kinds of interactions that occurred on the List. During my first six months of participant-observation I read the postings on a daily basis, writing reflexive memos during this time about what was happening and what my reactions were to various occurrences (Berg, 2004; Pellatt, 2003). I used these memos to understand my feelings and thoughts as I interacted with the text of the archives and with participants, as well as to understand what was occurring among List participants. I also coded the archives of List conversations that occurred between mid-July and mid-September 2009 (my first two months of participation) based on emerging themes and concepts (Charmaz, 2006; Corbin & Strauss, 2008) as a way to gain insight into general conversation topics as well as particular issues that seemed important to participants. As I

engaged with the archives I used theoretical sampling to seek and collect additional data related to emerging themes (Charmaz, 2006; Corbin & Strauss, 2008). Searches within the archives helped me to understand how various issues were brought up, how they were discussed in the past, and how members related to each other both before I joined and while I was there. The archives also gave me information about how particular participants' contributions changed over the years, as well as background information that helped me to prepare the interviews. Reading and analyzing the archives allowed me to more fully understand the conversational interactions and the opportunity to gather information relevant to the role the group plays in participants' lives.

The archives are a significant record of the List, because every interaction that occurs among the participants within the parameters of the List is available for reading and analysis. In addition, the archives are also provocative, because they do not constitute the whole story of what occurs on the List. The archives inspired me to want to learn more about this community, to obtain the perspective of a participant, to talk with other participants, and to meet participants in person.

2.4 Participant-Observation

Participant-observation is a key ethnographic process through which a researcher learns about other worlds, enhancing her sensitivity to the lives of community participants (Emerson et al., 1995). Being directly involved with others' ongoing interactions allows subtle facets of meaning to become evident, offering a more complete understanding of a setting and its participants (Lofland & Lofland, 1984). Through participant-observation, the ethnographer engages in learning the complex, intricate meanings present for the participants in a particular

environment. Traditionally the ethnographer has traveled to other physical places whereas in online ethnography the ethnographer interacts with others in a virtual online space. However, in each case, the elements of participation remain the same. In online ethnography, the ethnographer negotiates access, observes, and communicates with participants in much the same way that on-site physical ethnography occurs, placing the ethnographer in a position to offer a unique analytic viewpoint (Hine, 2000). The authority of the ethnographer is different in terms of surroundings, but not in terms of authentic experience. The role of the ethnographer is still based on "being there, participating and experiencing" (Hine, 2000, p. 46), and being open to whatever experiences may occur.

As a participant-observer of the List, I was able to interact with participants as issues arose and questions were debated. Being part of the group offered insights that would not have been available through other means (Fetterman, 2010). For example, as a participant, I read List postings on a daily basis, often throughout the day, making it possible for me to experience unfolding events as they occurred. This offered me understanding that might not have been available to me had I decided to do a retrospective textual analysis. In addition, even though interviews can offer many insights, they do not alone suffice as a way to understand behavior since often people represent themselves in interviews in ways that are inconsistent with their actual behavior (Kendall, 2008). Although interviews and archives analysis had the potential to afford me much information, I decided to incorporate participant-observation as well so that I could:

1) *engage more deeply with participants* as they posted, giving me the ability to understand what was happening in the moment, adding depth and meaning that would not be available otherwise. As a member of the group I was afforded the opportunity to glean the

meaning of participation as it occurred for these participants. Emerson et al. (1995) state that "[I]mmersion involves both being with other people to see how they respond to events as they happen and experience[e] for oneself these events and the circumstances that give rise to them" (p. 2). Participant-observation gave me a sense of how quickly responses occurred, offered insights into the emotional content of messages, and translated into a closer reading of what "being there" actually constitutes.

2) ***build rapport and situate myself as an insider*** who understood the inner environment of participants' situations, which would allow me to probe deeply once I began interviews. Forming relationships with people in a setting helps the researcher to gain knowledge of how such relationships develop within the context of the group (Emerson et al., 1995). By being immersed in the group I was better able to understand the significance (or lack thereof) of certain kinds of exchanges, the feelings that occurred during these exchanges, and the import of the relationships within the group and their bearing on decisions and everyday life. Accessing this kind of understanding helped me in making necessary connections that informed my interview questions and interviewee selection.

3) ***access a richer, more complete picture*** of the processes that occur, so that I could understand how these processes and interactions operate within the scope of illness as well as the everyday lives of participants.

Several things that I thought might happen by virtue of my participation might not have occurred otherwise. For example, each of my postings to the group contained a signature line with my contact information, making it available to everyone. Doing this offered an opportunity for participants to contact me privately to discuss occurrences in the group, and, as well, to

discuss their feelings about my participation. Having these discussions was more likely to occur due to my open availability as well as my approachability, as someone who was involved and interested. Furthermore, these discussions could happen at any time, and not be confined within the specific boundaries of an interview. By having this opportunity, my expectation was that my data would gain richness and complexity that would otherwise not be available.

My participant-observation occurred both online and face-to-face. I formally joined the group in July 2009, announcing myself as a researcher and a breast cancer survivor, and offering all of my contact information. I also asked if it was okay for me to be there. There was a small contingent of group members who actively expressed unhappiness about my presence. There were also members who were interested in what I was doing and supportive of it, as well as others who were unsure. I was very open about explaining what I was doing and answered all questions. I also sent out my IRB approval to individuals who requested a copy. List members engaged in some very intense conversations for the first couple of weeks, which subsided after several members reminded the group that the List is open to anyone and is publicly available on the Internet for anyone to read. During my first couple of weeks on the List, several members also asked me if I would be interested in meeting some of them in person at their October Gathering. Attending the Gathering gave me the opportunity to meet many participants face-to-face, which made all of us to feel more comfortable with each other, and also paved the way for interviews.

Throughout my participant-observation, I wrote memos and coded selections of the archives, which helped me in interview selection, interview questions, and overall analysis. In addition, when I went to the Gathering, I spent each evening recording notes and reflecting upon what had happened that day. For example, during the Gathering I noticed that attendees were

interacting with me differently than they had been prior to the Gathering, and I wrote about that experience.

2.4.1 Reactivity

An issue sometimes brought up with respect to ethnography, and participant-observation in particular, is the researcher's effect on the setting, known as *reactivity* (Emerson et al., 1995; Maxwell, 1996). Reactivity refers to a researcher's influence on a research site, an occurrence that quantitative researchers strive to minimize (Hammersley & Atkinson, 2007; Maxwell, 1996). However, researchers are always in some way impacting the social worlds that they are studying, and it is important to understand their effect (Emerson et al., 1995; Hammersley & Atkinson, 2007). Emerson et al. (1995) state that ethnographers' engagement "in the lives and concerns of those studied" (p. 3) offers researchers insights into aspects of social interactions that might not come to light otherwise. Hammersley and Atkinson (2007) argue that "participants' responses to ethnographers may also be an important source of information" (p. 177). For example, for the first two weeks after I joined the List, many of the conversations were about me. Reactivity was occurring because if I had not been there, these discussions would not have occurred. These conversations offered a rich opportunity for me to learn and understand things about the group at a level that may not have existed through any other channel. At that point I learned about various scammers and other "dubious" contacts that had been made with the List in the past, affording me an insider view of various events that had influenced members' responses to my entry on the List. Engaging in participants' worlds enhances the researcher's understanding of their perspectives, offering "clues to understanding the subtle, implicit underlying assumptions that are often not readily accessible through observation or interview methods alone" (Emerson et al., 1995, p. 3).

2.4.2 Reflexivity

Reflexivity occurs when a researcher strives to understand her own reactions, biases, and perspectives about the people being researched and how these may have affected the research (Corbin & Strauss, 2008; Pellatt, 2003). Charmaz (2006) describes reflexivity as the scrutiny of one's decisions and interpretations. Reflexivity is an "ongoing conversation" (Berg, 2004, p. 154) that the researcher has with herself in which she examines her experiences as they relate to her interpretations. In this way, the researcher acknowledges herself "as a variable in ethnographic studies, as he/she engages with the process of linking, bridging, negotiating, and translating between… cultures" (Oliffe, 2005). Markham (2009) argues that reflexivity helps the researcher to understand how her decisions are influencing the "evolving design of the study" (p. 142). She suggests asking oneself questions such as "How do I know that?" "So what?" "Why did I conclude that?" and "What led me to that perception?" (Markham, 2009, p. 143). As I progressed through the research, I wrote reflexive notes to question my personal feelings and reactions to various events that occurred. Using the example of my first two weeks on the List and the conversations that occurred at that time, I needed to question my own actions and decisions in my conversations with List members, how they affected my interpretations, and what my assumptions about the List had been prior to joining.

2.5 Interviews

I conducted 31 semi-structured, open-ended interviews lasting from 30 to 90 minutes. Of these, 30 occurred over the phone and one face-to-face. I electronically recorded the face-to-face interview and 29 phone interviews; one person did not wish to be recorded and I took notes while we spoke. In determining when to stop doing interviews, I strove for theoretical saturation

(Charmaz, 2006; Corbin & Strauss, 2008). This occurs when "gathering fresh data no longer sparks new theoretical insights, nor reveals new properties of your core theoretical categories" (Charmaz, 2006, p. 113). Corbin and Strauss (2008) state that total saturation rarely occurs, and that "sufficient sampling" (p. 149) takes place when the researcher concludes that categories have enough depth and breadth to explain a particular phenomenon. After I had done 31 interviews, I determined that I was not garnering additional insights related to the categories that I had identified. However, as a precaution, I decided to supplement the interviews with five less formal email exchanges with additional members to confirm some of the categories I had identified.

Qualitative interviewing gives researchers the opportunity to acquire in-depth knowledge about individuals' lives from their own perspectives, meanings and contexts (Henn, Weinstein, & Foard, 2006; Kendall, 2008). For example, semi-structured interviews are conversations, where themes may be initiated and suggested by the interviewer, but where respondents' narratives also guide the direction of further interpretive inquiry through the interviewer's active listening role (Holstein & Gubrium, 1995; Kendall, 2008; Kvale, 1996). In order to do this well, the interviewer should be well-acquainted with the respondent's world (Kendall, 2008), "drawing on background knowledge…incorporating indigenous interpretive resources, perspectives, and landmarks" (Holstein & Gubrium, 1995, p. 45), which suggests that my participant-observation and reading of the archives prior to conducting interviews were appropriate methods to acquire in-depth knowledge of the online interactions on the List.

Kvale (1996) states that interviews should be structured in such a way that encourages interviewees to feel comfortable. He suggests giving a preliminary briefing that situates the research and provides background information, as well as a final debriefing that gives the

interviewee a chance to absorb all that has occurred. Throughout the interviews, I strove to strike a balance between empathy and neutrality, offering encouragement while at the same time trying to ensure that interviewees felt as though they were in a non-judgmental situation (Kendall, 2008). Because of my participation in the group I was able to foster comfort and empathy, allowing me to be able to relate to participants on their own terms as well as build up rapport and trust, and facilitating my ability to put them at ease.

My interview strategy was to use semi-structured, open-ended questions (Charmaz, 2001, 2006; Hoffmann, 2007; Kvale, 1996). Kvale (1996) notes that interview guides can range from being a list of "rough topics" (p. 129) to being a list of detailed, sequential questions. Charmaz (2001) suggests that initial open-ended questions begin with phrases such as "Tell me about…?" "What was it like?" and "Could you describe…?" According to Hoffmann (2007), open-ended interviews offer informants the ability to have some control over the development of the interview, but also allow the researcher the freedom to expand on questions as necessary. My interview guides consisted of a number of questions I wished to ask informants, but the progress of each interview proceeded based on where the conversation went and what "knowledge evolve[d] through [the] dialogue" (Kvale, 1996, p. 125). Most of the interviews started out exactly the same, but due to their open-ended nature, they did not always follow the same path. (See Appendix A for a sample of interview questions.)

I recruited interview respondents by email, selecting them through theoretical sampling (Charmaz, 2006; Corbin & Strauss, 2008). Based on themes that emerged from my participant-observation, I started with individuals who had been on the List for a relatively long time and who were very active. I thought that their experience and knowledge would help me gain a broad understanding of List dynamics and help me to focus on emerging theoretical categories

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(Charmaz, 2006; Corbin & Strauss, 2008). I was also interested in understanding List interactions from multiple viewpoints, and chose individuals who could bring contrasting perspectives and experiences related to the emerging categories. As I progressed through these interviews, areas of interest that I investigated included:

a) ***Relationships and relationship building***, both online and face-to-face, and how these contributed to the acquisition and provision of health information, everyday life information, and social support. Because some members had become very close friends with other List members, and others less so, I was curious about how and why this occurred, and what this might mean. I was also interested in the role of the Gathering in forming relationships, prompting me to talk with participants who went regularly as well as others who went rarely or not at all.

b) ***Range of contact patterns with the List*** and what effect different amounts of contact had or did not have in participants' lives. For some members, interacting with the List occurred frequently whereas for others, there was minimal contact. One way I determined participants' contact with the List was based on average individual postings per month, which ranged from zero to 77 posts per month during the first six months of my membership. Although posting was not necessarily indicative of actual contact in that some members who rarely posted still read the messages every day, this strategy still proved useful in gaining insight into a range of interactions. Several individuals I interviewed had also been on the List multiple times, all of which made me interested in understanding the motivations for contact as well as the ebb and flow of interaction. In addition, I posted several messages on the List asking if there were any lurkers who would be interested in being interviewed, and I asked current participants if they could refer me to former members as potential interview subjects.

c) ***Participants' discussions of changes in the List*** over the years, both in terms of numbers and conversations, making me think that it would be important to learn more about those changes and to understand the meaning of the List for long-time members as well as newcomers.

d) ***Illness experiences*** – I was interested in participants' particular illness experiences, when they became members of the List in relation to their having breast cancer, or, if they had not had breast cancer, what their reasons for being there were. I approached some participants because they either had had recent health issues, or they had ongoing health issues, and others because their bout with breast cancer had occurred many years before.

I transcribed and coded the interviews as soon as they were completed. My initial coding comprised analysis of the data as individual sentences, paragraphs, and larger segments as I interpreted the meanings of interview participants' responses. I used *in vivo* coding when possible, basing my codes on participants' words (Charmaz, 2006; Corbin & Strauss, 2008). By the time I finished coding the eighth interview, I had begun to see larger concepts, and started combining the detailed, initial codes into larger categories. At that point, I began focused coding (Charmaz, 2006), which allowed me to synthesize the initial codes I had already identified into various theoretical themes that seemed to be recurring. As I progressed through the coding of subsequent interviews, I used a combination of initial and focused coding based on the themes that had already emerged as well as new ones. In addition, I used constant comparisons (Charmaz, 2006; Corbin & Strauss, 2008; Glaser, 1965) to compare similar incidents and perspectives across interviews, which allowed me to further refine and understand the data.

2.5.1 Characteristics of Interview Respondents

Interview respondents spanned a range of ages, education levels, occupations, length of time on the List, and experiences with breast cancer.

Age: The age of interview respondents was between late 40s and mid-70s. Three were in their late 40s, 10 were in their 50s, 15 were in their 60s, and three were in their 70s. This age range is typical for breast cancer patients and survivors.

Gender: Thirty were female; one was male.

Race/Ethnicity: Thirty were white; one was African-American.

Length of time on the List: Sixteen had joined between 1994 and 1999, 10 had joined between 2000 and 2005, and five had joined after 2005. Their length of time on the List ranged from a few months to 14 years. Seven interviewees had left at various points and then returned— some had left due to life circumstances that made it difficult to remain; others stated that they had considered themselves finished with breast cancer and ready to move on. Participants came back for various reasons, including recurrence of breast cancer, a new primary diagnosis or other life events that compelled them to want or need support, and simply missing others on the List. Two interviewees were no longer on the List. Interviewing participants who had been on the List longer was especially helpful in understanding the List from a historical perspective, offering insights that newer participants did not have.

Education levels and occupations: Interviewees were mostly college educated with over half having obtained an advanced degree. One was a high school graduate; five had some college; four had bachelor's degrees; and 21 had degrees or coursework beyond a bachelor's.

Ten participants were retired or on disability, all of whom had worked in either professional or administrative positions. Two participants identified themselves as housewives; one was unemployed; and 19 worked in professional or administrative positions.

Breast cancer status: Twenty-nine interviewees were either breast cancer patients or survivors. Because being a survivor of breast cancer does not discount that one is still a patient, I have not distinguished between survivors and patients. Of the two participants who were not patients or survivors, one had joined because a friend had had breast cancer, and the other because it was in her family.

Overall this group comprises middle-class, well-educated individuals who know how to use computers and the Internet, and how to use them to find information. Most were well-spoken and able to express their experiences with breast cancer and the List in a thoughtful manner.

2.6 Ethical Considerations

Ethical considerations related to ethnography in general and to this study in particular include privacy, informed consent, and confidentiality (Berg, 2004; Buchanan & Ess, 2008; Hammersley & Atkinson, 2007), as well as my role as a participant-observer (Kendall, 2002). In addition, privacy is most related to whether it is acceptable for a researcher to observe and report on a particular setting without obtaining consent from participants. In general, observation of public places does not require informed consent (American Sociological Association, 1999; Hudson & Bruckman, 2004) but differing perspectives on what is private or public in online settings can complicate matters. In addition, participants might be concerned about how what they say privately will be reported publicly (Hammersley & Atkinson, 2007; Kendall, 2002). Obtaining informed consent means that research participants are agreeing to be studied,

understand that they are being studied, and are informed about what the potential risks to them might be. It is also important to recognize that research participants might experience stress and anxiety as a consequence of being researched, and it is the researcher's job to minimize any possible harm (Hammersley & Atkinson, 2007). Building rapport and trust with study participants helps to alleviate anxiety associated with the research. Informed consent also relates to confidentiality in that a consent form explains how participants' identities will be protected and how their information will be used (Berg, 2004).

Ethical issues in online research include: whether particular online sites are public or private, or somewhere in between; what participants' perceptions of these sites might be in terms of privacy; whether or not informed consent is needed for studying and reporting about online forums as well as using quotations from them; what kind of content should be deemed private even if it is in a public forum (e.g., medical discussions) and, in view of these issues, whether researchers even have the right to observe and analyze these sites (Barnes, 2004; Buchanan & Ess, 2008; Elm, 2009; Hudson & Bruckman, 2004; Sharf, 1999; Vayreda & Antaki, 2009; Walther, 2002). Ess and the AoIR (Association of Internet Researchers) Ethics Working Committee (2002) suggest several questions that researchers should consider when doing Internet research, including,

- What ethical expectations are established by the venue? (p. 4)

- Is there a posted site policy that establishes specific expectations—e.g., a statement notifying users that the site is public….? (p. 5)

- Do participants in this environment assume/believe that their communication is private? (p 7)

These questions were useful as guidance in implementing ethical practices for this study, but they also highlighted some of the difficulties inherent in ethical research, especially when doing so online.

2.6.1 Privacy

There are various ways of interpreting whether an online space is private or not. Online forums have been seen as public spaces, as private rooms, or somewhere in between (Elm, 2009; Eysenbach & Till, 2001; Savolainen, 2001). How private an online site is can be conceptualized in terms of how difficult or easy it is to get into and view the site. Elm (2009) characterizes online space privacy as a continuum. A space that is *public* "is open and available for everyone, that anyone with an internet connection can access, and that does not require any form of membership or registration" (Elm, 2009, p. 75). A *semi-public* space is accessible to anyone, but to get into it requires membership and registration. A *semi-private* space requires membership and registration as well as membership in an organization that created the space to begin with (e.g., a professional organization). A *private space* is hidden from the public completely and available only to invited guests.

In addition, perceptions about the privacy of a particular online forum might differ from what the reality is. Eysenbach and Till (2001) write:

> Although publication on the internet may have parallels to publishing a letter in a newspaper or saying something in a public meeting, there are important psychological differences, and people participating in an online discussion group cannot always be assumed to be "seeking public visibility" (p. 1104).

Thus, even if a space is public, it might be perceived by participants to be private and those participants might be antagonistic about being observed by a researcher (Elm, 2009; Hudson & Bruckman, 2004).

The List website states:

> For your own protection, you should take care in what you write to the list. While the list is open only to subscribers, anyone can subscribe, and the archive is openly accessable [*sic*] ("A Word of Caution," para. 1).

Despite this statement being on the website, when I joined the List I learned that some participants were confused about how public their postings were. Several discussions during my first two weeks there revolved around who could see what participants wrote, and whether I needed informed consent to just read the archives. Several participants also did not seem to be aware that there were archives or how to access them—they received postings through their email, which gives a sense of more privacy than a public archive. Even if someone is on a listserv that goes to many people, if the existence of a public online archive is unknown (or forgotten), it is possible to believe that only people on the listserv are seeing what is posted. Using Elm's (2009) continuum of how public or private online spaces are, the List could be considered semi-public. One does have to register to post, but aside from that, everything posted is available in the archives to anyone with an Internet connection. However, for some participants, there was a perception that the List is private.

2.6.2 Informed Consent and Confidentiality

Informed consent in relation to online sites depends on where they fall on the private-public continuum and how to actually determine what participants expect. Hudson and Bruckman (2004) write:

> For some researchers, the Internet is like a public square, and for others a private living room, a town hall meeting, or a newspaper letters column. Each of these metaphors leads to different ethical conclusions. In a public square, a researcher may observe behavior in a generalized way and write about aggregated results. In a private living room, permission of the participants is required for any research (p. 128).

Interviews always require informed consent, which I obtained from each interview respondent. The issue was somewhat murkier in regard to whether I should obtain informed consent if I used quotes from the archives, since they are publicly available. Walther (2002) states that "if the research involves the collection or analysis of existing data (documents or records) when these are publicly available, this…qualifies the research for human subjects exemption" (p. 207). Hudson and Bruckman (2004) point out, however, that the nature of certain types of comments are indicative of what research participants' expectations are, and that many researchers take the stance that comments posted online are made by human subjects and should be treated as such. The List website states:

> People talk about very private things on this list. Please respect their privacy by not forwarding their messages to anyone outside the list without the author's permission ("A Word of Caution," para. 1).

This meant that, whether or not participants were aware of the public nature of the site, I had a responsibility to adhere to the stated expectations of the site. In addition, many conversations on the List comprise personal medical information, indicating that despite the archives' public nature, ethical treatment required obtaining informed consent. Therefore, I obtained informed consent from anyone whose quotes I wished to use.

Often participants in online forums use pseudonyms to hide their identity, and often they use the same pseudonym in multiple forums, making it possible for the individuals behind them to be tracked (Bruckman, 2002; Bruckman, 2004; Kendall, 2002). Kendall (2002) describes changing the online pseudonyms of the members of an online group for purposes of her study, noting that even though participants were already using pseudonyms, they are also an "identity peg" (p. 241) through which people can be traced. In addition, Kendall (2002) changed the name of her group, arguing that "groups also need protection from harmful effects of research" (p.

243). In order to protect participants' identities as much as possible, I used pseudonyms for all interviews and online quotations. I assigned participants separate pseudonyms for their interviews and online quotations as a way to keep their interview quotes as confidential as possible. I separated their names because several individuals commented during their interviews that it would not be hard for others on the List to identify them based on their comments, and two expressed a little discomfort at being easily identified. I thought that making it more difficult to link interview comments with online quotations would afford slightly more confidentiality. There were two exceptions to this separation: in one instance, the participant self-identified through a discussion of a particular role she plays on the List, and to illustrate her comments, I paired her interview with an online quote. In the second instance, it would have been difficult to explain the participant's story without using both. Other than these two instances, when I have used both archives quotes and interview quotes for the same participant, I have given them different names. In truth, it is likely that some participants will recognize each other based on their comments. Kendall (2002) noted that it is rarely possible "to protect the identities of the researched so thoroughly that even their own mothers (or more to the point, fellow participants) won't know them" (p. 242). Despite this, I strove to afford participants as much confidentiality as possible.

To add one more layer of confidentiality, I am using the term "the List," which is a pseudonym, for the name of the site. Using the actual name of the site has confidentiality issues in that many participants on the List use their real names, and their email addresses appear in their postings. Although anyone accessing the List can easily see this information, disguising its name offers a bit of extra protection. An issue that some researchers discuss is that even if the name of the site is changed, doing a search for someone's actual words would bring up the site

(Bruckman, 2002). In the case of the List, this is actually not possible—using a search engine to find participants' words cannot happen because the person who hosts the archives has set up barriers to prevent search engines from being able to crawl for quotes in the archives. (P. Bevin, personal correspondence). This gives participants additional confidentiality that I would not have been able to offer.

2.6.2.1 IRB

My exempt application to the University of Illinois' Institutional Review Board (IRB) was approved in May 2009 (IRB Protocol Number 09589—see Appendix B for IRB materials). As part of the application, I prepared informed consent forms for interview respondents and participants whose online postings I would use. Each person I interviewed by phone received an informed consent form through email for their review, and I requested that they review it before we scheduled the interview so that there would be as complete an understanding as possible about what we would be doing. Once the interview took place, I read the consent form over the phone and obtained verbal consent, all of which was recorded. For the one face-to-face interview, I had the participant sign a hard copy. I also emailed consent forms to List members whose online quotations I used. Those giving consent checked the appropriate boxes, typed in their names on the signature line, and emailed their consent forms back to me. Although I did not request this, some participants sent me pdfs showing their actual signatures. One person whose online quotes I used preferred to send me a hard copy of her consent form.

2.6.3 My Role as a Researcher in an Online Forum

One challenge to being a participant-observer of an online forum is that it is conceivable that participants might forget about my role as a researcher, or new participants would not know

at all without my telling them or reminding them. Sharf (1999) noted that she provided an introduction of herself every time she posted on the online forum she studied to make sure that new participants would know that she was a researcher as well as a reminder to others since often there were many people posting and they might not remember participants' identities. When Kendall (2002) did her research on her online group, BlueSky, she explained her research to each new person she met. She also reminded participants of her presence when sensitive topics were being discussed. Keeping this in mind, each of my posts to the List contained a signature line that listed my status as a researcher and a breast cancer survivor, as well as my contact information so that anyone reading my messages would be able to see who I was. In addition, I posted a monthly message that described my research for anyone who was unaware of my work and as a reminder to others.

2.7 Writing Up the Research

Writing ethnography comprises balancing descriptive representation of the world of those being studied with analytic concepts that offer insights into this world (Emerson et al., 1995). Emerson et al. (1995) state, "an ethnographic story proceeds through an intellectual examination of evidence to eventually reach its contributing central idea" (p. 171). Writing is part of the analysis in ethnography (Hammersley & Atkinson, 2007; Fetterman, 2010). Through the process of accumulating vast amounts of data and writing about it, ethnographers are faced with choices about what themes to highlight and write about (Emerson et al., 1995; Lofland & Lofland, 1984). Hine (2009) notes that the ethnographer must construct project boundaries, and that "the decision about when to start and stop, and where to go in between…is an intrinsic part of the relationship to [the field]" (p. 18). Although I did not know where exactly this ethnography would take me, as I progressed through the research process I became most interested in the interweaving of

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information behavior and social support and what this meant for the participants. Through this process of discovery, I was able to determine which data and what boundaries were most indicative of what I wanted to know, and how I wanted to frame my findings.

In writing this ethnography, I sought to intersperse personal stories, narrative about these stories, and analysis. In doing so, I included online archival material and interview material to illustrate various concepts and occurrences. At times, especially in the interviews, participants' stories meandered off topic, making it necessary to delete small sections of narrative in order to make specific points. When I needed to do this, I used ellipses to designate missing material, three ellipses if material was omitted within a sentence and four if the material omitted spanned full sentences. There were a very few instances where participants had used their own ellipses, which I left in. Although this could be a point of confusion for the reader, they are infrequent, and I could not see a way to distinguish them. In quoting interviews I also inserted brackets around words if I added them to the original text or if I replaced them for purposes of clarity or confidentiality. For example, in one quotation, the person speaking named particular identifying places, which I designated as [her city] and [my city] rather than make up names of places. In addition, I eliminated words such as "uh" or "eh" as a way to keep the narrative flow. For the online quotations I used similar methods, and in addition, corrected spelling in a few cases. There were few grammatical errors in any of the quotes I used, and if there were, I left them in.

CHAPTER 3

ENTERING THE COMMUNITY AND BUILDING TRUST

Ethnographers have long described the challenges of gaining access for the purposes of conducting naturalistic research of social worlds. Communities are often suspicious or fearful of a researcher's motives and may initially be wary of interaction (Hammersley & Atkinson, 2007). Prior membership in a group often confers greater legitimacy in the views of participants than approaching a group from the outside; however, gaining entry can also be facilitated through intermediaries with close ties to a community (Fetterman, 2008, 2010; Lofland & Lofland, 1984). Familiarity with a community's norms and practices, or possessing attributes similar to community members, also facilitates acceptance (Kendall, 2002). However, even when a researcher can claim familiarity and similarity, questions and challenges can arise upon entry into a community. As I began my research, I encountered my own challenges upon entry into the List community.

3.1 Making Contact

Prior to making a final decision to select the List as my research site, I spent approximately two years reading the archives. In reading the archives I was also acting as an observer—the archives reflect the day-to-day conversations of the List, and update within five minutes of participants' posting messages. As an observer, I was also becoming more familiar with the List's conversations and norms. My reading of the archives and my familiarity with health information seeking and breast cancer survivorship led me to believe that I had ample knowledge and understanding to be able to assure participants of the legitimacy of my research, and I anticipated minimal access problems. My first posting to the group explained my breast

cancer survivorship, my University affiliation, and my interest in learning more about the communication that occurs on the List. In addition, I stated that I had been reading the List for the previous two years, and assured members that I would not use any quotations without their permission. I also noted that I was interested in making a contribution that would inform others about the value of being part of an online support group.

Hammersley and Atkinson (2007) note that in ethnographic situations, people who are being observed "[test]…the researcher to see whether he or she is genuine and can be trusted" (p. 46). List members' reception of my announcement elicited a range of reactions as they tried to understand who I was. Participants expressed concerns about my legitimacy, fear of how the research might be used, confusion about my role in conducting ethnographic research, and apprehension about use of quotations. Questions that came up included: Are you really a researcher? What kind of research is this? What's ethnography? Will you be sending us questionnaires? How are you going to use our information? Why have you been lurking but not contributing? Some members feared that my presence would cause others to be reluctant to participate. Others wondered how I could be a researcher and a participant – how could I be objective? Several participants also requested copies of my IRB approval. A few members described feelings of trepidation and vulnerability, but also stated that they were tentatively open to my research. Others were fully supportive, offering to assist in any way possible.

List members who were skeptical had experienced negative incidents with newcomers who were not what they claimed to be. As with any online forum, the List offers the potential for people to assume identities and deceive others for various reasons (Kendall, 2002). In online health communities, participants are often dealing with serious and sensitive issues in their lives, making them feel particularly vulnerable (Høybe, Johansen, & Tjørnhøj-Thomsen, 2005; Radin,

2006). During my initial entry into the community, List members reported instances of marketers posing as researchers who tried to sell them products as well as researchers recruiting them for seemingly questionable studies. List members found these experiences both intrusive and disconcerting, causing them to seriously appraise newcomers identifying themselves as researchers. As Corinne noted soon after I joined:

> I've been on this list since 2002, mostly lurking, but always interested in whatever goes on, and so very appreciative of the ready support here, when I or others have needed it. Over time, I've been appalled at some of the bogus people coming here as "researchers" and I think I was the foremost ranter against the most recent one who did so – a "Dr. [Name]." Didn't trust her for a minute.

In my interview with her, Eve further characterized the List's reactions:

Eve: When you first came on the List, do you remember the third degree you got?

E: Oh, I do!

Eve: And it's because you were asking people to share with you intimate details of a very painful part of their lives. And you came—you were very up front. You said … that you were involved in a research study and so forth, and so on, but you got the 100th degree before anybody would trust you, and once somebody gets past that trust level, people share the most innermost feelings and if you don't trust, you don't, you hold back....That you were going to ask questions, that you [might] use what we're saying from the List. How do we know who the hell you are? We've had snake salesmen on there, let me tell you that. And we usually sniff them out immediately, who come on there with all kinds of hidden agendas. And we're pretty good about sniffing someone out. But you were very open about what you were there for. But before anyone was gonna—we've had researchers, people who say they're doing research have come on there before and it sets up a red flag. It does. And then everyone met you in person and some of that trust, you know, was cleared….

E: Oh totally, I know.

Eve: Yeah. But that took—when you first came on, who was going to open up to a total stranger who openly admits they're gonna use it in a project? I mean, give me a break. You know, you had to build a layer of trust before even these interviews would happen.

E: Yes. I agree.

Eve: And, but it was—it's not somebody who comes on the List, "I'm newly diagnosed three days ago and I want support or I want advice or I want help." That kind of person, for whatever reason, could be the most dishonest person but you don't—they don't come out and say they're using it. Which made me believe you were honest from the minute. Because you wouldn't have had to say it otherwise. You did say it.

Eve's comments highlight a dichotomy about "stranger[s]" approaching the List. She acknowledges that someone who comes to the List to talk about a diagnosis of breast cancer is responded to differently than someone who is a researcher. Acceptance and trust of someone who approaches the List as a breast cancer patient/survivor is more likely to happen sooner than for someone coming as a breast cancer patient/survivor *and* a researcher. In my case, I needed to establish validity as a researcher, despite my survivorship. I had to build up more trust and become more deserving of members' confidences. This is not surprising—as Eve stated, I would be using their information and they needed assurance that I would not use it inappropriately.

The reactions to my joining the List point to members' lack of clarity about my role(s), who I was, and what my purpose was. Some members were concerned about objectivity; others about how it was possible to be both a researcher and a participant. These concerns illustrate participants' awareness of quantitative research methodology, but less so of qualitative research. The most highly visible research on breast cancer consists of clinical trials. Due to their status as breast cancer patients and survivors, some List members have participated in clinical trials and most are very aware of trials occurring on an ongoing basis. Clinical trials have clear boundaries between researcher and subject roles. The purpose of clinical trials is to determine the effectiveness of medications or medical therapies, and prevention and detection of disease (U.S. National Institutes of Health, 2007). During clinical trials, subjects are often randomized into control and experimental groups, and are unknown personally to the researchers. The reporting

of medical research published in journals and news stories results in a List population that is sensitized to researcher and subject roles as being separate from each other. List members recognized the value of clinical trials and being research subjects, but the value of ethnographic research was less apparent. Despite this confusion, several members who were more supportive of my research drew similarities between my research and that of Margaret Mead.

To build up trust and assuage concerns, it was essential that I be totally open and provide information that would assure participants that my research was legitimate and that I had no intentions of exploitation. As people get to know a researcher and understand that she can be trusted and discreet, it becomes easier to negotiate access (Hammersley & Atkinson, 2007). I answered every question in great detail, sent out copies of my IRB approval, and revealed personal information in the spirit of sharing as any other List participant would. It is important to note that despite the challenges I experienced from some participants, there were members who did write supportive messages both on the List and to my University email account. Although the questioning took center stage, there were also instances of acceptance, exemplified by Chris' posting:

> I am guessing that most of you…out there will agree that Ellen has been up front
> with the research she is doing and has been patient in answering our questions.
> Ellen, I …admire your patience with all the nit picking about you and your
> background and research you have had to put up with. I said it before:
> WELCOME!

Chris' comments indicate the many types of interactions that were occurring: repeated questions, my patience in answering them, and some impatience about the process, basically a summary of the reactions to my announcement. Several days later, Chris also posted:

> [Many people] have written on this topic - I actually think it has been a healthy
> discussion and perhaps caused many of us to examine who we are as a

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community. The list has evolved over the years in response to the needs of the members.… I would like to suggest that all of us take a few moments and read the introductory page of the list and ask ourselves if we truly mean what we say or is that paragraph, above, just there for public relations and has no meaning in reality.

I read the welcoming statement as saying that anyone can join (students, concerned people, etc.) and I don't see where there are any pre-qualifications or admission test one must pass to belong. The tenor of the list the past few days has been: "yes you can join, but you have to meet certain unspecified admission standards and prove you are worthy to be here." So I will ask again: Do we mean what we say?

After this comment was posted, along with a few others acknowledging that Chris had a point, the discussion about my being there calmed down. In fact, the List became very quiet for a few weeks, and I was never sure if it was due to my being there (i.e., reactivity) or if it was a natural occurrence given that it was summer. I was worried that, indeed, I had had such an effect on the List that no one would ever talk again. However, after several weeks, conversations picked up again, and it almost seemed as though those related to my appearance had not happened. During that time, as well, several participants invited me to attend the List's annual Gathering, and I made the decision to do so.

3.2 The Gathering

The List is first and foremost an online community, but it also expands beyond its online borders. The online aspect of the community is significant in that it serves an important functional purpose for people seeking breast cancer information and support, but the online community also acts as a facilitator for deeper relationships that transcend online interaction. One way this occurs is through the community's annual Gathering, which is an opportunity for List members to connect with each other face-to-face, in some cases for the first time, in other cases, one of many. The number of attendees varies each year, but it is an event that many participants consider one of the highlights of being a member of the List, and participants often

bring spouses, friends, and other family members. Some participants attend almost every year, others more sporadically, and some List members have never been to a Gathering. As part of my entry into the community, I decided to attend the Gathering as a way for me to get to know the community better, and for them to get to know me. My goal was to have conversations and get a feel for the face-to-face aspect of interacting with List participants.

The Gathering I attended occurred over the Halloween weekend of 2009. The organizers had dubbed it the "Pirate Belles Gathering" (each Gathering has a theme), which included a pirate costume party planned for Saturday evening. At the time of the Gathering, I had been a member of the List for three months and was interacting regularly online, but when I arrived I sensed that participants were somewhat wary, and I felt wary as well. Although it had seemed to me that, for the most part, I had been accepted into the community, I sensed that I was not fully accepted. The members there gave me a cordial reception, but it was clear there was a level of hesitation on both "sides."

Someone directed me to the hotel restaurant where some Gathering attendees were having lunch. They introduced themselves to me and I began to associate faces with names. Few people looked like what I had expected, even the ones whose images I had been able to find on the Internet. Prior to the Gathering, I had formed certain visions of participants based on the language they used online as well as some of the pictures that certain names conjured in my mind, but I learned quickly that many of those visions were incorrect. Kendall (2002) has noted how meeting people face-to-face after having only known them online provides more information about their identities. Once I met participants, I was able to readjust various assumptions, making the people both more interesting and more real to me. I sat down and started talking to Natalie about a recent health scare she had been through. The conversation

went relatively smoothly and she seemed comfortable talking to me. I thought, "This won't be too bad."

I met more attendees at dinner and those who were sitting near me were interested in hearing about my research. We all began to warm up to each other. The next two days were very relaxed, with attendees taking nature walks, going swimming, eating together, and shopping. There were many opportunities to casually interact, and for me to have quiet conversations with many participants, learn about their experiences with breast cancer, with the List, and also other parts of their lives. Dinner the first night was followed by guitar playing and singing, chatting in small groups, and opportunities for acquaintances to become friends, and old friends to see each other again in person. I could see that there was a sense of warmth and caring permeating this community. That evening after dark, we participated in an outdoor memorial service for members who had died during the previous year.

As dinner approached the second night, the banquet room began to slowly fill with people in costume, for the most part pirate costumes, causing lots of laughter. But the evening's hilarity had just begun. After dinner we were treated to a puppet show, and several skits and songs by groups called "The Boobettes" and "The Ass-ets." At one point a group of performers were singing to the melody of the "Hokey Pokey," but instead of singing about the usual body parts, they sang, "You put your right boob in, you put your right boob out…," etc., as they danced around. Everyone was in hysterics, including the hotel staff attending the dinner, wondering who these people were who were having so much fun spoofing breast cancer.

Being able to spoof breast cancer and have fun with each other is as much an attribute of the List as being serious and helping each other. The conviviality that participants engage in with

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each other is part of what forms this group of people into a community. Being able to enjoy each other's company in a relaxed atmosphere is an aspect of the group that carries through both in online and offline contexts, meshing participants' worlds together, giving participants' feelings of being cared about. Being able to witness the Gathering gave me greater insights into how the group functions, and how participants interact with each other.

The Gathering helped me to feel more comfortable with List members, but, even more important, helped them to feel more comfortable with me. Several months later when I was interviewing participants, Cassandra talked about my attendance there.

> Cassandra: There was much trepidation…What's she gonna do? Like, what's she really gonna be like? Is she really nice?
>
> E: Well I was just as full of trepidation. [laughter]
>
> Cassandra: Oh, everybody fell in love with you, sweetheart.

Being at the Gathering also illuminated that, although the List is an online forum and a number of participants have never met face-to-face, seeing and interacting with others in a face-to-face setting holds great value. In my case, appearing in person was necessary for participants to feel comfortable with me.

3.3 Meeting Face-to-Face

Although individuals who participate in online communities sometimes meet face-to-face after having met online (Kendall, 2002; Rheingold, 2000), it can be difficult when community members are geographically dispersed. It is much easier when the online community is an extension of a place-based location (Kavanaugh et al., 2005; Wellman & Hampton, 1999). However, despite List participants living all over the United States and elsewhere in the world, there is a high level of interest in meeting each other, and members from diverse locations

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converge each year at the Gathering. Sophia, who has been on the List since its early days,

describes how face-to-face meetings evolved.

> In the beginning I formed friendships with just like a core group of people—most of them were funny, and smart, and wrote well. So I would enjoy reading. And then we could write back and forth. And…the second year I was on the List, Carmen joined the List. And [she] had an email address that was from the… County Library Association! So I wrote to her and I said, "Where do you live?" Do you believe she lived a mile away from me? Maybe a mile and a half. So we decided that there were other people in [the area] besides us. And we held a gathering. Just…there might have been four couples.…
>
> So we…decided that we could expand this....And we sent out an invitation to the List that we were going to have a gathering on such and such a date…and I opened up my home and Carmen opened up her home and we had quite a gathering.

After Sophia's initial small gatherings, participants started planning the first major List

Gathering, which was in October 1996. Rachel described the ways in which meeting in person

adds perspectives that enhance many List members' experiences of each other:

> [It] was great! I still remember the first one in Chicago and, just all the reactions people had to one another was really fun because you form images—you know, this was years before Facebook and photographs being available online so you really had not seen the faces of anybody. And you go in there and there are 100 people that you've been corresponding with and you have your own image in your mind of what they look like based on their written word and it was really quite stunning to, to have that experience. It was wonderful. And there were so many wonderful characters and personalities and, I mean I guess there still are but I just have such fond memories of the early years of the List and all the drama that ensued and all the intense discussions we had about so many things. It was a wonderful, formative, process for me.

The first Gathering was such a success that it became a standard practice. Each year significant

amounts of planning go into it. The Gathering occurs in places where members live and are

willing to take the lead in planning. Information about the Gatherings is posted on the List, and

participants talk about it both before and after. Many List members express pleasure when they

get to see pictures of the Gathering even if they have never participated. Immediately after one Gathering is over, discussions about where to have the next one commence, and List members put it to a vote. Various members play key roles in negotiating hotel prices, planning menus, and coordinating events and excursions.

List members also have a long tradition of meeting at smaller, regional gatherings both in North America and in Europe. Sometimes in the spring there is a gathering somewhere in Europe, and participants attend from Europe, North America, and even Australia. List members also visit one another while vacationing, and they visit members who are sick. While meeting in person is not something that everyone on the List does, the idea of it resonates with many participants. Even for those who have not met others, it is something that they have considered. Almost everyone I interviewed who had met at least one other person face-to-face found that being able to put a face to a name added depth to their relationships that had not been there before. Even though in many cases participants already have strong feelings for each other, the bonds often become stronger once they have met. Allison describes her thoughts about people who had attended a small gathering in her home town:

> I feel closer to…Bettina, whom I've met in person, who stayed on after the weekend, was here for my birthday, and her daughter played with my son 'cause she brought her daughter, and yeah. I'm close to her and to Mikki and to Jess because they all stayed longer. And…I'm also closer to Leah, who was only here for two days, but I've visited her...I'm closer to Sophie because I've met her, [and others]. Definitely.

For Allison, as well as many other participants, meeting in person solidifies friendships and has great value. In addition, participants who attend Gatherings do so because they do want to meet members they have only known online, or they wish to interact in person with those they have met before.

Not all List members meet face-to-face, and some have no wish to. Two of the participants I interviewed did not find such meetings worth their while. One person said, "I didn't enjoy them that much….I don't have anything in common with them except breast cancer and I don't want to build a relationship on breast cancer." The other stated, "I forget who I was sharing a room with but they weren't really interested in hanging out and talking and getting to know me….[I] basically found it stressful to try and hang out with all these people for such a long time." Interestingly, both these people still maintain some contact with the List, but meeting in person does not work for them. In addition, three other interviewees were quite sure they did not want to meet other members. Two of these individuals were lurkers and had no interest in social contact—reading the postings provided them with great satisfaction, and all the contact they needed or wanted. The third stated "If I get that personal, it's going to hurt me if I lose them. If I get that personal and I die, then I'm gonna hurt someone else that knows and loves me." Of these last three people, one was on the List for less than a year, one continues to read it, and the third participates occasionally. Yet despite these participants' lack of desire to communicate face-to-face, all but one expressed great affection for the List.

There is a core of individuals who attend the annual Gathering, with others attending every once in a while. In discussions with List participants, frequent attendees were proud to announce how many Gatherings they had been to. For these participants, being at the Gathering holds great value, although many others also appreciate its value, especially once they have attended one. Participants who frequent the event on a regular basis are usually the organizers of the event, and work hard to make it a success.

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In discussing "gaining acceptance of the people being studied," Lofland and Lofland (1984) write, "It is one thing to decide for yourself about interest, appropriateness, accessibility and ethics; it is quite another to get all the interested parties to go along with your plan" (p. 20). My attendance at the Gathering was one of the most significant contributions to building trust and facilitating List members' acceptance of me. Being there allowed members to achieve a greater level of comfort with me, and for me to see them in another setting and gain insights from meeting them face-to-face. The acceptance of the core of participants who organize and attend the Gathering was also crucial. As (for the most part) long-time members and individuals who hold a lot of respect among List participants, these were the people whom I needed to make comfortable. Because I took the time to get to know them and to let them get to know me, their perceptions of me became much more favorable. Several noted that they thought it was gutsy of me to make an appearance, and doing so made a big impression. Going to the Gathering also paved the way for my interviews with participants who had attended the Gathering as well as others who had not. Most participants from whom I requested interviews agreed easily. As interviews progressed, some members even stated online that they had talked with me and that it had been a positive experience, making subsequent interviews even more accessible.

Most of the participants I spoke with both at the Gathering and through interviews expressed great enthusiasm for meeting others in person. Within the context of the List, there is, overall, a feeling that meeting in person nurtures relationships and brings people closer together. In order for me to build trust among List participants, it was necessary for me to nurture relationships with members as well.

CHAPTER 4

INFORMATION'S MANY FACETS

The List is an environment that interweaves the very real concerns of breast cancer with other components of participants' everyday lives. It is first and foremost a serious space for figuring out how to address formidable health issues, but it is also a microcosm of life in general. Prior to doing this study, I examined two months of postings to ascertain the topics and common themes that participants talk about. I found that 62% of the postings were health-related and 38% were about other things, including pets, families, vacations, social events, and various other aspects of everyday life (Rubenstein, 2009). Conversations span such a wide range of topics that at times they seem similar to meeting neighbors on the street and at other times they mirror intense communications one might have with health care providers. Throughout the discussions, lightness intersects darkness, concern is peppered with humor, and crises evolve into celebrations.

Although my earlier and current studies broadly characterize topics as health-related and non-health-related, health is a part of everyday life and making divisions is subjective at best. For the purposes of this study, while I have identified categories related to information behavior concerns to explain various phenomena, I also note that information events are continually overlapping each other and often cannot be discretely separated out from others. This chapter first gives an overview of breast cancer patients' information needs, then discusses List participants' information behavior as it relates to breast cancer, other health issues, and everyday life.

4.1 Breast Cancer Patients' Information Needs

Usually the initial reason individuals seek web sites like the List is because of a desire for information about breast cancer. This search can be for both practical and emotional information, such as learning more about the physical aspects of dealing with breast cancer as well as how to cope emotionally with the illness. Breast cancer patients' information needs are complex and variable. For example, they seek information about physicians, the disease, how to combat fear and uncertainty, and how to prepare for the future (Moumjid et al., 2009). Other information needs include questions about prognosis, causes, risk factors, and hereditary risk, as well as sexuality, self-care and after-care (Lindop & Cannon, 2001; O'Leary, Estabrooks, Olson, & Cumming, 2007; Talosig-Garcia & Davis, 2005). Patients often feel uncomfortable asking too many questions of their doctors or do not always know what to ask, resulting in information deficits about multiple topics, including treatments, side effects, genetics, and spread of the disease (Beaver, Twomey, Witham, Foy, & Luker, 2006; Johnson, 1997; Lee, Francis, Walker, & Lee, 2004; Luker, Beaver, Lemster, & Owens, 1996; Moumjid et al., 2009). In general, patient information needs exceed the information offered by their physicians, and many are often unsatisfied with the extent and level of information that medical professionals provide (Moumjid et al., 2009; Rees & Bath, 2000; Thewes, Meiser, Rickard, & Friedlander, 2003). Even several years post-diagnosis, many patients still have questions that they are reluctant to ask their medical providers (Luker et al., 1996; Vogel, Bengel, & Helmes, 2008).

Reading the archives of the List bears out the findings of these studies. Postings appear on numerous topics. For instance, one participant, years after her diagnosis and treatment wrote, "Does the fear end?" and another participant (in a totally unrelated post), concerned about risk factors and genetics wrote,

I want to be tested for the presence of the BRCA1 gene. I keep running into stone walls with this request. I am willing to travel anywhere to be tested. I need to get my life on track and go forward. I cannot do that, however, as long as I know the specter of breast cancer hangs over my head. I don't want to be diagnosed -- I want to be prepared. Can someone help me, please? Thanks for any assistance you may be able to provide.

In reference to the amount of time patients spend with their doctors, someone else wrote, "I think that perhaps 20 minutes was not enough time to absorb the bad news and plan a new course of action. It's just too much. Your brain can't process all that so fast. So take it one step at the time." These comments give a glimpse into a wide variety of List participants' concerns, encompassing both emotional and practical aspects of breast cancer.

Studies indicate that patients' needs vary widely and are dependent both on individual preferences and personalities as well as the stage and progression of the disease (Brown, Koch & Webb, 2000; Harrison, Galloway, Graydon, Palmer-Wickham, & Rich-van der Bij, 1999; Rees & Bath, 2001; Williamson, 2005b). Rees and Bath (2000) reported that at the time of diagnosis—the primary questions are about prognosis and treatment, but later the questions gravitate towards recurrence concerns and by two years are more related to family members' risk of disease. Although some studies have reported that factors such as age, demographics, distance from diagnosis, or severity of the disease have some relationship to information needs (for example, older women desire less information than younger women) (Harrison et al., 1999; Lindop & Cannon, 2001), others have reported there being no significant differences among these variables (Luker et al., 1996; Rees & Bath, 2001).

Taken together, these studies illustrate the individual nature of information needs among breast cancer patients, and highlight the necessity for different types and levels of information sources to meet varied needs. Williamson's (2005b) study of breast cancer patients' perceptions,

values, beliefs, and meanings that they constructed around their information needs resulted in the development of a web portal, the BCKonline (Breast Cancer Knowledge Online) Project, which offered personalized search options according to the type of information needed (e.g., medical, supportive, personal), as well as levels of complexity and depth. Research also shows that accessing comprehensive information resources beyond that provided by medical practitioners can help to reduce information needs when patients are further out from diagnosis. For example, Beaver et al. (2006) found that women who participated in telephone interventions had fewer information needs a year after diagnosis as well as a significant reported decrease in symptoms when compared to a control group that did not have a phone intervention. Similarly, online groups also fill this void, proving to be valuable sources of information not provided by their physicians.

Although breast cancer patients utilize multiple sources of information, they prefer to access information from other people, including their physicians, other medical personnel, family, and friends (Brown et al., 2000; O'Leary et al., 2007; Talosig-Garcia & Davis, 2005). Patients are increasingly using the Internet to access purely informational websites as well as support group sites, although white women with higher socio-economic status are more likely than minority women or women of lower socio-economic status to use the Internet for this kind of information (Brown et al., 2000; Fogel et al., 2002; Satterlund, McCaul, & Sandgren, 2003; Talosig-Garcia & Davis, 2005). Because of a preference for information from other people as well as from the Internet, online breast cancer support groups have the potential to meet both the social support and informational needs required by breast cancer patients.

4.2 Seeking Information and Bridging Gaps

In trying to solve problems and understand breast cancer issues better, participants join

online groups in response to information gaps (Dervin, 1983a, 1983b; Kuhlthau, 1991, 2001).

They are trying to make sense out of a scary diagnosis as well as deal with the uncertainty of

their situation. Kuhlthau's (1991, 1999, 2001, 2004) information search process (ISP) notes the

uncertainty, anxiety, and confusion that occur as people navigate through their experiences, their

feelings, thoughts, and actions "intertwined in recursive interaction" (1999, p. 400). As

information seekers go through their search processes, they are seeking meaning as they integrate

new information into their current worlds. She states,

> Uncertainty and anxiety can be expected in the early stages of the information
> search process. The affective symptoms of uncertainty, confusion, and frustration
> are associated with vague, unclear thoughts about a topic or question. As
> knowledge states shift to more clearly focused thoughts, a parallel shift occurs in
> feelings of increased confidence. Uncertainty due to a lack of understanding, a
> gap in meaning, or a limited construction initiates the process of information
> seeking (Kuhlthau, 2004, p. 92).

Kuhlthau's six-stage process—initiation, selection, exploration, formulation, collection, and

presentation—builds on personal construct theory (Kelly, 1963; Kuhlthau, 1991, 2004, 2005),

which describes the "affective experience" as people integrate new information into existing

world views. Kuhlthau (2004) also draws on Wilson's (1981, 1997) work describing the

interrelationship between physiological, affective, and cognitive needs in the information seeking

process, focusing particularly on uncertainty and affective aspects of information seeking.

Kuhlthau (2004) writes, "The model of the information search process is useful for describing a

series of feelings and thoughts commonly related to the tasks in an evolving search process,"

noting the complexity of information seeking and its cyclical nature through "uncertainty and

increased understanding" (p. 94).

Dervin (1983b, 2003) incorporates a "situations-gaps-uses" model as a way to conceive of individuals' behavior as they construct their sense of the world. Dervin (1999, 2003) explains the sense-making process as one where chaos and order interact, noting two mandates:

> [O]ne is to make sense without complete instruction in a reality, which is itself in flux and requires continued sense-making; the second is to reach out to the sense made by others, in order to understand what insights it may provide into our continuing human dilemma. (2003, p. 332).

Dervin (1992, 1998, 2003) characterizes information as being "made and unmade in communication" (2003, p. 331), through users' observations and gap bridging, as well as the continual construction process of integrating and reintegrating information through time and space. She defines *situations* as the "time-space contexts at which sense is constructed" (1983b, n.p.); *gaps* as information needs that need bridging; and *uses* as the "helps and hurts" (1983b, n.p.) derived from the process. Throughout the process individuals interpret situations and seek meaning as they navigate through evolving realities (Dervin, 1999).

Sense-making and the information search process offer ways of thinking about the kinds of events that flow through the lives of participants in the List community. Initial contact is steeped in information gaps, uncertainty, and confusion. Individuals have questions and need or want answers. Sometimes the gap is very obvious – there are specific questions that need answering. This can be a very clear-cut, straight question, such as, "What are the side effects of Adriamycin?" Other times gaps are about needing a stamp of approval about certain decisions one has made or is in the process of making. This type of gap reflects a feeling of uneasiness, an uncertainty about how to proceed, and ultimately gets resolved through discussions with others. In this situation, in order to be comfortable with the decision-making process or to believe that one's choice is "right," it is necessary to know that there are others who agree. Abby, who had

joined the List when she was trying to make a decision about reconstruction, talked about several

ways in which the List filled her information needs:

> E: So when you found the List, was there something specific you were looking for?
>
> Abby: I was trying to figure out whether to do reconstruction at the time…I felt a little pressured by my husband to do it and I wasn't really sure what I wanted and the List was so supportive right there. They were just like ganging up on my husband [chuckle] [makes verbal fighting sound]. "It's your decision! Don't let anybody push you around." Yeah, I just felt really like, "Wow. This is cool. I got a whole team here." So, I was sucked in right away.
>
> E: And how did the List help you with your decision?
>
> Abby: Just validating my feelings for one thing. And then talking about different kinds of reconstruction, which I had not, hadn't really talked to, I mean when I talked to the surgeon [he] didn't bring all that up. And I was on a waiting list too… [so] during that time I got information from the List about what my options were… [and they] helped me make a good decision. With all the facts and all the information.

When she approached the List, Abby was uncertain about what she was doing in terms of

reconstruction. The feedback she received from the List was very different from that of her

husband or surgeon. With the help of the List, she was able to obtain practical information

related to reconstruction as well as validation for her feelings and for making her own decisions.

Abby felt supported and validated by List members, and knew that they were really listening to

her. Rather than having to think about her husband's agenda or lack of information from her

surgeon, she had found people who understood what she was going through and who were

putting her concerns first. The List helped her to focus on herself. Abby was trying to make

sense of her environment, dealing with the uncertainty of her decision-making process, and the

List helped her to move forward.

4.2.1 Rituals of Introduction

When newcomers first identify themselves to the List, they begin by introducing themselves and explaining the reason they are there. Often they ask questions right away, or they comment about what is happening to them. When Daisy joined she commenced with a simple announcement, offering an assessment of her condition and treatment, and how she had been using the List up until that point.

> I'm new to this list, new to the world of having cancer (dx 4/29) reading about such sad things, but such amazing love. I have been lucky to date - no positive nodes here - but the treatment is kicking my butt (or should I say gut?) I read…stuff in the archives looking for info and tips (thank you all). I really do believe we go on and step over and thru.

Although Daisy did not explicitly ask a question in this first post, she offered information about herself and talked about her information needs in managing the side effects of her treatment. In response to Daisy's posting, Sheryl replied, "Hope your treatment goes well. Any thoughts or questions you'd like to share here?" This is a common introductory scenario, where a newcomer's introduction elicits both good wishes and encouragement to ask for help, or current members who have been through breast cancer will share some of their own experiences, such as Maura, who wrote to another newcomer:

> Welcome to the list. A list no one wants to join, but we all understand what you are going through and understand how you feel. I think my first chemo was my worst. It seems I had an ache everywhere. Wishing you the very best in treatment. We are here to help you get through this. Hugs.

Orgad (2005a, 2006) and Høybe et al., (2005) have discussed the therapeutic and empowering aspects of shared breast cancer narratives, which are reflected even in these early introductory postings. Through these messages each person posting, whether a newcomer or longer-time member, tells a story, and embodied in these stories is information about her connections to

breast cancer. The process of telling stories to others provides nurturance and facilitates feelings

of inclusion and warmth, "invit[ing] empathy" (Preece, 1999, p. 72). Newcomers reveal

themselves by disclosing aspects of their treatment or emotional state (or both), and those

responding indicate their desire to help through their welcoming words and their own

disclosures. These introductory sequences help participants to establish valid connections with

each other right away. They function as social rituals in that they are common practice for

newcomers to make themselves known and for longer-time members to offer their assistance.

Many first posts go further than short introductions, and provide a plethora of information

right away. When Megan first began to participate, she presented herself in this way:

> Dear Everyone
> I have been lurking around on the list for a while, but now I would like to seek
> some help from your combined expertise and experience.
>
> I am 49 and had surgery [in] December for breast cancer - right mastectomy and
> axillary [dissection]. I had a 17mm tumor and 9 affected lymph nodes. It's Stage
> II and Grade 2 and ER+ and PR+. Now I am having to make some decisions
> about treatment. The oncologist is talking about chemo, probably radiation and
> tamoxifen. My questions are about the chemo and radiotherapy particularly.
>
> a) For chemo I have been given the choice of three different cocktails: ACx4 or
> CMFx6 or Adjuvant Taxotere clinical trial (random allocation to four different
> combinations).
>
> My questions: can anyone refer me to any research about the pros and cons of any
> of these treatments? And can anyone give me feedback of their experiences of
> side effects, how it felt to have any of these treatments?
>
> b) Radiotherapy. I had initially thought that I would probably not have to have
> radiotherapy if I had a total mastectomy (though that was certainly not the
> overriding element in my decision). Now I am told that there appears to be
> evidence to suggest benefit in having [radiotherapy] in addition to a mastectomy
> in certain cases including having more than a certain no. of nodes involved (my
> case). Again, can anyone point me to any research on this issue? And what has
> been the practice on this issue for other women on the list?

In this longer introductory post, Megan is in the middle of treatment and at an impasse in her decision making. She has been given three chemotherapy options and is also confused about the benefits of having radiation in her particular situation. She asks specific treatment questions, trying to fill gaps in her current knowledge by requesting recommendations for journal articles as well as personal experiences to help her figure out how to proceed. Megan's questions are illustrative of the conundrums that many patients face when dealing with multiple treatment possibilities. In many cases breast cancer treatment holds myriad options, each of which potentially alters statistical survivorship, and each of which can result in an assortment of side effects (Breastcancer.org, 2011b). There are few definitive choices, and discussions on the List attest to the different options patients are faced with and how much research many patients do prior to making treatment decisions. It is up to her to figure out what treatment to choose, and she reaches out to peers who have been through similar experiences. Sheryl answers Megan:

> Dear Megan,
> There is lots of evidence that Taxotere is good stuff. For positive nodes I believe it is Adria and Tax that are the treatment of choice, or Adria, Cytoxan, and Taxotere (or its close relation Taxol). I'll see if I can find my documentation and send it to you in an attachment.
>
> [Another List member] knows lots about radiation. My surgeon told me that in the past his patients who had mastectomies also had rads--he feels adding rads is extremely helpful and is glad doing so is coming back into vogue. I hate to make this all sound like a fashion statement, but medicine I think has its trends, too.
>
> Also, back to chemo: if you are her-2/neu pos, I believe it is adria that is considered to be more effective than CMF.
>
> Sorry that you have to contend with all of this cancer stuff. It seems so strange, doesn't it? At least the company is good.
>
> Be well,
> Sheryl

Sheryl's response exhibits the ways that long-time members try to help newcomers. Sheryl not only provides the medical information she is aware of, but also offers to find more ("I'll see if I can find my documentation…."). In addition, she refers Megan to another List member who might know more than her, and offers empathy as well as a slight bit of humor: "At least the company is good," which offers commentary on what List participants are like. While fully acknowledging Megan's pain and anxiety about breast cancer, Sheryl indicates that there is a level of lightness to be found, a prediction of sorts that while life is very serious during the acute treatment phase of breast cancer, there is hope.

Introductions serve several purposes for all parties. While they are important for newcomers as a way to gain entry, the introductory responses are just as important for current participants as a way to acknowledge newcomers, to offer them an initial glimpse into the List's potential, and to also feel helpful, which is one of the reasons they are there. When I did my interviews, numerous participants talked about how it was important to them to be able to give back to the group in the same way they had been assisted when they first arrived. Comments such as, "And I decided that because they were so kind to me that I would have to give in kind" and "[I]t is a way to…help others that may be going through breast cancer." In being there for newcomers and offering the kinds of responses they do, current participants are providing links of continuity that ensure the List's endurance by modeling social norms of helpfulness.

The practice of introduction and response, while not necessarily known to newcomers, sets the stage for future interactions. Baym (2000) has described the "distinctive traditions" (p. 1) that members of an online soap opera community used in their communicative practices. She refers to social norms and behaviors that communities adopt, such as an "ethic of friendliness"

(p. 140) or specific routines. Kendall (2002) describes traditions of hazing of guests and newcomers in the online community she was part of, indicative of how each community forms its own practices of engaging with people. Baym (2010) also notes that "[o]nline speech communities share ways of speaking that capture the meanings that are important to them and the logics that underlie their common sensibilities" (p. 77). The patterns of introduction in which List members engage are warm and friendly, natural outgrowths of how members view themselves.

The details of many introductory messages also bring up other information issues related to the culture of the List. In many cases, they extensively incorporate medical terminology. For instance, when Molly joined, she seemed to have a high level of comprehension about her experience even though she did not know what to do next:

> Hello. I am Molly, 66, and I had a lumpectomy last month. I had a .8 cm tumor removed. It was invasive, ductal, estrogen positive 89%, progesterone positive 17%. I was told to either choose lumpectomy plus radiation or mastectomy. Now I don't want to do radiation, and am considering whether or not I should have my breasts removed. I have read studies that suggest that radiation does not improve odds significantly for my age. My Oncotype DX says I have a 6% average rate of distant recurrence with 5 years of Tamoxifen. My surgeon says that there is a 1-5% chance that it spread to the body, since my sentinel lymph nodes were clear. I feel so fortunate that they found this, because they were not looking for it. All my mammograms were OK, including digital ones last month. My gynecologist insisted on an MRI mammogram to see cause of pain on the OTHER breast, and this was found. (Other breast is OK) PET scan showed no spread of cancer….I guess what I am asking the list is what do those who have experienced this think about my forgoing radiation?...Any comments welcomed.

Molly's first post (the above represents a merging of two consecutive posts) describes her diagnosis, her treatment, and her concerns. Like Megan's post, Molly is very exacting in her explanations of what she has been through and the decisions she has to make; thus, her questions

encourage more detailed answers as well. Claudia replies to Molly by giving extensive details of

her own experiences with breast cancer:

> I've had breast cancer twice -- had a lumpectomy and radiation, with Tamoxifen
> after the first dx (.9cm Invasive ductal, ER/PR+), partial mastectomy and
> contralateral reduction AND refused radiation after the second dx (DCIS -
> confined to the ducts). I was leery of radiation the first time around and did have
> immediate, though minor, lung complications. The second time I was not about to
> subject my chest to more radiation.
>
> Long term -- that's another story. Those radiation treatments after the first dx were
> finished in 1999. This past November I was dxd with cutanaeous angiosarcoma
> CAUSED by that radiation nearly ten years ago. Mind you, this is rare -- but it is
> becoming less so as time passes. My breast surgeon says she expects an
> exponential increase in these radiation caused cancers, as the choice of
> lumpectomy followed by radiation has increased over the past ten to fifteen years.
>
> Sooooooo... with a small and probably not so aggressive tumor (what grade was
> your tumor? Cellular differentiation?), I think you're wise to consider not doing
> radiation. But, that's just my opinion and it's based on a personal and not so
> common reason.
>
> As others have, I recommend that you get another medical opinion, knowing that
> radiation does have definite side effects and consequences.

In addition to giving her own details about her own cancer, Claudia's answer responds to

Molly's questions about radiation, first affirming her fear of radiation by telling her she is right

to think about her options, but also acknowledging that it is her own opinion and that it might

benefit Molly to get another professional opinion. This level of response is common, with

responses often matching the extent of the questions. Although this does not always happen,

those who can answer questions in depth usually do so.

Related to the culture of the List, these intricate questions and responses are indicative of

how some patients, and particularly List participants, become very well versed in the language of

breast cancer, language that they may not have known before. With a diagnosis of breast cancer,

patients who want to make informed decisions about treatment must become familiar with a new terminology. Using this language serves as a way of solidifying legitimacy with the List and with their physicians, giving them increased power as they negotiate their way through breast cancer. In turn, members who respond to medical queries also exhibit their command of the language, which offers newcomers assurance that there are others out there who understand their questions, have been in their position, and have something to offer them. The preceding posts exhibit high levels of fluency in the language of breast cancer, in most cases language that outsiders are not likely to know, or to understand.

The use of medical language and inclinations toward research are indicative of the kind of engagement participants have with breast cancer issues (and other health concerns) as well as the nature of who is likely to become a participant on the List. Participants are well educated and are able to express their medical questions. They might not understand everything, but they know enough to be able to ask questions. And for participants who are less able to process the language, there are always others on the List willing to help them wade through the terminology and provide explanations whenever they are needed.

4.3 Medical Providers, Information, and the List

In a medical climate where doctors are usually pressed for time, it is not unusual for patients to come away from appointments feeling confused or unable to recall what was discussed (Fogel et al., 2002; Williams, Davis, Parker, & Weiss, 2002). This occurs because doctors do not necessarily know how to talk to patients, information transmission is not matched with the needs of a patient, and many doctors are not comfortable having collaborative conversations with their patients (Duggan, 2006; Johnson, 1997; Williams et al., 2002). Brashers,

Goldsmith, and Hsieh (2002) characterize physician-patient information exchange as asymmetrical, in that doctors "ask most of the questions and patients provide most of the information" (p. 261). Sometimes medical information takes time to process and patients are unsure how to respond at the time they are receiving it. In addition, patients are often uncomfortable questioning their physicians, or do not know what they need to ask (Moumjid et al., 2009; Rees & Bath, 2000; Schwartzberg, Cowett, VanGeest, & Wolf, 2007; Thewes et al., 2003). These communication difficulties then leave gaps in patients' knowledge about their conditions and how to proceed. Patients do not have adequate information to make treatment decisions nor do they know what they should expect when they are undergoing certain procedures. As a way to counteract this, online communities offer participants opportunities to share information about their treatments, making it possible for them to be more knowledgeable and have more productive conversations with their physicians (Maloney-Krichmar & Preece, 2002, 2005).

List participants reported a range of relationships with their physicians, some describing them as excellent and others feeling as though their doctors were not telling them everything they needed to make informed decisions. For example, Jodie said,

> Well, doctors and nurses don't share very much although my doctor is very good about trying to give me as much information as he thinks I need. He's a very kind of warm person, but, you know, he doesn't come in and say, "Well, here's this study that's being done and you know, for people who've had mets for three years," or, you know, something like that. He just basically focuses on what's happening right now with me. So I don't get much information from him.

When participants described how information from the List is integrated with the information they receive from their physicians, most talked about how the List is another source of information.

Abby: It's just another source of information, one I trust, that these are people that have been through and experienced it. And doctors sometimes discount our experiences, so I find it's a good backup to doctors. But I'm not saying that I distrust doctors; I just don't trust them to give you all the information. Or to know it all. A lot of times they're just, their research needs are too broad and so they don't maybe keep up with the latest stuff like we do. And I have actually encountered that.

Two ways that participants use the List in the context of medical providers' information are to obtain clarification of the information their providers told them, and to find out what their providers may not have told them. In each case, they are comparing what they know with what other List members know or have experienced. For example, List members will have conversations with medical providers, bring those conversations to the List, obtain new or expanded information, and then return to their providers with their new-found information. The stories of several List members highlight how their conversations with other List participants helped them to better understand their experiences, influence their interactions with their medical providers, and in some cases, alter the course of their treatment.

4.3.1 Clarification of Information

Clarification of information occurs when a participant has been to see her provider and she did not receive enough information to understand what to expect. Often the questions come up later, after the appointment is over, making it hard to obtain answers. Clarification helps participants absorb the information they have, and helps them cope. Giselle described how the List helped her make sense of the information that she received from medical providers, making it easier for her to cope with a number of issues.

E: Tell me about your initial experiences on the List.

Giselle: Well as you can imagine I was terrified that this was the train that was going to kill me….I [joined] before I got the pathology report, so that was a three-

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day wait and so I joined in and I indicated that I was new and that I didn't know what was going on and I was really scared…. But when I did get the pathology report I remember typing it in and people helping to explain what it was, what the different terms meant, to the best of their ability and they were in all cases correct….[I]t helped me a lot, actually. Quite a bit.

I went to the List with just about every question that I've had. They told me what to expect from the type of chemo I was going to be given. They helped me with my nausea because, for instance, initially when they were giving me—I had Adriamycin, Cytoxin and, again, I had Taxotere separately. And the Adriamycin and Cytoxin made me very nauseous….They also told me about Emend and to take the Zofran before I got nauseous, which worked. Because my first chemo I was given only Compazine for nausea, which was worthless, which basically just mowed me down further.

And the nurse had said something about Emend and I came back to the List and said "Where's this Emend that I'm hearing about?" and they told me and I was given, always given links—people were always supplying informative links for me. And that helped me tremendously. I had questions—a lot of questions about reconstruction and I was given a lot of anecdotal information about different types of reconstruction.

There are several points of interest in this quote relating to clarification of information. First, Giselle brought her pathology report to the List to help her understand its contents. Pathology reports are generally incomprehensible to laypeople; the options are to call a physician's office and wait (usually) for someone to call back, or go to someone else who might be able to shed light on the language – in this particular instance, that "someone" was the List. In addition, Giselle used List members' knowledge to help her figure out how to deal with chemo side effects as well as reconstruction information. Regardless of the level of information Giselle was obtaining from her providers, she was also scoping it out with the List to help with her comprehension and with decision-making.

Trina also needed more information beyond what her physician told her. Recently out of treatment, she wrote to the List:

I have a question about neuropathy. I got neuropathy in October [last year], while receiving my first dose of Taxol. My symptoms got worse in March…, and my oncologist sent me to a neurologist. She didn't do much then, but told me to come back if my symptoms got worse. Well, in August, the "tingling" in my feet turned into pain, and the "tingling" has now moved up my calves and thighs. I finally went back to my neurologist last week. She confirmed that my neuropathy was getting worse, and decided to do a blood test. She didn't tell me what she thinks is causing this though.

Trina is aware of a gap in her understanding of her experiences. Despite her neurologist's acknowledgement that the problem is getting worse, Trina did not receive information about the underlying reason. Her last sentence, "She didn't tell me what she thinks is causing this" hints at several communication problems, although there is no way to know exactly what happened in the physician's office. Whether her physician did not give Trina enough information, or whether Trina did not process it or ask for anything more, she tries to confront her information need by opening up to peers who are not of the medical community but who have had experience with similar symptoms. After posting, Trina received several answers from other participants, who gave her suggestions or described their own experiences.

4.3.2 Bringing Information to Providers

Many interview respondents described learning of information on the List that they brought back to their providers for discussion, ultimately altering their treatment plans. The most striking examples of these occurred unexpectedly – when participants were just reading others' postings, and they discovered information that they had not been looking for, but which had major application to their situation. Williamson (1998, 2005a) described certain types of information acquisition as being incidental, or as *accidental information discovery*. In her study of older adults' information-seeking behavior, Williamson (1998) noted that although respondents purposefully sought out information, they also "picked up" information merely by

listening to the radio, reading the newspaper, or talking with friends and family. In her studies of students and academic employees, Erdelez (1996, 1997, 1999) has defined *information encountering* as "a type of information acquisition that involves memorable experiences of unexpected discovery of useful or interesting information that had not been sought, or the discovery of unforeseen characteristics of information that had been sought" (1996, p. 102). Information encountering occurs both when people are seeking information and when they are doing other activities that are not specifically information related. Veinot (2009a) delineated similar information acquisition among people with HIV/AIDS as *network-mediated information exposure*, which occurs when people acquire information "simply by virtue of listening to, looking at, or interacting with, people and documents in their social world" (p. 2319). Each of these constructs offers valuable ways of conceptualizing serendipitous information acquisition that can occur while participants browse the List.

For List participants, information encountering occurs while they are reading the List, either looking for other information or just reading to catch up, and by way of reading, they discover information that is related to their lives, but which they were not specifically seeking. One example is Allison, who when she was undergoing treatment was very confident about the medical care that was available to her but also conscious that physicians have limited opportunities to communicate. While she respected her providers' opinions and expertise, she also said, "They only have 10-15 minutes for each patient, so they don't have the time to explain things."

> E: So can you think of some specific information at any point that you went to the List for, and what kinds of answers you may have received?
>
> Allison: Well, one of the things was that when I was diagnosed it was a very small tumor and they didn't know much about the HER2 at the time—[the

information] was a bit inconclusive about small tumors and how much the HER2 positively affected the…prognosis. So they didn't recommend hormonal therapy. And I read on the List that several people who had a similar diagnosis *were* getting hormone therapy, so I asked about that and [another member of the List] responded and she explained to me the pros and cons of doing that…

So I went [to the oncologist the next week] and we discussed it. Because of my allergies [to some medicines] we decided to just do a test drive to start….And we tested Arimidex first and then we tested Zoladex,…separately and then together. And I had very few side effects so I stuck with that for the whole five years, or almost the whole five years. So the information on the List really changed my treatment plan.

Allison's physicians had not recommended hormonal treatment for her situation, but her participation on the List alerted her to the fact that other people with similar diagnoses were receiving different treatment. When she read the information and asked for clarification, she was able to then approach her physicians, which resulted in a change of treatment. Allison's doctors had her on a particular treatment path, but given the new information she received from the List, she was able to access tools that allowed her to engage more fully with her doctors. Although she had not been aware of a particular information gap, being on the List opened her up to discovering information about her particular situation. Erdelez (1996) notes that information encountering is facilitated on the Internet when someone is browsing or seeking (as opposed to doing something like making a web page), although the information discovered has nothing to do with what is actually sought. Allison was reading messages, and came across information that she was not looking for.

Several women who I interviewed on the List reported that their doctors never told them about lymphedema, which is swelling, numbness, and discomfort of the arm or hand that may occur after breast cancer surgery (Breastcancer.org, 2011a). According to Rebecca,

[M]y doctors had never said anything to me about lymphedema. There was never one word at the beginning about, you know, "this probably won't happen to you,

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but we just want you to be aware. These are the signs to look for," and …
probably a year after I finished treatment… my wedding ring was getting really,
really tight. And I thought, "This is crazy…I've worn this ring through two
pregnancies and why would I now, why would it get—I haven't gained any
weight and my ring is tight!" And it wasn't long after that on the List they were
talking about lymphedema! And I'm like, "Holy crap! …I had lymphedema!…
And I said [to my doctor], "You know, you need to mention this. Somebody in
this process whether it's one of your nurses or the surgeon or somebody needs to
talk to you about it, give you some handouts, some literature about it."

In recounting this experience, Rebecca brings to the forefront not only that her medical

providers neglected to give her some essential information that all breast cancer patients should

be aware of, but that she learned about it through other patients. Although it is a positive

experience to have figured out what was wrong, it also affirms that the gaps in patient-provider

communication often leave patients with questions that they do not even know they have.

Rebecca was faced with swelling that she was totally unaware was related to breast cancer, and

had she not been a member of the List, it is hard to know when or how her problem would have

been resolved. Also important is that she did bring this problem to her doctor's attention and

received the treatment that she needed; however, as Rebecca also said, "I wish I had—I would

have been right on it at the first sign instead of waiting until it was physically uncomfortable."

Unfortunately for Rebecca, treatment did not occur as early on as it would have had she known

about the condition. However, luckily, she was able to obtain the information she needed from

the List, as well as to make sure her physician understood that it was a problem that this was not

being communicated to patients.

Both Allison and Rebecca became aware of new options through their participation on

the List, and began to use that information to make further treatment decisions. In Allison's

case, the treatment she learned about through the List had not been recommended by her doctors,

and in Rebecca's case, she had not even been told about a potentially serious side effect. In each

situation, they unexpectedly encountered information on the List that offered them better tools to make decisions and proceed with a plan. In both cases, also, there were List participants who were able to give them access to information that they were unaware of, and gave them resources that they could use for their next conversations with their doctors.

4.4 Breast Cancer, Everyday Lives, and Information

Participants' information behavior demonstrates aspects of several information theories and models. Savolainen's (1995, 2004) model of everyday life information seeking (ELIS) provides a useful foundation for understanding the environment of the List. Savolainen (1995, 2004) approaches everyday life from the perspectives of "way of life" and "mastery of life," describing everyday life as "a set of attributes characterizing relatively stable and recurrent qualities of both work and free time activities" (2004, p. 1). "Way of life" is connected to the decisions individuals are faced with that are ordinary and routine, such as those related to hobbies and household tasks (Savolainen, 2004). "Way of life" choices occur through the monitoring of daily occurrences, as a way of seeking orienting information that keeps life "relatively stable" (Savolainen, 2005, p. 143). However, life is not always stable, and at times requires "mastery of life," which occurs when the stability of life is disturbed in some way and requires problem-solving (Savolainen, 1995, 2004, 2005, 2010). Savolainen (2010) writes,

> Generally speaking, the concept of ELIS refers to the acquisition of various
> informational (both cognitive and expressive) elements, which people employ to
> orient themselves in daily life or to solve problems not directly connected with the
> performance of professional tasks or full-time study….ELIS may have two
> modes. On one hand, it may refer to seeking of *problem-specific information*
> (e.g., finding a fact). On the other hand, ELIS may manifest itself as seeking for
> *orienting information* (i.e., monitoring of everyday events by using various
> sources and channels) (p. 1781).

As an everyday life information environment, the List serves both as a place to solve problems that have disturbed the order of one's existence as well as an information space that functions within participants' everyday lives. List members have faced serious disruptions of their everyday lives, yet at the same time, these disruptions evolve into what many refer to as their "new normal." Once someone has been diagnosed with breast cancer, that diagnosis becomes part of everyday life, something that is hard to remove from one's consciousness, and something that is factored into each participant's experience of life. This is certainly not true for everyone who has had such a diagnosis, but for participants who remain on the List, breast cancer is a significant aspect of life, something that has a place within the spectrum of their daily lives.

List members engage together in solving both major and minor crises, but the List also functions as an everyday life resource. Participants go to others on the List for many reasons, reaping a variety of benefits. For example, Charlene is a List member who works in an allied medical profession and is someone who through the years has offered extensive information when members have had questions about various procedures related to her expertise. Based on reading the List archives, my perception of her was that the primary reason she was on the List was to provide information and clarification for others. However, when I interviewed her, I learned otherwise.

> E: It seems like you're primarily there to help other people. I mean, do you feel that way?
>
> Charlene: I think it's the other way around, Ellen. I would love say I'm there to help people but it's really not why I'm still there. I'm still there because it helps me in every part of my entire life. I could wear your ear off telling you how what I've learned from the List is an analogy for the rest of my life…. The most important lesson from the List of any lesson that anybody should ever learn is not being afraid to stand up for your own well-being in all situations. I don't mean just in healthcare. I mean in everything…. Ninety percent of the ills that I have—

personal, financial, medical, and sociological, [for] most of those I can read the
List and find [answers for] them.

Building further on Charlene's comments, although the List's primary purpose is to provide a space for people to interact with others as they face various aspects of breast cancer, it is also a place that operates through the cadence of participants' lives beyond the focus of breast cancer.

Another way to think about the List as an everyday life information space is the way it is incorporated into members' lives. First, it is a site that many participants go to on a regular basis. It represents an element of ongoing life whether it is for problem-solving or orienting. As Eleanor, a long-time survivor, noted,

I've always gotten it in my inbox; it's there every morning and evening. Now,
because I'm retired, I probably spend an inordinate amount of time doing email
and reading stuff online, and so it's there. I do it almost every morning, and then
several times through the day.

She also stated, "I think I stay on it partly because I have some very good friends that are still on it," which is a common sentiment. The fact that many participants also become friends and feel comfortable talking about many aspects of their lives makes it a place that is ripe for monitoring information. Even when participants do not become friends, there is a sense of affection or attachment that many feel for others, which transforms it into a regular stop through the course of a day. Whether they are ardent readers and participants or only occasionally drop in, members of the List interact with the space to satisfy practical and immediate information problems, or scan it to see what information is available, what other participants are doing, and just to have contact. During acute phases of breast cancer treatment and other health challenges, participants are interested in solving, or at least alleviating as best they can, actual problems. The rest of the time participants are often "checking in" to see what others are up to, to say "hello," to help others, or just to read and feel a part of this community.

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As an everyday life information space, the List comprises a wealth of general health information exchange as well as discussions that have little to do with health (Rubenstein, 2009). Breast cancer and health-related postings include information about procedures, medications, side effects, foods and vitamins, but also more general discussions about other health issues, personal situations and concerns about other participants. Non-health-related postings include information about family and friends, discussions of social events, business pertinent to the administration of the List, and birthday announcements. Through this variegated tapestry, information behavior manifests in multiple ways.

4.5 Information Interactions

List members whom I interviewed reported several different types of information interactions with the List, comprising: 1) discussions of *breast cancer information*; 2) discussions about *other health information*; and 3) discussions of *information not related to health*. These interactions vary in intensity and shift through time depending on participants' life situations and needs. For instance, participants who used the List intensively for breast cancer information 15 years ago and never had a recurrence do not currently interact on the List in the same way they used to, but some monitor it on a daily basis to see if there is a way they can help. Others stay in contact with the List because they have an emotional connection with others but not because they are using it for their own health needs. Yet others continue to check in because they want to be present and feel the presence of others due to a small core of anxiety that breast cancer might appear in their own lives again and they derive comfort from remaining in touch with the List.

These categories of information interactions often intertwine, occurring in conjunction with each other, and their variegated nature lends itself to conceptualizing "weaving a web" as an apt description of what occurs on the List. The overlap of participants' individual and collective experiences through these categories forms a web of information interactions that change, adapt, and adjust through members' evolving participation. Information seeking and use shift depending on current needs and life experiences; however, it is useful to explore each of these categories as a way of gaining insight into different constructs of interaction with the List.

4.5.1 Discussions of Breast Cancer Information

Approaching the List for *breast cancer* information is, of course, an expected use of the List and the reason the List was developed. Although initially people come to the List because of immediate information concerns, the paths they take after resolving their questions evolve in various ways. For some participants, once their situation is stabilized, their information interactions relate more to ongoing survivorship, quality of life issues, and helping others. For other participants, after dealing with the acute phases of breast cancer they decide to leave the List and move on to other things in their lives. These scenarios are representative of potential information trajectories on the List, but also give an indication of how each person's experience of the List is unique. While asking the List for help and information with acute problems is often the first phase that occurs for many people, subsequent experiences with the List vary. As illustrations of varying types of involvement with the List, I offer examples of four people whose lives have intersected with the List: Bonita, Eleanor, Alice, and Vicki. Bonita and Eleanor have both been on the List for many years, but different aspects of it influenced their decisions to stay. Alice spent a relatively brief time on the List, obtaining what she needed from it, and then

leaving. Vicki was on the List a couple of times, obtaining information for herself but also for other people in her offline social network.

Bonita found the List through an Internet search soon after she learned of her diagnosis. Initially she found the discussions to be difficult, and she was not sure she wanted to be there.

People had just died. And the List was in mourning. So I'm reading all this dead stuff, dead people, dying and grief. And furthermore it just, it was very technical. People were writing in all this technical stuff. Which, I wanted the technical stuff to use as ammunition so I didn't have to have chemo 'cause I was terrified of chemo. But they weren't doing that. They weren't giving me the information I wanted. It was all how you needed chemo. And the God's honest truth, I would go to the computer and turn it on and just kind of squint my eyes and kind of look at the email sideways. And I remember that day when I said, "I am deleting these letters, they are really awful. And I can't, this is not good for me to read all this misery and tragic outcomes. This is not good!" And then there was this woman [who was dying], and she wrote about stuff going on with her and she ended her email, "love, love and kisses, hugs and kisses and oodles of lovey dovey." Really and truly, I thought "If this place has oodles of lovey dovey I can stay here! I can stay here!" This is a human place. It just isn't death, misery, grief and statistics. There's a kindness here. There's a spark of green life here. It isn't just black, grief and horror." And so then I decided to stay. And that was, it was very important to me to stay.

And, so I was writing in all these things about, "Do I really have to have chemo?" And this woman kindly wrote me back [about] some study in the Lancet. And the study said that people with tumors like mine—'cause I had five positive nodes, etc., without chemo had, I think, a 41% chance of surviving 10 years. People with chemo had a 52% chance of surviving 10 years. And I had said in my mind if chemo gave me a 10% better chance, then I would have to have chemo. Less than 10% I wasn't going to do chemo. And it was 11%. So, I was, "oh my God." And I also was afraid if I didn't have chemo and I died I would be real mad at myself….

I was writing constantly, reading constantly, day and night, day and night. I was gathering information, getting helpful hints, telling people what it was like, that being able to talk about these things to people who were very interested and who understood what was going on, what it was like, was just the most valuable thing. I think it would have been desperately lonely to go through chemo without having those people. I feel very badly for people who don't have someone to share that with.

Bonita specifically talked about emotional feedback that she got from the List, contrasting it with some of the technical information she encountered. While she received responses that offered her practical information about treatment possibilities, the emotional information was necessary as well to help her deal with the stress of going through breast cancer. The practical information helped her make a decision, and the emotional information helped her to understand that she could navigate the experience with the help of List members she was able to talk to about it.

Bonita also notes briefly that even during this time of gathering information about breast cancer, she was "telling people what it was like." Thus, she is not only a recipient, but also a provider of information. It is natural to think of providers of information as those who offer the information that guides others through their treatment decisions, but Bonita offers a reminder that the information provided by a patient is just as crucial because it influences the kind of information that others are able to provide. At this early point in Bonita's breast cancer journey the information she offers to the List is about her immediate concerns, so that she can make decisions about her next steps. In order to access the information she needs, she also plays a role as a provider of information. She engages in an interactive information exchange whereby she and others are both information providers and information receivers.

After initial contact with the List, participants' information needs and uses adjust as their knowledge and experience change, differing depending on individual situations. As Kuhlthau (2004) notes, information needs do not begin and end neatly, and often they are part of a constructive process, building on each individual's experiences and perceptions. Kuhlthau (2004) describes the phases people go through in understanding their worlds, a "process of construction [that] is dynamic and driven by feelings interacting with thoughts and actions" (p. 25). Bonita's

initial conversations with the List resulted because of uncertainty, confusion, and gaps in her

knowledge and understanding of her situation. As she gained more knowledge, she was able to

reduce her uncertainty, and with the help and information from others, figure out what her next

steps would be. Bonita's information world evolved from breast cancer being an immediate,

scary situation into one that became more manageable as she gathered and acted upon

information. Throughout the process of her diagnosis and treatment, she gathered information,

interpreted it, and grappled with making sense of her situation both cognitively and emotionally.

At the time of my interview with Bonita, it had been many years since her diagnosis, and

her need for breast cancer information had became negligible. She said,

> I don't read everything. I used to read every letter, every word. It's more like, like
> I have a service I can offer, which is the welcome letter since I've started it again
> and just, I think I provide emotional support to people in a useful way. I don't
> provide any technical support because it's all different now. The chemo regimes
> are different, the drugs are different.

Her relationship to the List has become much more multi-faceted than it was in the beginning in

that she participates for a variety of reasons beyond breast cancer, including friendships and

staying in contact with other members, but the core of why she is there is still connected to breast

cancer information. As a way of providing a warm, friendly information space for others, she has

taken responsibility for posting a welcome message for newcomers approximately once a week,

and she wants newcomers to know that they have come to a place where they will get the support

and information that they need. The welcome message serves as an introduction to the

community, addressing many information concerns and fears that newcomers might have, and

encourages people to participate.

Welcome to all. We hope you will join in on our discussions. We talk about many things on this list. It might at times appear that we never talk about breast cancer, but that is not true. Some of us are newly diagnosed and some of us are in treatment. And some of us have finished treatment but remain here, bound by our common experiences and our care for each other. The letters here are about the breast cancer experience: fears, lack of knowledge, the rigors of treatment, effects on self and families. And some of us, either newly diagnosed or long time members, also write about the joys and difficulties of ordinary life. Please keep reading below to find some useful info, and to read a bit more about [us]. And, when you are ready, please write a little about yourself, and please feel free to ask for information and support. There are a lot of people here who know a lot about breast cancer and its treatment, and about life during and after BC. Best wishes and hopes.

Despite that Bonita's reasons for remaining on the List have changed from being an active patient to someone who offers emotional information to anyone who needs it, the common threads connecting the varying aspects of her participation have been related to the acquisition and provision of breast cancer information.

Eleanor's participation on the List is also steeped in breast cancer information, but in different ways than Bonita's. Eleanor has been on the List since the mid-1990s although she participates only occasionally now. Where Bonita noted that the reason she decided to stay on the List was because it had a "touchy-feely" aspect to it, Eleanor, who is retired from professional work in a scientific field, was attracted to the List because of the scientific discussions about breast cancer. Eleanor described her participation as being somewhat quiet during her first couple of years, but after she went to her first Gathering, she became more involved. Around the same time, she also started going to national breast cancer advocacy meetings, through which she learned more about breast cancer and felt as though she could offer more information to people on the List.

Eleanor described many changes on the List over the years, especially since the days when there were hundreds of members and the activity was quite brisk. She said, "The whole

tone of the List has changed a lot over the years, and because we get relatively few new people—

it's kind of just evolved into more of a social support group." For her this is less satisfying than

discussing the scientific aspects of breast cancer, and is one reason why she is less active.

However, she also said, "Although I have to say, when anybody new does come along, or the

people that like the science will post something, it often precipitates a nice debate." Eleanor

continues to stay on the List, checking in on a daily basis with the intent of helping others and

providing information if they need it. About her participation she noted:

> The fact [is] that there are things [that] do come up that I feel like I have
> something to offer. And if new people come on, of course it's great because
> there's so many people then that really try to help that person. Because it doesn't
> happen that often. I guess [I] read it and try to offer what I can.

Eleanor sees her primary contribution to the List as someone who is able to contribute scientific

evidence that enhances discussions of various breast cancer issues. For instance, there were

heated discussions about when women should start having mammograms after the Preventive

Services Task Force of the Department of Health and Human Services announced that having

routine mammograms was not necessary for women in their 40s, an argument that was counter to

advice women had been receiving for many years (Rabin, 2009). While many participants on the

List expressed feelings of disbelief and offered their own stories about how, if they had not had

mammograms, they might not have survived breast cancer, Eleanor suggested that there were

other ways to think about these recommendations:

> That is what they are - recommendations. For women under 50, they are advising
> that women and their physicians talk about their personal risk for breast cancer,
> the benefits and harms of screening, and possible prevention. Rather than
> routinely advising all younger women to get screened, when the evidence has
> shown that the reduction in mortality because of the screening is very modest,
> they suggest that it be a personal decision rather than a public health decision.…
> The evidence is still out on whether clinical breast exams save lives. The evidence

is still out on whether digital mammography improves outcomes…. I know there are LOTS of women who are screaming that they wouldn't be here if it weren't for mammograms. That is not evidence; that is anecdote.

Eleanor is well respected on the List despite the fact that she does not participate often anymore. While she remains a member and reads the postings on a daily basis, she does not use it for her own information, and she primarily offers scientific information as a way to point out that it is important to be aware of what evidence shows beyond participants' stories. In my interview with her, she did admit that she appreciates others' experiences and sees value in them, but she also feels that stories are individual and not necessarily indicative of scientific evidence. In contrasting Bonita and Eleanor's interactions with the List, although they both have a strong sense of breast cancer information as part of the reason they are there, their particular interests are somewhat different. Bonita is more interested in the emotional aspects of breast cancer whereas Eleanor is primarily there for factual information.

In contrast to both Eleanor and Bonita, Alice's experiences with the List were more much detached. Alice, who was on the List for less than a year as she was undergoing treatment, was an observer of the List; she did not provide information about herself, but nevertheless found the information she read to be both comforting and enlightening:

> I was logging on every day…. You know, they were talking about diet and they were talking about, you know, sores, and they were talking about all these things that were…sort of common problems that people have when they're going through chemo…. But I found it particularly helpful because I was pretty miserable about the chemo. Not so much because of nausea because they had anti-nausea drugs, but I had sores around my mouth and they were just, oh god, it was really bad…. I would just read them every day and it was, like, here's all these people who are dealing with exactly this. And it's not just one other person, it's six or seven or eight or nine or ten other people. And somebody's saying "Well I found this really helpful," and somebody else saying, "Yeah, I did too." And then somebody else saying, "Well, I didn't really find it very helpful." And it was just all—you just felt like there was this larger group of people. And that's just what I

was looking for…I felt like people were talking about exactly what I wanted to hear about.

For Alice, interacting with the List had a receptive quality in that she did not participate actively in information exchanges, but, rather, read the information as it appeared. Nevertheless, it was a purposeful process because she did log on to see what was being discussed, and did find information that helped her with some of her concerns. Being able to access the experiences of others who were undergoing exactly what she was going through provided her with relative peace of mind. However, once Alice was through most of her treatment, she did not see any reason to continue. For Alice, use of the List was purely for the short-term, giving her what she needed at a specific time in her life.

Vicki's experience on the List illustrates another way that participants interact with the information there, which is to obtain information on behalf of others. Although she uses the List to access information for herself, Vicki also talked passionately about obtaining information there that she brought back to her face-to-face support group. In one instance, the information she obtained prompted her group to advocate for doctors in their area to perform a more updated procedure for lymph node removal, which would reduce the possibility of lymphedema, a side effect of breast cancer surgery that causes arm swelling and discomfort.

> Vicki: I got…information [about sentinel node biopsies] from this group, and I took it to my face-to-face group, and nobody there was aware of it, but we found out more about it, and…I wrote a letter to all of the hospitals in the area and to the doctors and the radiologists and no one was trained! …and we even had a "sugar daddy" [who] said that he would foot the bill for the doctors to go get the training. And it was our face-to-face group that did that. And we all signed the letter, and one day we had this [new] woman come in and we asked her, her story, and she started telling us. And she says, "and they took this blue dye and they--" And we all went "hooray!"

Vicki also described obtaining information for many other women in her geographic area, telling them about various procedures and treatments she learned about from the List, as well as bringing questions from them back to the List. Vicki's information facilitation cast her in the role of being a bridge between the List and her face-to-face community, putting her in the position of being able to access new information for both the women there and her local medical community. In social network theory, having social connections beyond one's immediate close friends and family means having access to information and resources that differ from those of close associates (Burt, 2001; Granovetter, 1973, 1983; Haythornthwaite, 2005; Portes, 1998). People in other social circles are considered to be weak ties who offer benefits that our strong ties are not able to provide. In Vicki's case, she did not feel as though she knew List participants really well, which situates them as weak ties. It was an important network, but a looser tie than her other networks. But because the List comprised weak ties, she was able to access information that she would not have otherwise, and which she could share with people with whom she was closer. Having this access not only allowed her new information, but gave her the resources to make significant alterations in her environment both for herself and for others. She became an agent of change who influenced major decisions related to breast cancer treatment for patients and physicians where she lived due to her status of being a bridge who made it possible to expose each of these groups to new information.

Bonita, Eleanor, Alice, and Vicki exhibit several different ways that participants use the List for breast cancer information. Each represents particular facets and needs that the List fulfills for many others. Bonita developed intense interactions with others on the List through her early days of breast cancer, spending much of her time gathering and using the information while at the same time offering information, but she especially valued the emotional aspects of the List.

Bonita is illustrative of the many participants who easily provide words of wisdom and hope when others are in need of them. Eleanor was at one time more active on the List in the past, but she currently interacts with the List to provide others with scientific evidence as it relates to breast cancer. She does not obtain breast cancer information from the List, and would likely go to more scientific sources if she needed it. Eleanor represents others on the List who are very knowledgeable about breast cancer and other medical conditions and who, although once very active, do not post often anymore. At times they seem absent, and yet they are always present even when they are not posting. They do, in fact, read the List, or at a minimum, scan postings regularly, evidenced by their quick responses when serious health issues come up with others. Alice was a lurker, gathering information and benefiting from it, but leaving when she finished treatment. Alice needed to know that she was not alone, but she did not want to converse with List members. Several infrequent posters described similar benefits, noting that they were happy to let others be more active, one saying "I'm delighted to be on the fringe." Vicki garnered the resources of the List to help others. In her case it was her face-to-face community, but others have been on the List on behalf of spouses, other family members, and friends.

Breast cancer information plays multiple roles over the course of people's lives, with differing scenarios for different people, and the need for information as well as one's connection with it are very individual (Luker et al., 1996; Williamson, 2005b). Distance from diagnosis certainly plays a role in how individuals view breast cancer information, but distance does not necessarily mean that someone will stop interacting with the information (Mayer, 2003). Eleanor, Bonita, and Vicki remain on the List, but interact with it in different ways; Alice is no longer there and neither provides nor receives information. Participants access the List and

derive benefit from it in various ways, whether it is getting information, providing information, or just reading as a way to remain connected.

4.5.2 Discussions of Other Health Information

Conversations about health information other than breast cancer are a bit more difficult to distinguish in that it is not always clear if a given health problem might mean a return of cancer, or be a long-term side effect of treatment. Sometimes health problems might be totally unrelated to breast cancer but one cannot be completely sure. Other times a particular problem is clearly unrelated to cancer. However, in many cases people who have had breast cancer become more vigilant about their health as survivors, and the things they think about or become concerned about even if they are not related to breast cancer become more important as ways of potentially combating future cancer occurrences (Mayer, 2003). Thus, in discussing this aspect of the List my goal is not to try to draw a distinction as to what may or may not be a breast cancer or breast cancer survivorship issue, but rather to engage in understanding how health issues other than direct breast cancer treatment are integrated into the fabric of the community's discussions.

List members who are undergoing medical procedures often report to others on the List about what is occurring. When Vicki had to have two surgeries in quick succession—the removal of a tumor on her neck as well as a mass on her thyroid—she announced both surgeries to the List. When I asked her why, she replied:

> Well, I was hoping that maybe there was somebody on the List that had been
> through it—that had been there, done that. And what were [the] ramifications of
> their surgery, and non-surgery, or how did they treat it…And I was interested in
> hearing the pros and cons of [going on Synthroid]. And I was glad to know that
> there are other people that have, you know, that have gone through this, and I was
> hoping to get some good feedback, and I did. I got a lot of good feedback.

Vicki expressed a common feeling about being on the List—that someone else might have words of wisdom about a particular health issue and might be able to help in some way, even if it is not about breast cancer. Bonita's words sum up this idea when she says,

> There's a wealth of knowledge on the List about a million things. It's that, what, six degrees of separation or whatever. It's—there just is so much knowledge there that someone's going to know something about something…So it's a good resource in general. Like an encyclopedia.

Much of the literature about online health communities stresses how patients learn from each other, but usually in these communities there is a focus on one particular health problem. The List also has a focus on a particular health issue, but it is not limited to that. At times there is no one who is going through anything that is directly related to breast cancer, and at other times there are only a few participants dealing with breast cancer. Because there is a preponderance of long-time survivors on the List, a lot of participants are on the List because they want to offer help to those who might need it, or to merely catch up with their friends. Because of this underlying diversity of purpose, conversations turn elsewhere, giving the forum the feel of a community where people can talk about health (and other life) issues that are not related to cancer.

In describing interactions with the List about other health problems, Natalie noted, "There's always something coming up, and there's always—it's always good to have a sounding board that you can throw a question at and you know you're going to get a response." Natalie had had a scare with a nagging cough that upon testing showed a suspicious mass in her lung. She ultimately had surgery and it was benign, but until she found this out, she underwent great distress. Natalie brought her fears and concerns to the List, reaping much support for her predicament. Between the time the mass was found and making the decision about surgery, she

brought several options to the List for input, clearly laying out the pros and cons of different

treatment paths she could choose, asking for advice from List members as a way to help her

come to terms with the situation. List members responded by asking her questions as well as

offering suggestions. She stated,

> It helped me to sort out my thoughts…. 'Cause having to put that stuff on paper
> helped me to formulate, you know, things a little better…. I guess it helped to, on
> the one hand it, it kind of gave me confidence that I was making decisions that
> were, you know, that I was doing the right thing by…getting it checked out, and
> having it looked at.

Natalie's problem caused her great alarm, but as she was weighing procedures and consequences

with her physicians she was also bringing these conversations to the List, trusting that members

would be able to help her figure out what to do next.

Members of the List also share information about illnesses of family members and

friends, sometimes to get support, and other times to gather information that might help. As a

member of the List, Sophia already knew that its members would offer her what they could, but

her description of the help she received while going through her husband's illness surpassed even

her own expectations. Sophia commented on what happened when her husband was sick:

> Sophia: When my husband was diagnosed with metastatic liver cancer, I wrote
> the List for help. And, and, nobody ever denied me. It was always a safe place.
> No matter what I was going through. And, even though it didn't have anything to
> do with breast cancer, these people were always there for me.
>
> E: So how did they help you when your husband was ill?
>
> Sophia: Well, Rachel in particular found, you know, a liver cancer website. And I
> said, "I can't do this." So she signed in *for* me.
>
> E: Wow.
>
> Sophia: And, I gave her all the particulars and all the…treatments and the

prescriptions and the, you know, whatever it was. And the diagnoses, and the blood results and the pathology and this, that, and the other. And she came back and gave me their responses. I mean I've never seen such selfless people in my life.

This incident and others like it are indicative of how List participants extend the boundaries beyond breast cancer and beyond members' own illness information needs. Because members are in many cases very interconnected with each other, they are expansive in the things they do for each other as well.

In addition to major health events, the forum is also peppered with other, less-critically-oriented information exchanges, making the space feel like a community space where people interact by trading other resources that have an impact on everyday life. For example, one topic participants talk about is diet and supplements:

Abby: I've gotten things from them like, you know Vitamin D, knowing that that's—it just prompts me to do more research on Vitamin D so as a result I take Vitamin D where I hadn't before…. And then to stay away from certain things, you know, like soy, though I wasn't hormone-receptor positive. But still I stay away from it anyway.

Rhonda: [T]here was a patch last year I think when we were all going through a cholesterol issue. Which isn't…directly breast cancer related, but, you know?... And whether to take statins or not.

Jill: Jodie told me that raw cabbage…suppresses thyroid hormones. And so, she's an herbalist of—I mean she's a real herbalist. She has, she's been studying it seriously for a long time.

Through these kinds of interchanges, List members are able to integrate their acute events and fears with the kind of information that friends might exchange at any time talking casually over coffee. Participating in these conversations also provides opportunities for chit-chat, which allows people to talk in ways that are not feasible in crisis situations. McKenzie (2010) demonstrates the development of relationships among midwives and their patients through the

small talk that occurs during clinical encounters. She notes that exchanges are interspersed with both clinical discussions and more casual conversations, and that the more mundane conversations help in setting up a foundation for support that goes beyond a provider-patient relationship. In this way, as well, being able to discuss medical information on the List that is not immediately important sets up relationships that help participants feel more comfortable with each other on many different levels beyond that of being a patient.

4.5.3 Discussions of Topics Other than Health

In addition to health concerns, List members engage in discussions and commentary that have nothing to do with health. From jokes and limericks, pets, computer problems, family, to vacations, there is rarely a day when something pertaining to ordinary, non-breast cancer life does not come up. Off- topics conversations are often interspersed with other discussions. Soon after I first became a member, there was a lot of chatting about various Gathering activities. After the Gathering there was more discussion, both about the event that had just occurred and about planning for the next one. When drastic weather occurs, members inquire as to the safety of others. Participants talk about their vacations, their children, and other day-to-day experiences. For example,

> Briana: It has been very cold here for the past week. And although I decided I wouldn't risk ice skating because I didn't need fractures, I succumbed yesterday. My old skates were beyond repair, but my 13-yr-old has the same shoe size and he really needed new skates. Ahem. So I tried them out for a minute...and then another minute...and soon I was flying over the frozen lake as if I hadn't taken a break from ice skating for years. I felt so alive! It was lovely. I remembered all the long trips I used to make and just enjoyed the sunshine, the music on my ipod and the sound of my skates on the ice. Somewhere in the distance my son was waving for me to return, but I pretended not to see.

> Erin: Oh, Briana! What a great feeling that must've been! I remember having similar thoughts when I went waterskiing for the first time in years, three years

after treatment. At age 65! It was an "I'm gonna be OK" feeling, even though I was quite weak in arm strength. 'Twas almost as thrilling as my first sky-dive, on my 60th birthday!

Claudia: Ahhhhhhhhhh.... Sweet, Briana! Your description of your pleasure was so real, I could have been there with you, even though I haven't skated since I was a teenager. Thanks for the pleasure by proxy!

This conversational thread is a bit deceptive. It seems as though it is a discussion of having fun, and, indeed, it primarily is. But what makes it deceptive is that there is also reference on Erin's part to her bit of fun, waterskiing, three years after her treatment. And it is not clear from just reading Briana's posting whether she is writing due to just the pure enjoyment of ice skating or if it is a commentary on her life after cancer—there is no other reference in the thread to breast cancer. However, whether or not the initial posting was just for the purpose of chatting or as a commentary on life after breast cancer, there are several ways to think about the occurrence of off-topic conversations on the List.

Sometimes off-topic conversations are blended with on-topic discussions, making them seem as though they are just part of the fabric; other times, there are strings of off-topic conversations. For example, someone who is talking about a health problem will also inject information about the weather. Or several participants, as above, talk about something entirely unrelated to breast cancer but it stirs many responses. One might wonder why someone would mention these other topics in a breast cancer forum. One approach to thinking about the List's environment is to consider it a community space, where people gather to share information or run into each other and start talking. Oldenburg (1999) designates such places as third places, which are physical places where people feel comfortable just dropping in and chatting. However, an online space can also be a place where people hang out and comfortably interact with friends (Kendall, 2002; Soukup, 2006; Steinkuehler & Williams, 2006).

Steinkuehler and Williams (2006) and Yee (2006) have described how people become involved with each other socially in massively multiplayer online games (MMOs), especially in games where players need to collaborate with each other to play successfully. Collaboration requires conversation, and these conversations often go beyond simple game-playing, delving into humor, mentorship, and other everyday life activities. One reason this happens is because players interact on a daily basis, increasing opportunities for them to socialize. Other online spaces are set up specifically for social interaction, such as Kendall's (2002) BlueSky, where participants considered their friendships there to be of primary importance. Winzelberg et al. (2003) reported off-topic discussions in the breast cancer support group that they studied, noting conversations about birthdays and other family events; however, off-topic social interaction in health forums seems to be rare, at least based on the literature that discusses them. Preece and Maloney-Krichmar (2005) noted that social contact among participants on the Kneeboard they studied was limited and that beyond talking about knee-related injuries, there seemed to be little else of common interest. Weinberg et al., (1996) stated that online participants in their breast cancer study did discuss topics such as family, jobs, and social activities, but only in reference to how their medical condition affected these areas of their lives. On the List, common interest topics beyond health abound, making this space somewhat different from many other online health forums.

Pettigrew (1999), Fisher (2004), and Fisher and Landry (2007) described similar settings as information grounds, where "people 'visit' and engage in social interaction [having] conversation[s] about life in general and about specific situations lead[ing] to the formal and informal sharing of information on a range of topic and in a multitude of directions" (Fisher, 2004, p. 757). Pettigrew (1999) and Fisher's (2004) original conception of information grounds

stated that "People gather at information grounds for a primary, instrumental purpose other than information sharing" and that "social interaction is a primary activity at 'information grounds' such that information flow is a by-product" (Fisher, 2004, p. 758). Fisher's (2004) examples of information grounds include community spaces such as foot clinics and public libraries, where people gather for specific purposes unrelated to information exchange, but end up sharing information anyway. Later, Counts and Fisher (2008, 2010) investigated whether the use of mobile social networking services fit into the information grounds framework. They found that people using a particular mobile technology software used it primarily to gather information about social engagements. In their study, Counts and Fisher (2010) acknowledged that the main activity of social coordination was an information sharing activity. They extended the information grounds framework to state, "people gather at mobile information grounds for a primary purpose of social coordination, with other forms of information sharing secondary" (2010, p. 104).

The List loosely fits into the information grounds framework, due to there being secondary information sharing among participants. What is most striking about information grounds is the richness of information exchange unrelated to their primary purpose that occurs, which is exactly what happens when List participants talk about anything unrelated to breast cancer. As in third places and information grounds, the casual and serendipitous information exchange that characterizes these venues is easily replicated on the List. Although participants gather there for certain informational purposes, they also pick up other bits of information from casual conversations. Even though the List has a specific purpose, there are multiple other ways that participants interact, acquire and provide information, integrating various thoughts and

conversations among the more serious health-related issues that members face, and through which they engage others.

Because so many List participants are long-time survivors, the group serves multiple purposes and acts as a space where participants can catch up with each other by communicating about their daily joys and triumphs as well as difficult events in their lives. In her study about the relationship building that occurs between pregnant women and their midwives, McKenzie (2010) describes "the mundane yet rich talk that researchers commonly overlook as insignificant" ("Theoretical framework," para. 4). Although she is talking about a particular context, the patient-provider interaction, she identifies casual, sociable conversations as an important way to develop that relationship. Within the ambience of chattiness between pregnant woman and midwife, a collaborative atmosphere of information exchange allows the participants to get to know each other and helps them to develop a trusting, reciprocal relationship. Similarly, Fussell and Setlock (2003) described the small talk conversations that occurred in a mental health self-help chat room as enhancing relationship development. They further noted that these conversations occurred only when nothing else was occurring, but when someone arrived who needed help, members of the chat room gave them their full attention. Haythornthwaite (2001), in discussing an online distance education program, noted that informal discussions are "particularly important for creating bonds of community and group identity" (p. 214).

Among members of the List, there have been discussions about the off-topic chattiness that occurs, and perspectives on this vary. For some, the exchange of non-pertinent information is enjoyable and in some cases, necessary. For others, getting away from the business of breast cancer has sometimes been a subject of contention. During my interviews, I heard both sides of this issue. Several participants referred to the fact that one cannot always talk about breast

cancer, especially given that there are so many participants who are many years beyond treatment. According to Melissa:

> I think that off-topic is something that we've thought about off and on from the beginning and I think that it's something that's necessary. You know a lot of people, especially when we had, you know, 300-plus people on the List and it was an off-topic discussion, you know people would say, "You know, that's not what we're here for," "What if somebody new looks at the List and they see you're talking about your cat's hairball?" and "That's going to make them leave 'cause they won't think whatever," and, but I think that it—you can't just talk about cancer. Well, I guess you could maybe on a different list if that's all you want to talk about. But I think this is more of an all-around, everything support group. This is more of a life—a group of people who've been through the storm together or through the same kind of thing and you can't shut out the rest of your life. And there are people on the List who, you know, have cats and everybody wants to talk about their cats or their dogs or their kids or their grandkids, or, you know, I'm sure if there were more men on the List there would be car discussions.

Melissa's view is shared by others who consider it an appropriate place to have a conversation about other topics. In my conversation with Cassandra, she was also supportive of off-topic discussions:

> E: So what about all the chit chat that happens? What do you think about that?
>
> Cassandra: Oh, the fun stuff? I love it! I absolutely love it. It means that we're people…. We are people. We are not just breast cancer. And one of the things that's really nice is to get someone new on the List that understands that what that means is we don't live our lives every single day thinking about breast cancer solely. That that can pass. In the beginning you certainly do. But it doesn't have to be forever. And I think that's given a lot of people hope that they'll get past it.

> Other members have expressed different viewpoints. According to Rachel, who is no

longer a member of the List, "We used to regularly go over the limit in terms of number of posts and there were all kinds of discussion about what should be posted, when, and not putting off-topic information on there, and so on." In the early days of the List there was a limit of five posts per person each day (now the limit is 10), with a maximum of 150 posts per day. Because there were many more members, this limit was often exceeded and the List shut down. After the limit

increased, some participants complained that increasing the limit resulted in more off-topic

postings. Some members could not tolerate the chatter, or they thought it was too trivial. I asked

Rachel if she missed the List after she left, and she replied:

> Honestly, no. I found it a relief. But I also have been known to drop in to the
> archives from time to time and just check out how people are doing. I did that for,
> you know, every few months for a while. But mostly when I dropped in on the
> archives I thought, "This is why I left!" 'Cause it was just too much chit-chat for
> me.

Similarly, although she is still a member, Miriam said, "I think the List gets away from breast

cancer a lot and sometimes I wonder if that has an effect on newcomers who are lurking." There

is some fear that newcomers who find the List might not realize that the List really is devoted to

helping people with breast cancer, and they will leave. Dale also said,

> [My participation]…has lessened because I think it's evolved more into a social
> networking list and that's just my opinion and also the further out I get from
> breast cancer, the less questions I have. Okay? I go for my checkups and
> everything, but, and this is, I don't know how to say this without sounding
> negative, but I'm not looking for a social networking list like Facebook. And
> that's how I feel, that's how I kinda see the List today. And I'm not saying that's
> negative, but I have a social support system and I don't need the List for that.
> Hence I'm more reluctant to participate. For example, you know, somebody on
> this List might report that their sister-in-law's hamster died, then there's 15
> responses, "oh the poor hamster."

During my first few months on the List during the extensive discussions about the Gathering,

some participants questioned whether it should be discussed, noting that it is off-topic subject

matter and that approximately four months of each year conversations about the Gathering

dominate the List. There was concern that newcomers might very well be confused about the

purpose of the List, or conclude that members of the group were so close that they might not be

open to newcomers. Several responses to this included suggestions that participants label their

off-topic conversations as such in the subject lines: "So long as the subject line indicates it's

about the gathering planning, those who are interested can open it and those who aren't can skip

it or delete it," as well as have signature lines that explain their status as breast cancer

patients/survivors. Another suggestion was that Gathering discussions should occur elsewhere

with a weekly link posted on the main List website for anyone who wanted to join in. One way

that members have compensated for some of these concerns has been to post a welcome message

on a regular basis letting newcomers know that members are there to help them. Members also

pay close attention when newcomers announce themselves, being very solicitous and gently

coaxing them into the discussions.

In response to some of the objections about off-topic discussions, and in particular, those

about the Gathering, Jamie, who has never been to a Gathering or met anyone from the List,

wrote,

> I happily followed along enjoying the talk and the building excitement as the time
> got nearer and nearer for this years' gathering. I feel fairly certain that I'd never
> turn up at one of the gatherings and yet sometimes I am almost aware of the
> excitement, the smiles, the warm hugs and the great conversations I know are
> going on. I would miss not being able to participate in this small way that helps
> me stay connected to those who I seldom talk to, and would really miss sharing
> the comfort of their joy and anticipation.

And Erica added,

> We've had this discussion more than once, and it usually comes back to the same
> thing.
>
> This List isn't JUST about Breast Cancer - it is about all of us and how cancer
> influences our lives - how we cope, how we support each other, how we rant, how
> we get off topic, how we get back on topic when need be....
>
> Sure people have left and stated that it was because of the OT stuff - but I think
> those people would have left eventually, having either gotten what they needed at
> the time, or having found that the List was not a good fit for them. Many more
> have stayed either because of or in spite of the chatter.
>
> This is not just a List. It is a community. There is a core group of neighbors who

have been here forever, with people moving in and out all the time. It is a fluid, living thing that evolves and changes as each of us does, and everyone who has been here has left a mark.

Erica's comments point to several important aspects about the List, breast cancer, and breast cancer survivorship. "This List isn't JUST about Breast Cancer" speaks to there being other things in life alongside of breast cancer, even when life feels as though it is *just* about breast cancer. Other things happen while patients are undergoing treatment – people go to work, they have families, they see friends, read books, and more. Breast cancer takes up a huge portion of one's thoughts and actions, but everyday life exists in conjunction with breast cancer. As a newcomer, Lesley recounted her reaction to off-topic discussions by saying, "To me it kind of helps me get to know who they are for real and, you know...I kind of think that, you know…I could discuss anything and, you know, get it out there."

It is difficult to know the precise impact of off-topic conversations. Two out of the five former members I interviewed talked about having been unhappy with the nature of the conversations. Some participants still on the List were not sure how they felt about some of the off-topic conversations, and some of those members do not contribute the way they did in the past. These participants offered comments such as "[The] depth of discussion…has become more superficial over the years," and "the whole tone of the List has changed a lot over the years, and because we get relatively few new people, it's kind of just evolved into…more of a social support group." Sassenberg's (2002) research on Internet relay chat groups noted that groups that do allow off-topic conversations are more likely to develop interpersonal relationships as well as interact face-to-face. He also states that off-topic, socializing conversations have a role in piquing interest in meeting others participating in these conversations.

One way to characterize conflicting opinions about what the List is or should be relates to differences between common bond groups and common identity groups (Sassenberg, 2002). Sassenberg (2002) describes *common bond* groups as those that are based more on personal attraction to individuals in the group—the importance of the group is because of the people there, not what the overall mission might be. Members of *common identity* groups are more likely to be attracted to the group as a whole in terms of what its goals and purpose are, rather than on the individuals. These distinctions are intriguing when applied to the List, because neither explicitly applies. The List is really a hybrid, exhibiting elements of both, and as such, speaks to there not being one specific vision.

Off-topic discussions are likely a function of the List being an unmoderated group – there is no one aside from List members themselves to monitor the conversations, and thus, no one to "police" them. Many health forums have someone who monitors discussions to some extent and who intervenes when discussions are off-topic or need clarification, in some cases removing unacceptable posts (Bonniface & Green, 2007; Eysenbach, 2003; Preece, 1999; Vayreda & Antaki, 2009). The List, however, operates somewhat like a collective with different members voluntarily taking on different responsibilities, such as posting welcome messages and birthdays, updating the website, and running a non-profit arm, the Friends of the List (FL), which raises money to help List members needing support. Although the List has an owner, members report that he takes a very "hands-off" approach and does not intervene at all. This means that it is the responsibility of List members to set the tone of the List and make decisions as to where discussions go. Arguello et al. (2006) write:

> In online groups, conversation is the basic mechanism by which participants
> derive benefit. Whether they are explicitly soliciting information or assistance or
> implicitly seeking to direct the group's attention toward topics in which they are

interested, individuals who attempt to start conversations are trying to increase the likelihood that the group will provide benefits they value. The community's response, if any, is what satisfies the poster's needs.

As with any social environment, the atmosphere and content of the List are a result of contributions of the participants who are there the most, as they are the ones who have stayed and steered the List into being what it is today.

4.6 Conclusion

Information exchanges on the List encompass topics that range from the day-to-day experiences related to anyone's life, to serious health issues both related and unrelated to breast cancer. Participants described many instances of obtaining useful information that helped them make sense of their breast cancer experiences as well as influence treatment decisions. As an information space, participants also demonstrate that everyday concerns are part of the breast cancer experience, beyond the actual nuts and bolts of breast cancer. People who are many years out are examples of the survivorship experience, which serves to help newcomers deal with issues of breast cancer as well as illustrate to them that life goes on. As a space where participants talk about multiple aspects of life, there is disagreement about the benefits and appropriateness of off-topic conversations, but List members manage to resolve these differences when they come up.

Much of the information that List members exchange and describe is infused with emotion. Whether someone is telling her own story, or responding to someone else's, there are both explicit and implicit emotional underpinnings. When participants ask seemingly straightforward questions about chemotherapy and radiation, they are also experiencing uncertainty and trying to bridge gaps in understanding, which indicate emotional involvement. Conversations on the List are permeated with incidents of information and emotion, each

building on the other, exhibiting the interconnectedness of participants' emotional and

informational needs as they traverse the information gaps inherent through breast cancer

treatment chaos as well as other, more ordinary life experiences.

CHAPTER 5

COPING THROUGH SOCIAL SUPPORT

Participants who join the List do so to make sense of their situations and to access ways of coping with breast cancer. Being able to connect with sympathetic individuals while coping with illness and other everyday life challenges forms the foundation for List interaction. Obtaining social support is particularly important for people dealing with uncertain health situations in that social support networks can a) help with evaluating information and shifting perspectives; b) offer acceptance and validation in the face of difficult situations; and c) help with developing coping skills (Brashers, Neidig, & Goldsmith, 2004). Social support plays a significant role in helping people to feel better, cope better with illness, recover better from illness, and live longer (Cohen et al., 2000; Wellman & Gulia, 1999). Whether participants become intimately involved with others on the List or only communicate on the periphery, the essence of the List is its members' ability to be available to other participants who are in need in some way, to offer each other stories and wisdom based on practical and emotional experience.

Research shows that when people are able to garner the resources of others to help them through difficult times, multiple benefits accrue—positive social engagement with others brings positive emotional outcomes (Dunahoo et al., 1998; Folkman & Moskowitz, 2004; Lyons et al., 1998; Wells & Hobfoll, 1997). In online health communities, participants are able to reap benefits from the communal resources and collective knowledge of individuals who have undergone similar experiences (Maloney-Krichmar & Preece, 2002, 2005; Preece, 1999; Preece & Ghozati, 2001). Because seeking social support is often a collaborative activity among participants who are engaged in similar goals (Brashers et al., 2002), online communities are often able to offer more satisfaction than individual communication, resulting in outcomes

similar to those obtained through professional help for both physical and mental ailments (Davison, Pennebaker, & Dickerson, 2000; Gould & Clum, 1993). Specifically, the helpful nature of interpersonal interactions offering advice and information in online health communities brings patients comfort (Preece, 1999; Preece & Ghozati, 2001; Sharf, 1997) and helps to reduce depression, stress, and social isolation while increasing the ability to deal with physical pain (Gustafson et al., 2001; Høybe et al., 2005; Lieberman et al., 2003; Weinberg et al., 1996; Winzelberg et al., 2003).

Participation in online health communities offers empathy, social support, and insights often not available from medical providers who are unable to spend significant amounts of time communicating with patients or their families. The ability to access the assets available through many online groups translates into multiple opportunities for communication and sharing, which often results in changes in outlook that can confer a better quality of life (Lieberman et al., 2003; Klemm et al., 2003). Moreover, in addition to being able to receive experiential help *from* others, offering help *to* others has the potential to elevate self-esteem (Helgeson & Gottlieb, 2000).

5.1 Conceptualizations of Social Support

Literature and research on social support offer myriad conceptualizations and typologies, many of which differ from each other (Barling, MacEwen, & Pratt, 1988). Goldsmith (2004) acknowledged the difficulty in integrating the diverse aspects of social support into a "single conceptualization" (p. 13). Broadly, social support is "any process through which social relationships might promote health and well-being" (Cohen et al., 2000). Having access to social support, or even having perceptions that one has access to social support, can act as a buffer that helps individuals cope with stressful events (Cohen et al., 2000; Cohen & Wills, 1985;

Goldsmith 2004). Additionally, being part of a social support network helps people to maintain positive affect and feel secure (Cohen et al., 2000). Social support networks comprise varied resources; for example, some people provide emotional support while others provide material support (Wellman & Gulia, 1999).

Lin (1986) offers a "synthetic definition" of social support as a way to capture its many attributes: "the perceived or actual instrumental and/or expressive provisions supplied by the community, social networks, and confiding partners" (p. 18). In addition, Lin, Ye, and Ensel (1999) categorize social support into structural and functional elements. Structural elements refer to levels of social participation and social relations; functional elements refer to the "communication and transaction activities serving a variety of needs" (Lin et al., 1999, p. 346). Lin et al. (1999) note that the functional elements of social support have been discussed in various configurations, but include categories such as enacted support, tangible support, perceived support, and others. This section looks at social support on the List through the lenses of 1) social relationships; 2) two types of enacted support: emotional and tangible support; 3) perceived support; and 4) the relationships between social support, social networks, and social capital.

5.1.1 Layers of Social Relationships and Social Support

Lin (1986) delineates three layers of social relations: 1) the outer layer, which comprises the community and most general relationships within a "larger social structure" (p. 19); 2) a middle layer, comprising people in a shared workplace, kinship, or friendship, and which "provide[s] a sense of bonding" (p. 19); and 3) an inner layer of intimate relationships with whom one confides, which are "binding in the sense that reciprocal and mutual exchanges are

expected, and responsibility for one another's well-being is understood and shared" (p. 19).

These layers roughly correspond to Gottlieb's (1985) formulations of social support into macro-,

mezzo-, and microlevels, which Lin depicts as "belonging, bonding, and binding" (p. 20). Lin

(1986) characterizes the external layer as having less impact on people's lives than the middle,

which has less impact than the intimate. Gottlieb (1985) states that at the macrolevel, "social

support is measured in terms of social integration/participation. Here, social support is tapped by

measures of people's involvement with the institutions, voluntary associations, and informal

social life of their communities" (p. 10). Having affiliations at the macrolevel, or outer layer,

allows people access to potentially supportive relationships (Lin, 1986). Gottlieb's (1985)

mezzolevel is composed of people with whom there is more regular interaction, and the

microlevel corresponds to one's intimate relationships (Gottlieb, 1985). In essence, these layers

operate as a continuum through which social relations become established (Kawachi & Berkman,

2001).

Lin (1986) and Gottlieb's (1985) three-tiered constructs offer a useful way to understand

the social support relationships that members have with the List; however, because these

constructs are related to integration into the entirety of individuals' social worlds, I am

modifying them to describe participants' involvement with the List only. The categories of

belonging, bonding, and binding are still operational, but I use them in terms of how participants

are integrated into the List, rather than all of society. *Belonging* (the outer layer), in this case,

refers to participants for whom the List has a place in their overall social structure but involves

less attachment; *bonding* (the middle layer) reflects those who have a casual, but significant

cohesion with the List; and *binding* (the inner layer) refers to the intimate affiliations that some

participants have with others on the List. As with information exchange and variations in

participants' need for information, the desire and need for sharing social support with others on

the List shifts based on life situations along this continuum, sometimes spanning more than one

level at any given time. (See Table 1 for corresponding definitions.)

Table 1
Layers of Social Relationships

Lin (1986)	Gottlieb (1985)	List Categories
BELONGING (outer layer) Comprised of community and general relationships within a "larger social structure"	**MACROLEVEL** Involvement with institutions, voluntary associations, informal social life of community	**BELONGING** List has a place in overall social structure, but involves less attachment than other categories
BONDING (middle layer) People in shared workplace, kinship, or friendship	**MEZZOLEVEL** People with whom there is more regular association	**BONDING** Casual, but significant cohesion with group
BINDING (inner layer) Reciprocal/mutual exchanges expected; confiding relationships	**MICROLEVEL** Intimate relationships	**BINDING** Intimate, close relationships

Several examples illustrate the range of feelings of attachment and social support

involvement that participants have in relation to the List. Amy has been a member of the List for

three years, and although she reads it "faithfully," she posts rarely and has other support groups

in her life, both face-to-face and online. Not all these groups are related to breast cancer, but in

terms of support, she finds them more engaging. Regarding the List Amy says, "I just didn't find

it as inviting," and "I really don't feel that connected too much with anybody on there at this

point." She also says, "I haven't made any close bonds with anybody." Amy remains a member

of the List; from time to time she does contribute information and links to online articles, and

occasionally asks for or offers words of social support. For example, at one point she was

apprehensive about an oncology appointment and requested prayers and good thoughts, which were willingly supplied by others on the List. Despite this occasional appeal for support, Amy's integration with the List, both in terms of affect and level of participation, is most closely aligned with *belonging* (the outer layer).

On the other hand, Chris, a man diagnosed with breast cancer in the mid-1990s, found the List to be very welcoming and full of support. Because he was male, he had found it difficult to access information about breast cancer specifically related to men, and, in fact, in the medical community a man with breast cancer was considered to be akin to a post-menopausal woman with breast cancer. He said, "Some doctors go through their career and don't see a case of male breast cancer." My conversation about his experience on the List at that time brings out some of his regard for List members during his illness:

E: And so how was it to approach the Mailing List, how was that as a man?

Chris: I don't know how I found out about it. I know part of that was out of frustration. I tried to find a face-to-face group and they didn't want me because I was a male. I guess talking about breast and breast cancer and mastectomies and all those things might have made them uncomfortable. I'm not sure, but here there was a breast cancer resource center associated with a YWCA. But they just didn't want me. They just flat out said, "Maybe you should find something else." And the best that I could find in this area was a cancer support group, not a breast cancer support group. And I tried that and that just wasn't for me. So it really, at the time, and it might be different now, I don't know, there really weren't any face-to-face support groups that I could find, that welcomed me. I was a strange cookie to them, being a male.

E: So what was the reception of the List when you first started?

Chris: Oh, wonderful! So what if I was a male? I had breast cancer. That was terrific. I mean, it was wonderful. They answered my questions; I found like I had found a home. And at the time there were a couple other guys on there. I think I'm probably the only guy on there now.

In Chris' first few years on the List he was a regular poster. He asked for and received support and information. As the years progressed and his bout with breast cancer receded, he became a very infrequent poster. These days Chris sometimes posts approximately once a month, but sometimes as little as every few months. However, he also notes,

> "I go on it every day and see if there's anything new…. I don't know, it's like, it's part of my routine checking in every day, you know, to see what's going on…. You know maybe it's, in some way it's a security blanket. Just knowing everybody's there."

Even though he is not currently active, Chris admits to feeling comfort by being there. Chris noted that he received extensive support when he went through breast cancer, but also said of the List, "[T]hey provided a support that I don't know that I would have gotten any other place.... [T]he List made it so much more bearable, providing primarily information and the written emotional support."

Chris' consideration of the List as a crucial support when he was undergoing treatment but much less so now offers insight into how some members' relationships change, encompassing multiple levels (Gottlieb, 1985; Lin, 1986). At one time the List was much more integrated into his daily life, corresponding to the *binding* (inner) level; now it is much less so. In Chris' case, his current involvement spans the *belonging* (outer) and *bonding* (middle) levels; although he feels much less of an emotional attachment to the List and needs it much less than before, he still checks in every day. His participation primarily has elements of being in the outer layer, but at the same time he does check in every day, which seems more relevant to a bonding description, such as a workplace or friendship. He still shares a bond with the List, albeit much less binding than it once was.

Similarly, Melissa's tenure with the List has varied, although straddling more of the center and outer layers than the intimate. Unlike Chris, Melissa did not find and join the List early; she discovered it three years after she had completed treatment. Melissa, who is retired, went through breast cancer 16 years ago and has been off and on the List several times. Although she reads the List every day and offers support by bolstering other participants when they are going through difficult situations, she considers herself to primarily be a lurker. She does not need information about breast cancer, nor does she feel that she can provide much information given the length of time since her treatment, but she does try to provide support when she can. When Melissa first joined, she still felt frightened about breast cancer and needed to hear other people's stories. She described the "push and pull of the List," wanting to get to know others, but being afraid that they might die, which at one point influenced her decision to leave. She has now been back as a member for seven years but tends not to share much of her life with the List.

> E: So if you had something going on in your life that wasn't related to breast cancer, would you come to the List about it?
>
> Melissa: Probably not, because I'm not that—I'm more private than that. Like I'm on Facebook and, you know, I have friends who post when they're going through issues and whatever. I mean I've been sick as a dog for the last three weeks but I haven't posted anything…. And I never really posted that much on the List either as far as if I had issues going on like biopsies and stuff, so…. It is kind of strange; I never thought about it.
>
> E: It's very interesting, actually. So you get the messages every day and you post encouraging things for people who need it.
>
> Melissa: Right.
>
> E: You talk about it being a social network and support, so it's interesting to me that there are things that—it sounds like there are a number of things that you don't post there. Am I understanding that?
>
> Melissa: Yeah. And I never thought about that but I don't. Like I just had a biopsy last year and I didn't post anything about that.

E: Hmm. So, why, do you think?

Melissa: [chuckle] I don't know. Maybe I'm just a weirdo. (laughter)

E: No! No! Not at all! It's—

Melissa: I don't know; I really don't know! Because I do look to this group for support. But you know, I have a really supportive family and maybe—I don't know.

E: Okay. So your family knew about your biopsy?

Melissa: Yeah. And I live with my parents [and sister and niece]….Yeah, we're there for each other every day whether we like it or not!

E: So do you feel like you use your family or friends for more serious kinds of things?

Melissa: Well, yeah, probably I rely on my family more for anything real personal.

Melissa's life is integrated with the List in that it holds importance to her, but it is less integral to her life than it is for others. She has strong feelings about List participants, but at the same time keeps herself somewhat separate. It is hard to know if it is a self-imposed barrier because it might be painful to become more integrated, or if it truly is because she has other people in her life, particularly her family, who are physically there for her on a continual basis. Whatever the reason, her level of affiliation with the List fits with the *belonging* (outer) layer in that it is a community that she sees herself having a part in, but it is not a community of her intimates. Her affiliation also fits the mezzo/middle layer because she does "look to this group for support," constituting some affective attachment. Melissa has a place in the larger structure and considers herself somewhat bonded to List participants, but she does not confide in them. She has caring feelings for the List and recognizes herself as part of a community, but she has not integrated the

community closely into her everyday life. It is there for her, and she is there for the community, but it is less concentrated than other relationships in her life.

At the micro/inner level of the continuum (Gottlieb, 1985; Lin, 1986), there are significant *binding* relationships on the List. Gottlieb (1985) writes, "[The microlevel approach] is based on the belief that social support essentially stems from the deep emotional nurturance which only a select few can provide…." (p. 12). Lin (1986) states that, "Here the relationship tends to be binding in the sense that reciprocal and mutual exchanges are expected, and responsibility for one another's well-being is understood and shared by the partners" (pp. 19-20). Deep affection and caring for others is evident among many List members, illustrated by comments such as, "Everyone, I so appreciate your care and your love," or,

> It was just over a year now that I found this wonderful group of folks (yes, men and women). The list has been a wonderful support and therapy and growth and news group. I have asked so many questions, and gotten so much help….It's amazing how much you come to care for so many people in such a short time.

Although members are dispersed and usually cannot be physically present to help others during difficult events, they compensate for this by being virtually present through their words, contributing to an atmosphere of mutual support. Approximately one-third of those I interviewed described List members as good friends, something that is rarely commented on in other research about online health groups. Maloney-Krichmar and Preece (2005) noted that some members of the knee injury message board they studied had formed close relationships, but also reported that some felt they had little in common with others beyond knee injuries. A few List participants stated that they did not feel they had much in common with others there or were uninterested in being close friends with them. For instance, "There's nothing wrong with the people. It's more a reflection of me—I've got my friends here, my family's here and everything." But most of the

participants I spoke with expressed a desire to meet others in person at some point, indicating an interest in developing personal relationships to some extent. Those who do cultivate relationships often experience deep, binding connections. Two examples illustrate the intensity of feeling that some participants experience.

Allison has been a member of the List for six years, deriving and contributing social support consistently. Finding the List while she was still in early treatment, she continues to read messages every day, and remains very active by posting information, support, articles, and talking about her own trials while at the same time offering comfort and reassurance to others.

> E: So, can you contrast your early days on the List with what you consider your participation to be now?
>
> Allison: Well, I think at first I was just learning, learning to cope, learning to not get upset about everything that happened to me and not be afraid of everything that happened to my body. Not to be afraid of dying and leaving my children behind. So that was a learning process. Learning to just wait. That was the hardest part for me. To wait. To see if it would come back. And now it's more like I have old friends, good friends on the List and I hope to give something back to the newly diagnosed that I have received from this List. So I try to offer hope to new people and give them information. I still look for research and things and I try to post that to the List for people who are newly diagnosed….
>
> These people are my friends. Not all of them, obviously. Some I know better than others. But they have become my friends, and a sort of a family and they are the only ones who really understand what it is to have had cancer…this is the only place where people really understand that.... I can't imagine not interacting with all those people that have become my friends. When I go on vacation I miss them.

In the beginning, Allison used the List as a way to counter her fear and to access information, deriving great benefit from being there, but as time progressed, she became very attached both as a recipient and provider of support and information. Allison's description of the List as "a sort of family" demonstrates the closeness that she feels for members of the List. She also said, "But when I have those fears [about breast cancer] I write to the List. I don't call my [local] friends."

Eve, who has been on the List for many years, also has developed meaningful friendships. She described in detail her perspectives:

Eve: [M]ost of these people I've known for many years if not personally, many personally, of course, but if not personally certainly from posting and private emails and just years of being together in the same boat. I've never met Lisa… but she and I have been friends or email companions for, I can't remember how long…. A long time. And that's what I'm saying about the bonds you form on the List. And… some you become very close with. I'm close friends with Sophia, I'm close friends with Kate and her husband. They live nearby—we see each other several times a year. We have dinner together, we're invited to parties—all from the List.

E: Right.

Eve: This happened from the List. The List. Isn't it funny how we refer to it? The List? And it means—when you say it, it means so much. "The List." Doesn't it? It means so much when you say "The List." It does to me. When I talk to my husband about it, I say "The List." He knows what I'm saying.

E: So, would you go to the List for something that wasn't related to breast cancer?

Eve: Oh my God, yes! Oh my God, yes! Everybody does. If you're on this List, these are your friends. These are people that you feel, you know, sometimes we call each other. Janine hasn't been around in a while. But she has become a really close friend, and when she got her recurrence she called this house and the first person she told was my husband and he put me on the phone and she said, "You have to talk to me, you have to listen." And she was sharing this personally as well as with the List. She said, "I don't want you to just see it on the List." So… you make amazing attachments here.

Both Eve and Allison are very involved with others on the List, although in different ways. Eve has attended most Gatherings since her early participation in the mid-90s, and she sees other participants from the List at mini-gatherings and for dinner engagements. Allison has attended no Gatherings due to other commitments, but she has been to and hosted mini-gatherings. Allison and Eve also stay in touch with other List members through phone calls, email, and Facebook. Both participants are representative of List members who are highly integrated with each other, engaged in multiplex relationships that incorporate more than one medium to maintain contact,

blending their social worlds both online and offline (Haythornthwaite, 2001, 2005; Preece &
Maloney-Krichmar, 2005).

With each example of social relationships on the List and at each level of the three-tiered
construct, as I have modified it, there is evidence of provision and receipt of social support but to
different extents. For Amy, whose relationship with the List is on the *belonging* level, there are
occasional acts of offering and asking for support. Both Chris and Melissa illustrate the ways
participants can span multiple levels. Chris once was very involved, placing him at the inner, or
binding, level. Currently, he straddles *belonging* and *bonding*—although Chris does not actively
participate very often, he does check in every day, making the List both part of his larger social
structure (belonging) as well as that of a friendship network (bonding). Melissa's participation
also spans *belonging* and *bonding*; she also reads it every day and feels attachment to the List,
but does not post her own life events there, preferring to offer words of encouragement when
they are needed. Last, Eve and Allison exhibit *binding* relationships to others on the List. They
both consider others to be their good friends, involving themselves in multiple ways with each
other, describing deep affection.

5.1.2 Enacted Social Support

Enacted social support refers to "what individuals say and do to help one another"
(Goldsmith, 2004, p. 13). Although there are variations in the typologies and terminology of
enacted support, most incorporate the following: a) *emotional support* (caring, concern, empathy,
and reassurance of worth); b) *informational support* (information, advice, and new perspectives);
and c) *tangible support* (offers of goods or services) (Goldsmith, 2004). Participating in online
support groups offers the potential for members to garner all of the above types of support to

varying degrees, depending on the composition of other members. *Emotional support* and

informational support are well documented as being the primary components of online support

groups (Høybe et al., 2005; Lieberman & Russo, 2002; Preece, 1999; Preece & Ghozati, 2001;

Radin, 2001, 2006; Sharf, 1997). *Tangible support* is not well documented in the context of

online groups, and, in fact, Shaw et al. (2000) discount it as being available through online

support. Mok, Wellman, & Basu (2007) wrote of tangible support across distances, "Many of the

tangibles are related to face-to-face contact: you cannot Fedex care for the ill" (p. 434).

However, it is still possible for some tangible support to occur through online groups, especially

if members meet face-to-face at any point or live geographically close (Dunham et al., 1998;

Radin, 2001, 2006).

Each of these categories provides useful tools for examining the enacted social support

that occurs on the List. In the rest of this subsection I discuss *emotional support* and *tangible*

support as they occur among List participants. *Informational support*, which is defined as

"providing knowledge that is useful for solving problems, such as providing information about

community resources and services or providing advice and guidance about alternative courses of

action" (Wills & Shinar, 2000, p. 88), is related to information behavior, and in particular

information seeking and provision. I have extensively documented information behavior on the

List and its relation to supportive feelings and actions in Chapter 4, and discuss the relationships

between information and social support in Chapter 6.

5.1.2.1 Emotional Support

Emotional support occurs through expressions of caring, love, and encouragement

(Friedman & King, 1994; Shaw et al., 2000). Lin (1986) describes emotional support as the

expressive dimension of social support, exhibited through sharing and venting about problems

and affirming others' "worth and dignity" (p. 20). Emotional support takes place when

individuals discuss feelings, share experiences, offer sympathy, and provide hope (Helgeson &

Gottlieb, 2000; Shaw et al., 2000; Wills & Shinar, 2000). Emotional support is also a result of

empathy, which occurs when people are able to express shared understanding and compassion

(Preece & Ghozati, 2001). Benefits of emotional support include enhanced self-esteem, reduced

anxiety and depression, and better coping ability (Wills & Shinar, 2000).

Evidence of emotional social support is present throughout the discussion threads in the

List archives. On a very basic level, comments such as "we're here for you," or "we'll be

thinking about you," indicate that participants are paying attention and offering comforting

words that let each other know that there are people who care about them. These kinds of

exchanges provide emotional nourishment, helping List members get through whatever they are

dealing with. An example of the emotional support that participants offer to one another is seen

in the following excerpts from the archives. Joy, a breast cancer survivor who had been through

breast cancer several years before, found indication of another possible cancer event. She wrote,

> Well today started off normally…. Or so I thought.... I have a red mark on my "bc
> breast"…but it's also…full of scar tissue so although I could feel it was hard, it
> did concern me but didn't really worry me. BUT, wow, [it] most certainly worried
> [my doctor] !!! He did not like the feel or look of this redness or the little lump at
> all and whipped me right off to have it biopsied immediately. Shock wasn't even
> half of what I felt. Sick to my stomach? Those thoughts once again of what if it is
> and of course, if it is, then it's mets because it's the same breast and getting
> myself totally worked up….I asked [my doctor] what if it is and he said
> "mastectomy." Yep, I said, both off….
>
> Guess what I am doing this weekend? Yep, playing that game that so many of
> us know so well - the waiting game!!!!! Please keep fingers crossed for good
> results.

Among the responses to Joy's posting were many expressions of caring, sympathy, and hope:

- Oh, Joy, what a way to start a "normal" day! Although it won't make the waiting for biopsy results any easier, please remember that you can have a recurrence without it being mets [metastatic disease].… You are a strong woman and whatever this is you will be able to deal with it.
- Holding your hand and breathing with you some gentle back rubs and a few tears---not in sadness----but in fear and hope.
- Oh, Joy, you poor dear. I know that waiting is so hard. But as others said, it isn't necessarily mets—I'd even say probably not. I will be thinking about you all weekend and hoping it is nothing. Please keep emailing.
- I would send you every ounce of my strength if I just know how to package it up to get it to you.....in the meantime, lots of prayers and warm healing hugs, and a an old tough shoulder to lean on.

Each time someone posted a message of encouragement, Joy responded by saying things like, "Thanks so much. It sure helps to know that I have you with me as I 'wait' !!!" and "Thank you so much - you have no idea how much I appreciate that !!!!!" This type of exchange is common. The comment, "You are a strong woman," offers Joy feedback on her ability to cope, and lets her know that she is held in high esteem. Other thoughts, such as "I will be thinking about you," and "lots of prayers and hugs," relay the information that List members care about her.

Some important aspects of the message Joy posted and of the responses she received are related to context, communication, and shared meanings in the community. The people to whom Joy is posting and who can offer her emotional understanding can do so because its context is known—Joy, first of all, is known to the community, but also, others have experiential knowledge of her fears and concerns. People who have not directly undergone what Joy is encountering have still been exposed to it through the List community. As members of the List, they know how to communicate with her, to share in her distress.

Much of the literature on online health communities discusses that one of the reasons people benefit from them is due to being able to communicate with others with shared

experiences. For example, Lieberman and Russo (2002) noted the "sense of similarity" (p. 324) and shared beliefs that patients in online breast cancer newsgroups had about coping with breast cancer, and van Uden-Kraan et al. (2008) described the "recognition and understanding" (p. 408) that patients in a variety of online support groups described. Preece & Ghozati (2001) note that the empathy that is present in online health communities is based on knowing and feeling what others are going through, and Levenson and Ruef (1992) state that "Empathy is a fundamental part of the social fabric of emotion, providing a bridge between the feelings of one person and those of another" (p. 234). The emotional support that is elicited through Joy's concerns is related to other List members understanding what she is going through and what she is thinking about.

Joy's announcement and List members' responses are full of shared meanings, both experiential and through the language she uses. When she talks about her doctor's reaction and her shock, the underlying message is a fear of recurrence, something that many List members can appreciate. Joy also refers to "mets," which is a well-known abbreviation for metastatic disease among breast cancer patients and List members, but likely unknown to people who have never had contact with cancer. When her doctor told her "mastectomy," it is not clear whether he meant both breasts or just the affected one, but in giving him the reply "both off," she is echoing many breast cancer patients who decide to have a bilateral mastectomy to guard against any possible occurrences of cancer. In referencing "the waiting game," she is alluding to the common experience of patients who are waiting for the results of medical tests – in her case she has to wait over the weekend, which is a familiar experience to many. The undercurrent of all of this is not only her fear, but her knowledge that the people with whom she is sharing this information will understand her fear and each aspect of what she is experiencing.

The responses Joy receives affirm that List members are well aware of what she is

potentially facing. Those who reference "mets" make clear that this is common terminology. The

description of her as "a strong woman and whatever this is you will be able to deal with it" is an

expression that invokes prior knowledge of Joy both as being strong because she had been

through cancer before, as well as a reference to other challenges she has had to endure. "Holding

your hand and breathing with you some gentle back rubs…." and sending her "every ounce of

my strength" and "lots of prayers and warm healing hugs" are reflective of group practices when

anyone needs comforting words. Each of these responses are easily understood as soothing

words, but actualizing them are feelings of empathy, personal understanding, and knowledge of

exactly what Joy is experiencing.

Members of online health groups can offer emotional support to patients in ways that are

different from other people in their lives, such as family members or friends, who may not

understand or are unable to provide appropriate comfort (Sullivan, 2003). This is because of their

intimate understanding of each others' experiences, and because of "a sense of shared similarity"

(Lieberman & Russo, 2002). For Joy, a lot of the nurturing and encouraging feedback she

received exhibits her long tenure on the List. Newcomers, also, are able to garner strength and

feelings of comfort even when first making contact with the List. Lesley, a newcomer to the List,

described what it meant to her to be able to talk to other breast cancer survivors:

> By the time I found the List I was, I was a little over a year out from my
> diagnosis…. But everyone around me was kind of sick of hearing about it.
> And…like I said, I didn't know anybody that was going through the same thing.
> So I didn't really have anyone that wanted to hear about it anymore. I kind of had
> used up my brownie points with my family. Not that they, not that they didn't
> care, I don't want to say that. Not that my friends didn't care either. It was just
> kind of, you could kind of see it. You know, everybody wants you to get better
> and everyone wants you to be healthy again and unfortunately that's not the way

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you feel and so you're looking, searching for those people that, that they don't, that's not the response they give you. Their response is—their first response is not "oh no, here she goes again." Their first response is, "Okay, yeah. We've been there, now go ahead"—you know, you don't have to start with apologizing for bringing this up. You just start with, "Okay you guys, this is how I feel." I think I wanted to share it with people who would, who would understand. Who had been there and who, like I said, you know, before, who spoke the same language…. I guess I just didn't want sympathy. I wanted empathy.

Upon finding the List, Lesley was able to access the emotional resources of people who understood her, people who could offer her the empathy that others in her life were unable to, because they did not understand the toll that having breast cancer could exert on someone, even when out of treatment. It is difficult for someone who has not been through a particular situation to be able to comprehend the lived experience of someone else's challenges. Sympathy can be offered, but empathy does not occur. Lesley knew that the people around her cared about her, but they were unable to support her in a way that she needed.

Emotional support occurs in multiple ways, when others show compassion and caring, when people are able to share their experiences, and when they offer hope and sympathy. On the List, each of these occurs, as well as empathy, which is particularly helpful because members have the opportunity to talk with others who truly understand. For both Joy and Lesley, there were List participants who knew exactly what they were going through, and being able to access patients and former patients who can provide the emotional support of other patients

5.1.2.2 Tangible Support

Tangible support occurs when there is provision of material resources and aid (Cohen & McKay, 1984). This can happen through financial help, household help, childcare, cleaning, shopping, and repairs (Wills & Shinar, 2000). Semmer et al. (2008) make the point that receiving tangible support can also be perceived by the receiver as emotional support, because when an

individual provides tangible help it is possible to construe it as being a caring act. In an experiment designed to determine if study participants could distinguish between types of support, Barling et al. (1988) found that participants discerned emotional support as present no matter what other support was received. Tangible support does not occur in a vacuum; it is imbued with meaning, both positive and negative depending on the spirit in which it is given and received (Semmer et al., 2008).

Although tangible support is not usually considered an integral aspect of the kind of support that occurs in online health communities whose participants are dispersed geographically, it is not entirely absent. When it does occur, it is more likely to be in the form of sending emails about information requested (Coulson, 2005; Mo & Coulson, 2008). Members of the List also exchange information and articles through email, but, in addition, they talked about providing and receiving goods, money, and services. One of the more visible ways that members provide tangible support is through the group's non-profit arm, the Friends of the List (FL). One of the original purposes of the FL was to raise money to provide scholarships for members to go to the Gatherings, and to help members in need. Eve described the FL in detail:

> We offer our assistance if somebody is having financial problems. We offer our assistance, scholarships [to the Gathering]…. If you have a problem and you write, mostly to Sophia, because she is the treasurer and holds the purse strings, anyway, and then Sophia would write to us that somebody is in need, didn't say the name usually, and would we approve X number of funds for this individual. And then it would be anyone who wanted to give a donation in that person's name, who knew about it, could give a donation in that person's name. Anybody else would donate to the fund in general and we would then say, "Well, we're giving $500 to this individual." And that's what FL does. And it's very helpful, it's like an adjunct to the List. These people have come to us over the years with all kinds of assistance.

List members described instances of being helped by the FL with medical, rent, and moving expenses. Cassandra said, "We didn't have enough money to cover [my hospital] deductible. And they gave me [the money] to do that."

Beyond the assistance that the FL offers participants, List members related other instances of tangible support. Lisa, who had been put on a new medication that caused her hands and feet to feel like they were burning, stated,

> I just started on Xeloda…and suggestions were given confirming things to use for the side effects. For the burning on the ends of the feet. And I have products, in fact, one lady sent me a sample of things to use, bag balm on my feet and hands and to put gloves and sock-like things on my feet at night to really keep them from burning so much.

Sophia talked about visiting a List member who was dying:

> I was with Nell, oh, just before she died. She told Kelly and me that she really wanted her kitchen cleaned. So Kelly flew in from [her city] and I flew in from [my city]—to Nell and we cleaned her kitchen. It was something I could do. Something I could do. I appreciated them letting me into their hearts and their minds and their souls and being friends. There's nothing quite like that.

Each of these interview excerpts offers a glimpse into the different varieties of tangible support that participants have received or provided. FL is a small subset of the List, but is representative of the List as a whole. Lisa's receipt of products to help her with her side effects and Sophia's visit to a dying List member reflect the acts of individuals, but are in keeping with the values of caring for others. These tangible activities are reflections of the emotional regard participants have for each other – beyond offering words of support to each other, members make an effort to do more. Because most participants do not live near each other, this means that extra energy is going into their actions.

The tangible support offered here is interwoven with aspects of emotional support. It can be interpreted as emotional support in two ways: a) the intent behind the tangible support is based on caring emotions, and b) those receiving the tangible support feel valued. Moreover, although the primary purpose of each of these supports was to explicitly help others, they also have attributes of gift-giving. Gift-giving has multiple purposes and meanings, including status, expected reciprocity, and coercion, as well as social bonding and altruism (Komter, 2007; Skageby, 2010). Gifts are also tied into emotions – often expressions of love or sympathy. Carrier (1991) states, "[W]hat makes a gift is the relationship within which the transaction occurs" (p. 122). The way that participants discussed their involvement in these gift-giving activities gave little indication of expected reciprocity or coercion. Sophia indicates that her travel to clean a dying member's kitchen is an act of reciprocity, when she states, "It was something I could do…. I appreciated them letting me into their hearts and their minds and their souls and being friends"; but there is no stated expectation of reciprocity. All three instances of gift-giving are related to feelings of concern, offering a glimpse into how emotions are tied into the acts of tangible support.

5.1.3 Perceived Social Support

As an introduction to the concept of perceived support and its presence among List members, Carla's statement offers some insight:

> The List means to me, they are my friends, the people that I know if I called upon to give me support tomorrow they would be there for me. They would be there and I just know they would. They would be there with information, they would be there with love, they would be there with understanding, 'cause they've been there, they've done that. And it's just like they are invisible sisters…. all of them, those wonderful people. And I know they would be there for me. There's no doubt in my mind. And they're there for others.

Carla believes that List members are available to her, indicating one key element of perceived support, which is the belief that support will be forthcoming if needed (Lakey, McCabe, Fisicaro, & Drew, 1996; Sarason, Sarason, & Pierce, 1990). When Carla first joined the List in 2005, she participated often, asking many questions and joining in on the discussions. Currently she posts rarely, as little as once a month, and she has never met anyone from the List in person. Yet she has consistent positive feelings about them, and despite her low level of participation, fully expects that others on the List "would be there for me." Carla's belief is likely based on having been helped by the List when she first joined. She said, "And did the group help me? Of course the group helped me. Because I learned that I was really not alone. I was just like most of the women that had been there."

Perceived support can exist whether or not support is actually available, and there is not necessarily a correlation between enacted support and perceptions of support (Lakey et al., 1996; Sarason, Pierce, Shearin, Sarason, & Waltz, 1991; Sarason, Sarason, Shearin, & Pierce, 1987). Sarason, Pierce, & Sarason (1990) state that two important points are "(1) the concept of perceived support as a sense of unconditional acceptance no matter what happens and (2) the role of social relationships in creating this perception and in validating it over time" (p. 97).

Perceptions of social support as well as actualization of support have been shown to be related to personality (Cukrowicz, Franzese, Thorp, Cheavens, & Lynch, 2008; Sarason et al., 1991). For example, traits such as extraversion, agreeableness, and conscientiousness are positively correlated both with perceived social support and the ability to garner social support resources (Cukorwicz et al., 2008, p. 667). These differences in personality traits as they relate to social support are rooted in childhood experiences and attachments, as well as personal social

network experiences (Sarason, Pierce et al., 1990). In addition, perceptions of support are based on attributes such as affection, trust, and feelings of self worth. Most participants I interviewed either expressly stated belief in support being available to them, or, through their positive attributions about the List, implied that expectation. Of course, being a member of the List is a self-selecting process – people who get nothing out of being there do not stay.

A few interview participants did note feeling unsupported at times, and, in fact, left for a while. Kate stated, "I was on the List for a while, then I got seriously flamed." Kate left, but stayed in touch with several List members. After becoming very close with one List member through face-to-face meetings, she decided to return, saying she missed being there. She said,

> I came back and had all these friends! And, you know, people were glad to get me back, and I felt welcomed, and—I started going to Gatherings—and really meeting people face-to-face, and I just made friends! Really good friends…. I don't remember the details of why I went back. I just decided to go back. It might have something to do with, you know, meeting Sophia in person—

Although Kate left because she was unhappy with her interactions there, she also had some level of enacted support due to personal relationships she had developed, leading her, eventually, to believe that returning might offer some benefit.

Rebecca joined the List soon after finishing treatment, feeling as though she needed support, but when she joined,

> I felt overwhelmed by it and I felt that I was a freshman and I had just encountered a sorority—you know, of really good friends. I felt, yeah, I felt a lot of friendships and history and clique—you know, kind of a clique there. And that intimidated me. Um, but not enough, not enough to make me go away…. I participated [and] a few times I would post something and I would get completely ignored and not get one response. And so I would feel like my fingers had been singed. And then I would go back into lurking again.

Despite these early experiences, Rebecca made personal connections with others on the List, becoming friends with a few participants. She was active on the List for two-and-a-half years, leaving when she went on vacation. She continued,

> The decider was we were getting ready to go on a trip and so I was packing reading material and in goes all my copies of MAMM and Breast Cancer this and Cure and I just thought, "Oh my god. You know, I haven't packed one thing to read that's not dealing about breast cancer. I just need a novel. I need Good Housekeeping. I need, you know, some—so I just thought, "You know, I need to like cut off the—that connection for a while and just see what happens. To see if I can become a little more well-rounded." Because I just still felt this—and the List was the only place I could get my, my breast cancer fix, if you will, as far as—other people with the same feelings.

Rebecca left the List for six months, returning after her son had died. She said,

> The day [he] died, and we came home and I was in shock, the first thing I did was try to go on to the List…. and then I've been on ever since…. I would say I've got a lot more close friendships now as a result of [him] dying--

Rebecca's perceptions of support varied depending upon the enacted support she received. At first she felt unsupported, as though participants were not interested in helping her, but as time went on and she made more connections, her feelings shifted and the List served a purpose in her life – as she said, it gave her the opportunity to be with others who had "the same feelings." Returning soon after her son died indicates that she ultimately ended up feeling supported, or she would have had little reason to return.

In Rebecca, Kate, and Carla's experiences, perceptions of support were related specifically to enacted support—if they received enacted support, they perceived that support was available to them, but, in the case of Rebecca and Kate, they did not perceive support when it was not specifically enacted. Conversely, Alice, who was a lurker and did not engage with the

group, did perceive support. I discussed Alice's story in Chapter 4, noting that even though she was only an observer, she found the information on the List to be comforting:

> [Y]ou just felt like there was this larger group of people. And that's just what I was looking for. I didn't really want to write in. I think if I had had symptoms that were really different from what people were describing, I think I probably would have. But I felt like people were talking about exactly what I wanted to hear about…. I mean, it felt like social support to me.

Turner, Grube, & Meyers (2001) build on Cutrona & Russell's (1990) theory of optimal matching, which suggests that specific kinds of social support are more effective when they match specific stressful events. For example, emotional support might be more important during certain types of illness, and tangible support might be more important at other times. Optimal matching is also related to obtaining support from similar others who have been through similar stressors (Cohen & McKay, 1984; Hogan, Linden, & Najarian, 2002; Thoits, 1984; Thoits, 1995). Turner et al. (2001) also note that specific types of social support might not be available among one's local social networks, but that it is possible to access this support online. If someone with an illness knows no one else with the same illness and has no one to talk to face-to-face, obtaining this through online support is an example of an optimal match. For participants who remain on the List, there is some element of optimal matching—in some way, the List is meeting their needs. When it does not meet their needs, reactions occur, for example, Kate left the List for a while, and Rebecca became a lurker. For both, their relationships with the List changed, making it more of a match later on. Both Carla and Alice experienced optimal matching even though their perceptions of support were based on different criteria.

5.2 Conclusion

Social support among List participants consists of multiple layers and interconnecting events, emotions, and perceptions. Support occurs in several ways, through enacted support

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whereby participants offer emotional, informational, and tangible support, as well as perceived support. These various types of support interact with each other, forming the List into a caring community of people who express empathy, who help each other and who, because of these exchanges, feel nurtured. Being a part of the List gives participants the ability to gain support from people who understand their circumstances, and it also gives participants opportunities to give support to those in need. Through their interactions, discussions, and tangible exchanges, List members have developed a community that has a rich culture steeped in diverse demonstrations and conceptions of social support.

CHAPTER 6

INTERWEAVING INFORMATION, SOCIAL SUPPORT, AND COMMUNITY

There is an interwoven quality to the ways that List participants exchange information and social support, which speaks to an inextricable connection between the two elements. Expressions of support and information exchange occur both concurrently and in tandem with each other throughout much of the conversation. Each has a distinct place and function within the communication that occurs on the List, and they are also each integral to each other, together contributing to the creation and maintenance of the community. List members' information and social support interactions mold the community, crafting its knowledge, norms, and understandings through collective and individual actions that open up channels of communication and afford access to larger social networks and social capital.

6.1 Creating Community

The List is an information space, a social support space, and for many, "a group of friends." A web of connections becomes available when one joins the community, with participants utilizing it to different degrees, gaining different benefits and contributing at various levels, but there are certain attributes that form the core of this community. Knowledge of community norms and unspoken meanings accrue through continued engagement, through language, actions, and through what Wenger (1998) calls a "shared repertoire" (p. 82). A community builds up a history that shapes how people interact and the way they understand each other.

In some ways the List shares characteristics with communities of practice, groups "of people who come together to learn from each other by sharing knowledge and experiences about the activities in which they are engaged" (Preece, 2003, p. 72). The phrase "community of practice" once described any type of community that engaged in discussions of specific topics but now is primarily used in reference to the informal learning and sharing of experience within and across formal organizational structures such as business, government, and education (Preece, 2003; Wenger, 2006). Nevertheless, two concepts integral to communities of practice, tacit knowledge and the development of informal, collaborative narrative practices (Brown & Duguid, 1991), have application to the social construction of the List community. For example, while communities of practice recognize the authority of a larger enterprise, they also adopt their own ways of understanding operating procedures that have more meaning in the context of their everyday lives (Wenger, 1998). In addition, much of the work done by patients is invisible to the medical establishment (Strauss, Fagerhaugh, Suczek, & Wiener, 1997). Similarly, List members create meaning among themselves that differs from the formality of medical constructs in that they are learning to navigate these with the help of other patients and laypersons. List members also create meaning as a community on an ongoing basis, both related to and outside of medical contexts.

6.1.1 Tacit Knowledge and Community Practices

Tacit knowledge is unspoken, or taken for granted, knowledge (Wenger, 1998). Preece (2004) writes, "Tacit knowledge consists of beliefs, opinions, sensibilities, styles of doing things, and lore that maybe [sic] expressed in stories and anecdotes, a glance, a nod, body language or go unsaid" (p. 295). Online communities whose communication is based solely in text develop

tacit knowledge through their words. Tacit knowledge is socially constructed, often routinized and unconscious, and based in the practices and understandings held by group members (Baym, 2000, 2010). Høybe et al. (2005) describe how storytelling among members of an online breast cancer group contributes to shared social experiences and communication through interactions that help to reduce fear and social isolation. Carlick and Biley (2003) explain that narrative helps people cope with cancer. The creative acts of constructing and telling stories, as well as writing them down and reading them, offer the opportunity for reflection through which meaning and knowledge develops (Orgad, 2006). In addition, narratives of illness enhance learning and understanding, as well as offer therapeutic benefit (Garro & Mattingly, 2000).

The stories List members relate build community cohesiveness that becomes part of the group's knowledge base, often not consciously known, but assumed. When List members discuss their concerns and fears, they do so on the assumption that there are things they do not have to explain; it is already a given that they are communicating with people who automatically understand what they are going through. One reason for this is the empathy that breast cancer patients and survivors have for each other, but another reason is because of the shared experiences of the group, *as* a group, its history, which develops over time. Eve describes this "knowing":

> That's why you stay on the List for support and there isn't a [person] on that List who has had [breast cancer] but who does not, at some point or another, feel like an ache or a pain or a crick somewhere and "Oh my god." You know? "It's coming back." It's a very common feeling and you stay on the List because those fears are discussable….And a relative is the last person that wants to discuss it with you ….A child, or a husband. They don't want to—they want to forget about it; they don't want to go through that again, either. So the List gives you that opportunity to vent no matter how foolish it might sound. To vent and have people understand.

Eve is talking particularly about people who "stay on the List." There are certain benefits that newcomers who come to an online health support group would reasonably expect to find, such as information and social support, but there are other aspects to any community that are not known until one has been there for a while. Newcomers who come to the List do not yet know that many participants live with thoughts about the "other shoe dropping," a return of cancer. Participants who have been on the List for a while know that there are some participants who have been through multiple bouts of various cancers. This usually only comes up explicitly on the List when someone encounters symptoms of something (and it can be anything, as we've seen in several accounts), and is not something that a newcomer would be aware of; however, the idea of a new cancer episode is ingrained within many members' consciousness.

Haythornthwaite, Kazmer, Robins, and Shoemaker (2004) noted the shared bonds and history of online students who take classes together in a distance education program, who have specialized community knowledge that often has to be explained to nonmembers of their community. The understandings created among members of online communities frequently form through language and humor, situating them as speech communities, whose sharing of language indicates knowledge of cultural norms and communicative practices (Baym, 2000, 2010; Philipsen, 1992; Wilson & Peterson, 2002). List participants create bonds through their use of various turns of phrase and insider joking. Use of acronyms, such as "NED" ("no evidence of disease") and "DISH" ("damn, I'm still here") pepper conversations after participants have doctors' appointment or reach anniversary milestones. List participants also declare different levels of being a "DISH," based on each five years of survivorship: gold, platinum, or diamond. These levels are known best by long-time members, but crop up every once in a while and engage the rest of the community. Other terms like "chemobrain," which refers to the reduction

of memory that may be a side effect of chemotherapy; "chemopause," meaning the onset of menopause (either temporary or permanent) as another side effect of chemotherapy, and "rads" are also commonly used. Some of these words are not particular to the List as they are common terms among cancer patients, but they still function as a way to enact bonds among List members. New participants learn these new words and phrases over the course of their interactions on the List.

Community practices take hold in other ways. There is a tradition of making tongue-in-cheek, but also serious, statements that attest to members' desire to support one another. When participants are having surgery, often other participants will make comments like, "I'll be hovering with my squirt gun. And I'll stay with you until you get your results. Tell the techs we are all looking over their shoulders!" Often members describe their squirt guns as being filled with chocolate or India ink, ready to attack the medical providers if something goes wrong, or hiding under that table as protection for the patient. The allusion to using squirt guns first appears in the early archives as a way to respond when "anyone" tells participants that they should be glad to be alive, and also as a way to vanquish medical problems. In response to one member finding out that she had malignant results, Erica wrote: "We're all gearing up with you, loading our squirt guns, rounding up the chickens, and hauling out the billy clubs to whack Mr. Nasty on the head. Keep the faith." One member who is no longer on the List stated, "Of course the whole idea was fanciful and amusing, but it served as giving support to the person in need and by thinking of the exam room filled with all these friends, all these squirt guns, was somehow comforting." This practice first began in 1996 and continues to be used in one form or another as a way to offer comfort and support. It is also a practice that long-time members are aware of, but which newcomers can only learn about through continued participation.

Similarly, at one point when several participants around the country were dealing with various procedures at the same time, Claudia said to one of them, Dana, "[My husband] and I will both be there with you and the rest of the list [during your surgery], after which we'll beat it [across the country] and virtually sit with Brooke through her test." Statements like these reflect one way that List members give support to each other as well as a humorous touch. In an online community where people usually cannot physically "be there" for others, making light comments about being there virtually exhibit caring, but also exhibit a particular community standard of integrating humor even during stressful times. Natalie said, "I think it's important. I think you have to keep that little bit of lightness in it." Humorous comments also serve the function of building community, analogous to the way off-topic conversations offer other points of interaction.

Community practices and understandings arise through connections among the participants, the information they generate, and the social support they enact and receive. The provision and receipt of information and social support foster engagement, which in turn crafts a community. When Eve compares talking to others on the List with talking to family and friends, she is also explaining the differences between the kinds of conversations she can have (or wants to have) with her family as opposed to those that are more easily carried out with List members. Eve's comments indicate how the connections between the social support and information that are available on the List help create a separate space for a community of breast cancer patients and survivors to vent, to develop their own stories and community apart from other people in their lives. It is also important to note that there are people on the List for whom families and friends are their primary sources of support when they are in need of help. A few people made comments such as "[my] family, of course, supplied the most, the emotional support. I could not

have gotten through it….So the emotional support I got from my family." Others declared that they would go to the List "almost before I tell my kids, for example." And many fall somewhere in between. Yet despite these very different pronouncements, there is still cohesiveness, because people espousing various levels of association continue to be connected to the List in some way. The affinity that occurs comes into being because of shared history and experiences even when the emotional connections differ.

6.1.2 Community Roles

Community roles contribute to List cohesiveness. Baym (2010) situates roles as contributing to the shared identity of a community, noting that "[m]any regulars take on specific roles…by enacting consistent and systematic behaviors that serve a particular function" (p. 86). List participants adopt roles both consciously and unconsciously. Community roles also provide predictability and stability, helping members understand their identities within the context of the group and helping to form cohesion (Maloney-Krichmar & Preece, 2002).

Community roles are enacted both within the online space and outside the space, making some roles invisible. Both visible and invisible roles shape the social structure of the online space. In the same way the communities of practice are invisible to their employers and exist as a subset of the formal work that occurs in work places (Brown & Duguid, 1991; Star & Strauss, 1999; Timmermans, Bowker, & Star, 1998; Wenger, 1998), so are the myriad practices and interactions that occur on the List—affiliated with the List, but not visible. This is an intriguing dichotomy because the existence of the List (and similar online health support groups) is, in itself, a somewhat invisible entity in the realm of formal medical structures, yet within the structure of the List, as well, there are invisibilities. However, despite the invisibility of some of

the List activities, they are all essential to the social construction of the List as it operates on a daily basis and in the lives of its participants.

The most formal enactment of roles is through the nonprofit arm of the List, Friends of the List (FL), where various community members voluntarily become officers and board members, engaging in activities such as fundraising, designing brochures, and working on the website. Semi-formal roles have also evolved among members of the List in that there are particular individuals who regularly post birthdays, memorial dates, and welcome messages to newcomers. These formal and semi-formal roles require a level of commitment, making them conscious role enactments. The participants who perform these regular actions do not just tune in when they feel like it, but involve themselves in a concerted effort to maintain List management in such a way that others participants can feel a part of something. Each time the monthly memorial list is posted, members thank the person posting it, reinforcing the significance of her role as well as continually re-solidifying this aspect of List culture. Other roles that members enact, which are informal but occur fairly regularly, include humorous postings, such as "Friday funnies" and postings of health-related articles that they think might be of interest to others. In addition, various participants take on the responsibility of planning the Gathering, which comprises visiting hotels, bargaining for affordable rates for rooms, and planning menus. All of these activities have been occurring for years, and provide structure and continuity for List members, but certain of them, such as the work of the FL and much of the Gathering planning, are invisible to the majority of the List—discussions occur off-List, through other channels outside of the online List space.

It is important to note, also, that some of these activities are purely social and not related to breast cancer or general health, but are off-topic. Birthdays and "Friday funnies" invite participants to connect with each other on other levels, adding dimensions of interpersonal engagement. In fact, even though birthday announcements appear as an on-List posting, participants are encouraged to send birthday greetings off-List so as not to use up the daily List quota of 150 postings. Automatically, this particular aspect of the List opens up another channel of communication, contributing to the mixture of off-List/on-List interactions that occur among participants. My personal experience with contributing to and receiving birthday wishes has included opportunities for increased off-List involvement, as participants often write more than just "thank you," but also detail what they have done on their birthday, potentially prompting additional communication.

Contacting others "off List" is common, and I was curious about participants' reasons for doing so. I asked Vicki why she decides to contact other members directly:

> How do I decide? How do I decide? That's a good question….Yeah. I don't
> know, come to think of it. In fact today I just contacted somebody off list and I'm
> trying to think of why I did it. Oh, just to offer, just to offer a word to them when
> they sound so frustrated. And in this [situation], you know, let them know that
> maybe somebody's been there, done that, and there's a light at the end of the
> tunnel, you know. I don't—it's kind of strange. I never thought about why do I do
> that. It seems kind of automatic.

Making contact with participants off List has the aspect of being an intuitive gesture, something that members do not particularly think about, but just do. It seems counterintuitive that in an online environment making personal connections out of the bounds of the environment would occur, and, as well, be productive, but they serve as an additional channel for participants to make connections. Illustrating this is the fact that most, if not all, of the FL board members have

had personal, off-List interactions with other List members beyond the parameters of the online space. In keeping with concepts of multiplexity and integration of social worlds (Haythornthwaite, 2001, 2005; Preece & Maloney-Krichmar, 2005), the more participants interact, the more they are tied to and involved with each other.

Other informal roles that participants adopt are mentors and mentees, which are both visible and invisible. The roles of information and support providers and seekers are the most visible roles that participants perform and see others performing, and are the foundation of List activity. When experienced members offer information and support to less experienced members, everyone sees these interactions. A participant posts a question or gives an update, and other participants chime in with advice, reassurance, or whatever the posting requires. Visible relationships provide mentoring models for everyone on the List, inspiring participation and contributing to the development and maintenance of behavioral norms. Participants join in on the conversations when they feel they are able to contribute practical information, and they also join in to offer words of support even if they cannot add any practical information.

Invisible mentorship relationships develop when participants post questions and other List members respond to them outside the parameters of the List, either through email or by phone. For example, Rebecca and Lily first met on the List, but ended up also conversing directly with one another, making this relationship less visible than other relationships where there is a group effort to mentor one or more participants. Rebecca described her mentor/mentee relationship with Lily, "She was probably my closest friend because I mentored her during her treatment. And so we communicated off list, and, you know, for six months or however long her treatment—and we're still really, really good friends. We're still close." Making direct overtures

to other participants gives mentees a particular person to contact when they have questions. These mentoring relationships have the potential to become very personal because of this, with the mentor becoming particularly invested in the welfare of the mentee, increasing the emotional involvement the individuals have with each other and often evolving into face-to-face encounters. For example, Rebecca noted that when Lily travels through her area of the country, they always spend some time together. Having this alternative channel for relationships to develop also fosters commitment to the List as a whole because participants' involvement with each other cements their belief in the importance of what the List can offer.

Mentoring relationships are cyclical, changing as newcomers, who join as information and support seekers, become more knowledgeable and mature into mentors, who are information providers and support providers. Cassandra said, "Well, you know, the dynamics of the List are fascinating. And this is something that I got into right away, too. Watching the newbies come into the List and then they would be the new wave of people giving advice." Through this process, participants move from being novices to experts (Lave & Wenger, 1991; Shaw, Han et al., 2006), taking on new roles as they accumulate new experiences.

Roles on the List continually overlap and change, depending on participants' needs and inclinations. Changes in online community roles speak to a dynamic environment; for communities to be sustainable, they must accommodate several generations whose collective knowledge and experience evolve in response to diverse membership and altered perceptions (Riel & Polin, 2004). List participants who are new patients are likely to be information and support seekers, and survivors are more likely to be providers of information and support. However, survivors seek information and support at different points in their lives, as well.

Members' levels of participation also vary: some members participate actively and visibly, some actively check the List but are less visible because they post intermittently, and there are participants who rarely interact, all of which has impact on what roles are played. In addition, individual participants can have multiple roles depending on various events and the needs and requests of other List members. For example, Melissa recounted several roles that she sees herself as adopting:

> I mostly lurk, and, you know, cheer people on when they're getting good results, or, you know, console people when they're having issues, but most of that's, you know, if it's a good something then I write, you know, "Yay!" "Yippee" "Dancing with [joy]" and all that stuff on the List, but then if it's something that I feel that I can help with, you know, if they're having a problem or an issue, then I usually write a private email.

Melissa describes herself as a lurker, but she does also post to provide encouragement, although only intermittently when she sees a reason to do so. She also contacts people privately if she thinks she can offer help. Melissa's actions indicate that she is a provider of support and of information when it makes sense to her, and although, in my interview with her, she stated that she does not approach the List for information or support, in a sense she does. Even though she is a lurker, she is still seeking information that will allow her the opportunity to help. Melissa's comments echo Vicki's in that she also describes making contact with other participants off the List as a way to make additional contact with them.

Often participants do not see themselves as consciously adopting a particular role. Many List members I spoke with said things like, "I'm just a participant," "I'm just one of the crowd," or "I truly do not have much to offer." They see themselves primarily as part of the community, without a specific function. However, they *are* adopting roles, by virtue of being members of the List. In joining the List and participating, roles evolve intuitively, because some participants

need help, and others want to help. Individuals are also sometimes cast into roles that they did not seek or expect. Jessica, who has been dealing with metastatic disease for a number of years, is looked up to as someone who is courageous in the face of daunting odds. When I asked her if she considered herself as having a particular role, she replied somewhat ironically, "You know, I'm the hero…my job is to put a bright face on for breast cancer patients. Other than the fact that I do seem to be inspirational for some people I don't know that I have a role." Showing yet another side to the assignment of roles, Alice, who lurked on the List only during her treatment, stated, "To me [the List members] were like role models"; and Catherine, who has been a long-time lurker noted, "the list provides awesome role models" Although Alice and Catherine both preferred to be observers without contributing to conversations, they still assigned roles to other members without their knowledge at all.

The roles that List participants adopt arise from community and individuals' needs and serve several functions. Roles contribute to the structure of the community—FL volunteer roles have particular consequences on certain aspects of the organization of the community, but other, less formal, roles do as well. Sometimes participants choose their roles, as in the FL, but usually the roles arise out of the continual give-and-take nature of participants' everyday conversations. In addition, the intermingling of visible and invisible roles contribute to a mixture of online and offline community, and, as well, to multiplexity of media among participants.

6.2 Strong Ties, Weak Ties, and Relationships

> And, so I've met a lot of people, and also, because of the international nature of the List, I've met some people overseas, as well. I traveled to Australia—on a business trip, and I met several of the ladies there which was just wonderful. And I traveled to [Europe] on another business trip, and I met Allison. And she pulled a bunch of the ladies from England and around over there and there was this little

meeting then. And this spring we're, we're again planning [another get-together in England]. That's going to be fun—I can't wait for that.

I excerpted the above quote because it represents possibilities. Not everyone has the opportunity for worldwide travel, but the social relationships that build through engagement among List members offer them opportunities to broaden social networks and develop social capital in multiple ways. Participants meet online through the common bond of breast cancer, which gives them links to other people, information, and social support resources through both individuals and the collective actions of the group. This process, first, gives them access to breast cancer and other health resources, and, second, gives them access to other social resources that can provide additional value to their lives, such as personal relationships that develop into significant friendships. This added value does not happen for everyone who is a member of the List—not everyone wants to form deep friendships or meet others in person, but the existence of the List provides the possibility for anyone who does decide to take advantage of it.

Building relationships on the List occurs through the shared experiences of members, the exchanges of information and social support, and in the norms that are established through these processes. As relationships form, participants are creating an environment that also builds their social capital. Lin (2001) defines social capital as the "investment in social relations by individuals through which they gain access to embedded resources to enhance expected returns of instrumental or expressive actions" (p. 19). Through the social ties that exist among individuals and their networks, social capital affords access to resources such as information and social support (Lin, 2001; Wellman & Frank, 2001; Wellman & Gulia, 1999). Lin (2001) and Ferlander (2007) identify two perspectives on social capital that characterize it as: a) an individual asset, focusing on the ways that individuals utilize resources acquired through their

social connections and b) a collective asset that "enhances group members' life chances" (Lin, 2001, p. 22), incurring social trust and norms. Social capital occurs through the relationships individuals have with each other through their participation in groups, and is characterized by reciprocity as people exchange resources (Bourdieu, 1985; Portes, 1998). Social capital resides in the "actual or potential resources" available in one's networks (Bourdieu, 1985, p. 248). Social networks are made up of connections among people, ranging in strength from weak to strong ties, each of which confers different value in terms of access to resources (Haythornthwaite, 2002, 2005). Tie strength is related to emotional intensity, intimacy, and reciprocal services (Granovetter, 1973). Strong ties comprise people who are close to us, are similar to us, and with whom we are most socially involved. Weak ties comprise casual acquaintances who are less connected to us.

Social capital is often referred to as *bridging* and *bonding* (Putnam, 2000). Bridging social capital connects individuals and communities to new resources through weak ties, people who are outside of their strong tie social networks, whereas bonding social capital is found among individuals' close associates. Preece (2004) calls bonding social capital "the glue between members of a community" (p. 297). Coleman (1988) argued that strong ties in dense, bounded networks confer greater benefit than weak ties due to strong feelings of trust as well as the enforcement of community norms. Conversely, Burt (2001) argued that close networks result in restricted access to information because of similar access to resources and perspectives among people in these close networks, restricting the opportunities that can be accessed through other, weak, networks and non-redundant sources of information. In reality, both weak and strong ties provide benefit depending upon the type of help one needs (Granovetter, 1983), and most people are surrounded by both "dense, bounded groups and sparse, unbounded networks [existing]

simultaneously at work and in communities," which might change depending upon the situation (Wellman, 1997, p. 183). Network members provide "emotional aid, material aid, information, companionship, and a sense of belonging" (Wellman & Frank, 2001, p. 233).

Within the social support literature, there is a type of support called *network support* (Goldsmith, 2004), sometimes discussed within typologies of the enacted support, sometimes couched in other language, such as "feelings of belonging" (Cohen & McKay, 1984) or "social embeddedness" (Barrera, 1986). Feelings of belonging and social embeddedness are indicative of there being significant others in one's life who can provide buffering against life stresses (Barrera, 1986; Cohen & McKay, 1984). Lin (1986) and Gottlieb's (1985) three-tiered structures of social relationships give insights into how individuals are tied into their networks, and how at different levels, social support can become available (see Chapter 5 in this dissertation for a detailed discussion). Wellman and Gulia (1999) expand on these connections by noting that social support networks comprise varied resources, with different network members providing different types of social support.

Being online offers additional opportunities to enhance these multiple networks and social ties, and facilitates their continual evolution. Ties of varying strength are reinforced through email, social networking sites, and blogs, extending means through which people are able to gather information and become connected to other people. Online interaction affords the ability to build social capital by fostering new relationships that can offer more objective perspectives on people's experiences (Barnett & Hwang, 2006), as well as strengthen already established relationships. Moreover, online interaction can provide additional richness to them, opening up opportunities for engagement that might not be available offline (Baym, 2000; Haythornthwaite & Hagar, 2005; Orgad, 2005b; Preece, 1999; Steinkuehler & Williams, 2006).

As List participants engage in sharing information and social support, they are building social capital. Some participants become quite involved with other participants, enhancing their engagement through multiple media, whereas others engage to lesser degrees. By virtue of being a member, an individual has access to the various resources that the List offers, but different individuals utilize these resources to various extents. Breast cancer is the primary point of contact—a participant who is interested only in breast cancer can build capital by interacting with other patients and survivors, and garner the resources that can help with navigating through the breast cancer journey. Participants can also become more attached by becoming more involved with each other through friendships. These options of being on the List for breast cancer and making friendships are not mutually exclusive—participants often become very close friends because of breast cancer. The resources differ, though, depending on the types of ties participants form. Multiplex friendship ties can give access to other resources outside of breast cancer whereas someone who is on the List only for breast cancer resources will have different points of access.

6.2.1 Intersecting Bonds

There is a core of participants, many of whom are the most active, who express deep, caring attachments to each other. Many of these participants have been on the List for many years. Eve said, "It's like a family. They're there. They understand….So we get this tremendous sense of family and support." From Eve's perspective, the List approximates family, close ties who are there for each other. Jodie talked about how bonds form on the List:

> You get to know so much about one area, you know, of people's experience. Even if you don't know a lot about other areas, they're sharing something very intimate with you. You know, they don't, you don't hesitate, you know, to talk about these

things that, you know, ordinarily…you wouldn't share with acquaintances, you know. And, because people let down their guard and trust that much it helps you to let down your guard and trust them.

Jodie is indicating the levels of trust that List participants have for each other, even though not everyone knows each other. There is the bond of breast cancer, which brings participants close together quickly. Participants talk about very personal things, furthering their connections. There is also the prevalent use of real names, which makes it harder to be anonymous. Although anonymity in text-based communication makes it easier for people to talk about sensitive issues related to illness (Barnett & Hwang, 2006; Orgad, 2005b), it is difficult to be totally anonymous if you are using your own name. Jodie noted that in another online health group that she is a part of, someone was found to be using a pseudonym and participants there felt betrayed.

Offering another perspective on bonding, Bonita said,

There's a lot of disparate personalities that if we met in other, without the breast cancer thing as the common bond, I don't know how many people would have become that close. Although, it's sort of like this filter thing. The people who join the List and stay, I think, share a lot of common characteristics. And if you join the List, if you don't even bother to join the List, that separates you out. You read the List and "aaah" that separates you out. If you don't want, if you want purely technical stuff and you can't bear the social stuff, that will separate you out. So it kind of, we have a lot of common characteristics that because of the way the List and the email is set up, that I think it results in that. Kind of the distillation of characteristics that we all have in common.

Bonita describes a self-selection process that ultimately determines who is on the List, who becomes most active, and who stays. In addition to active participants, the self-selection process also applies to members who are comfortable with the type of activity that occurs on the List even if they are not particularly active—they still check in although they might not want to become involved at the same level as others. Bonita also delineates how bonds form among people who "share a lot of common characteristics." These common characteristics are, first,

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related to breast cancer, but also related to the ways people interact with each other. It is "the social stuff" that provides form to the List; it is the social aspect of the List that creates the bonds that inspire participants to meet in person when traveling or planning and going to Gatherings. Participants become curious about the other participants and become more interested in pursuing social interactions both on and off the List. The social interactions provide openings for bonding social capital to develop, in many cases, strong bonds that result in participants providing resources such as places to stay when traveling or visiting others who are sick or dying.

Bridging social capital is evident among List members as well, demonstrating how both bridging and bonding social capital can co-occur in one group of people who, despite similarities, also are different enough from each other that they have access to other resources. Breast cancer has the characteristic of promoting tight bonds—people who have had breast cancer are often anxious to communicate with others who have been through it as well. Because breast cancer can strike anyone, in an online community it brings together disparate people who would never have had contact otherwise. This is where bridging social capital takes hold—the varying backgrounds of breast cancer patients offer access to resources outside of one's social circles, and through the List, composed of people from divergent places and backgrounds, participants are able to gain new information and other resources. Charlene, a professional health care worker, talked about making phone calls on behalf of other List members, specifically because she was familiar with certain procedures and able to converse comfortably about them. She recalled one incident where a List member was complaining about procedures she was having:

> I said, "You know something? You don't want to have your bone scan and your heart scan because they do what?" She said, "Well they put the IV in my neck." I said, "What?" She said, "Well I just hate it when they do those because it's so

painful. It takes so long to stop the bleeding and I've seen my blood shoot across the room" and I'm going, "You've gotta be kidding me!" She said, "Charlene, you've never put a needle on a person's neck to do that thing?" I said, "Hell, no! There's only one procedure we do that for." And so I was so infuriated I…called that hospital to see if she [was right about the procedures she was having]. I thought maybe they did something else on her. Ah, oh, no, they did that! And I called every hospital within 280 miles and asked them did they put in an IV…in the neck of anyone [having those procedures]. Come to find out that the one procedure they do it for…, this hospital at one time did and then they would follow it up with the bone scan and the MUGA. But when they stopped doing the procedures that you had to have it in your neck for, they still put in the IV in the neck. I gave her the names of every hospital and every nuclear personnel I spoke with. I told her to take it to her oncologist and give it to him and have him take it to the radiologist and say "This must stop."

Charlene's description of this incident exhibits, first, the extent that some List members are willing to go to help others, and, second, the access she had to resources that were not available to the List member she was acting on behalf of. This is also similar to circumstances where List members acquire information from other members that they are able to bring to their physicians to discuss treatment changes. The bridging social capital that is available on the List exists because even though there are members who are tightly bonded, they are also bridges to other social networks whose resources they can capture as a way of assisting List members.

The Gathering, also, is representative of the mix of bonding and bridging social capital, strong and weak ties, and the intersections of participants' social worlds. A loose core of participants is always at the Gatherings; they are the people who make sure it happens every year. Other participants come some years; some come rarely or just to one. There are also the participants who have never attended a Gathering. Even if participants do not come, they are, for the most part, at least somewhat aware of it happening as information is posted to the List frequently. Often those who do come bring someone else—spouses, significant others, grown

children, and friends. This collection of people brings a wide array of assets and personalities, linking people in ways that exceed the boundaries of what might be expected in such a forum.

The List is a single online space, but it is comprised of people who have varying ties with each other as well as with others outside its parameters, and whose emotional attachments range between being extremely close to very little attachment at all. Because of the mixture of diverse ties and levels of bonding, participants benefit from both bonding and bridging capital—participants have access to some of the same resources, but they also have access to other resources.

6.3 The Informative Nature of Social Support

When a List participant communicates information to another participant (as opposed to making a general informational announcement to everyone), it is usually an expression of support, specifically, *informational support,* defined as "giving information and advice which could help a person solve a problem and providing feedback about how a person is doing" (Schaefer, Coyne, & Lazarus, 1981, p. 386). Conversely, when a participant offers support through words or tangible assistance to another participant, she is also offering information—information that she cares (Barling et al., 1988; Cobb, 1976; Semmer et al., 2008). It is difficult to extricate information and social support from each other, as expressions of support permeate many of the informational messages, and at the same time, serve as information themselves. The following selection of excerpts captures the ways that information and social support become intertwined through one person's posting of concerns and List members' responses.

Janine is a long-time member who checks in from time to time, sometimes to see what others are up to, and at other times to talk about various concerns. In this particular series of posts, she describes some health issues she is having:

> I'm having a bit of a medical scare…. At the end of December/early January, I started seeing double when I was driving at night. A little scary, because I'd see two oncoming cars, one of them in my lane. And when I went to the opera, there were two sopranos on stage, and when I went to a house concert, the fiddler had two bows (at least they were in sync).
>
> But I was focusing on work and other stuff, and didn't get around to checking into it for a few weeks. Thought it was due to the new glasses I got in November, so I had the optician check that the lenses had been ground correctly, then made an appt. with the prescribing optician to have the rx checked…. [H]e said there was nothing wrong with the prescription, and either I needed an extra prism, or something could be wrong with a nerve that was controlling some muscle. Referred me to a specialist, whom I saw Friday for a very long examination.
>
> The eye doc said there's nothing wrong with the muscles, and he thinks this is just a result of aging, but referred me for an MRI of my head. I asked him what that would rule out, and he beat around the bush, saying it could be a hundred different things. Last night it hit me that one of those things is metastasis to brain/optic nerve. Wow. I don't even know about the other 99 things it could be, but that one I know about.
>
> Had the MRI yesterday…man did they get me in fast…. The radiologist's report will be at the eye specialist's…tomorrow. I'll go pick it up then. It's stressful to wait for word that could mean so much.
>
> In the meantime, I'm trying to remember to breathe….

This post is full of information about factual events related to Janine's double vision and medical appointments. Janine also indicates emotional aspects of these events, including her fear, some humor ("at least they were in sync"), her stress, and "trying to remember to breathe." But this is not all she is doing. Although not specifically requesting support, she is communicating her need for it, first, just by virtue of writing the post, but also in the way she tells the story, saying things like, "Wow. I don't even know about the other 99 things it could be…." And "man did they get

me in fast." These comments indicate worry. The natural response for List members is to offer

their support in several ways:

> Erin: Oh, Janine! So sorry you're going thru this! My SIL [sister-in-law] called
> today with her results. She had much the same problem and same tests, including
> the brain MRI. Turns out she has signs of beginning glaucoma. Dr. said she
> could have laser surgery, to stop, hopefully, or at least slow the progression-or-
> she could use drops twice daily. She's VERY active (at 79, runs circles around
> me) so opted for the laser treatments. Hope you have better luck and easier
> treatments.
>
> Sheryl: My fingers are crossed…hoping and wishing for it just to clear up….
>
> Nina: Janine, my fingers crossed for you too. If I read it right, you get the results
> today, thank heavens you don't have to wait longer. I hope it's a nothing, and that
> whatever's causing it is something straightforward to deal with.
>
> Sheryl: I did just read a line on some website somewhere that thyroid disease
> affecting the eye muscles can cause double vision---in fact, this was the
> first cause mentioned….
>
> Valerie: Janine, I have my fingers, toes, eyes and tongue crossed! Hoping all
> comes out well or, at most, negligible.
>
> Briana: Wow Janine, that must be scary! I think it's most likely caused by plain
> old working too hard and not getting enough sleep. I don't think the tech would
> have showed you the images if he'd seen anything that worried him. Hang in
> there!
>
> Daisy: Oh Janine, it really could be a dozen different things. I am praying that
> it is a silly nothing that is fixable.

Through the rallying of support for Janine, there is a community response, filled with a mixture

of emotional and informational content. There are many expressions of sympathy, reassurance,

and hopefulness. In addition, there are also some posts offering information about potential

diagnoses that would be less scary than the worst outcome that Janine is worrying about.

Whether it is informational or emotional, all of the content comprises social support in some

way. All of these expressions of social support are also information for Janine, letting her know

that others in the List community care about her. Both the emotional and informational content

indicates that participants are thinking about Janine and trying to help in some way. When she

received the results of her test, Janine wrote:

> [N]othing goin' on with the brain or eyeballs that shouldn't be. I guess I just need
> a special eyeglass prescription. Sooner rather than later, as my vision is getting
> noticeably worse.
>
> Thank you all so much for "breathing with me"…while I waited what was only 3
> days, but seemed like an awfully long time. It was a great comfort to be able to
> tell you all what was going on.

Janine is affirming that the information she received from List members offered her comfort. As

a veteran poster, Janine knows that posting will probably bring some benefits – one cannot

always know for sure, but having the experience of it offers members a measure of knowing that

this will happen in the future – in effect, this is perceived support – the perception that people

will be there when needed. Both this perception and the actual enactment of the support are

information that the receiver experiences as helping her make sense of her world.

In her study of people dealing with HIV/AIDS, Veinot (2009b) states that from users'

perspectives, information and emotional support are "overlapping experiences" (p. 12). These

overlapping experiences are true for List participants, but I also argue that there is more to these

experiences. A connection between information and social support was first made by Cobb

(1976), who wrote:

> [S]ocial support is conceived to be information belonging to one or more of the
> following three classes
>
> 1. Information leading the subject to believe that he is cared for and loved.
> 2. Information leading the subject to believe that he is esteemed and valued.
> 3. Information leading the subject to believe that he belongs to a network of
>   communication and mutual obligation (p. 300).

As one of the earliest discussions using the term "social support" in describing the role of social relationships in moderating stress (Goldsmith, 2004), the remainder of Cobb's (1976) article focused on the relationship between social support and stress in various situations. Subsequent social support research has also focused on how social support moderates stress and its effect on health and well-being. However, the idea of *social support **as information*** has rarely been expressed. Concepts such as perceived support and informational support, as well as the idea that emotional support is present through the enactment of tangible support (Barling et al., 1988; Semmer et al., 2008) are related, but do not really address the idea of social support being information.

Other work linking social support and information draws attention to the way people access information in supportive environments such as health clinics and midwives' appointments (Fisher, 2004; Fisher & Landry, 2007; McKenzie, 2010; Pettigrew, 1999). In addition, research on affect and information behavior delineates the importance of recognizing the role of emotions in information seeking and use (Dervin, 1992, 2003; Harris & Dewdney, 1994; Kuhlthau, 1991, 2004, 2005; Wilson, 1981, 1997). Harris and Dewdney (1994), in their research on battered women, noted that information seekers valued emotional support from those who were helping them cope.

In integrating enacted support, perceptions of support, the emotional aspects of social support, and provision and access of information, there is not only an interconnection between social support and information, but such a close association that at times one is not easily discernable from the other. My interview with Rhonda, who has been a member of the List on two separate occasions, reveals additional nuances to the social support-information relationship:

E: So, how would you say you use the List these days? Like, what does it do for you? Or not?

Rhonda: It's safe—Well, you know it's, to a degree it's a safety net or a comfort blanket. I'm not quite sure which of those. Both, maybe. It's—I know I can post something there if I need to. I know it's a group of friends that I probably should contribute more to, and don't do enough with. But they're there, you know? And I also know that, yes, I mean, you know, that it's a way of getting another perspective on how people deal with this. And often a completely different perspective. That's, I think, one of the things I get from it.

Rhonda's perspectives about the role of the List in her life speak to the interplay between information and social support. At one point, Rhonda had left the List for a number of years after an initial bout with breast cancer, but later, when she found out that she had breast cancer for a second time, she returned. Rhonda's description of the List as a "safety net or a comfort blanket" echoes the thoughts of others, who have also referred to it as a security blanket. Some participants have stated that one of the reasons they stay on the List is "just in case" they have breast cancer again. It is a source of comfort because of the knowledge that when there are things that need sorting out, this is a place to go. Much of that knowledge is based in perceptions of social support, which for Rhonda and many others comes from having experienced needed support in the past, and which is information that they carry with them, ready to use. Rhonda's experience and perceptions of the List have given her the information that she is cared for, valued, and among a network of others in this community, "a group of friends."

The conjunction of information and social support in List conversations occurs in several ways, with a continual interplay between them. Communication on the List is interlaced with both, with expressions and enactment of support co-occurring with informational exchanges. A posting on the List about a participant's troubles, seemingly an informational announcement, also implicitly expresses a need or desire for support. Support responses, whether they are

emotional or tangible, are also informational, offering the receiver information that has impact on her understanding of her world.

6.4 Conclusion

In this chapter, I have illustrated the continual interplay of information and social support as they occur on the List. I have also described how social support plays an informational role beyond being "informational support." Wellman's (1997) characterization of most people being surrounded simultaneously by a diverse array of networks ranging from dense and bounded to sparse and unbounded is also an apt description of the kinds of networks that are available through the List. This interweaving of networks creates a web of interactions through which participants are able to access a variety of people, information, and social support, culminating in what one participant identified as "a microcosm of the rest of the world." The interconnections among participants through shared experiences, shared practices, and tacit knowledge contribute to building and maintaining a cohesive community based on trust, social networks, and social capital.

CHAPTER 7

CONCLUSION

> At this point it's just maintaining contact with all of the wonderful people that I know…. I'm not there to ask any questions at this point, but I do feel like occasionally I can contribute when new people do drift onboard.… When somebody does find us, I feel like I have a good knowledge base that I can poke into to offer, you know, suggestions or answer questions or , and just, you know, hangin' out…. Keeping up with what's going on with people and, you know, just being there to be supportive. Like with people who have had recurrences and are going through things, and for everyone, you know, with their scares and, like I wouldn't dream of leaving it behind at this point.…It's a big part of my life because those friendships that have developed over the years, you know, it's been seven, well, 6-1/2 years, and having been to four Gatherings and met as many people as I have—those friends that I have on the List are just as important to me as the ones that I see in person on a regular basis. –Jessica

Jessica's comments above illustrate several elements of List participation that contribute to a complex culture of interconnection. For many participants, membership spans multiple years, which contributes to the collective memory, as well as experience. Even though some participants are well beyond breast cancer treatment and do not know what is most current, others, because of their interests or recurring problems, are well versed and can offer excellent advice and resources. Whether or not a participant's knowledge is current regarding breast cancer information, there are always members who offer encouragement to those who need it for any kind of life event. And there are members whose relationships with each other have developed into thriving friendships. Jessica's comment, "I wouldn't dream of leaving it behind at this point" is illustrative of many participants' feelings. The List is, most importantly, a place to contribute to and obtain help related to breast cancer, but it is also a place where participants are able to reap much more.

My goal through this research was to understand the interactions occurring among members of the List, an online breast cancer forum, and how they contribute to information exchange, social support, and formation of community. In order to do this, I undertook an ethnographic study incorporating archives analysis, participant-observation, and interviews. My interests spanned several areas, including how the group facilitates information exchange, what the role of social support is for people dealing with illness, how participation in the group influences health decisions and practices, and what the meaning of the group is for its members. Although I had these specific interests about the group, I approached the study with the idea that my research might reveal interactions and processes that had not occurred to me.

My observations and analysis revealed a complex culture that was a microcosm of everyday life as well as a part of participants' everyday lives. List members' involvement with each other was more complex than what has been reported in other studies of online health communities in that interactions comprised an extensive array of topics besides breast cancer, and relationships that formed on the List transcended the online environment. Discussions on the List comprised a broad range of topics—not only breast cancer information, but also other kinds of health information as well as information totally unrelated to health. Many interview respondents noted strong emotional ties to others on the List that continued even after participants left the List, and many acknowledged its strong presence in their daily lives long after they had had cancer. In addition, participants place a high value on meeting each other in person, and in communicating in ways other than the online forum.

In progressing through this research, I also found that information behavior and social support were interwoven, inextricably linked in such a way that most conversations are suffused with both, occurring in conjunction with each other. My analysis showed that interactions that

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initially appeared to be either information exchange or expressions of social support actually comprised elements of both, threaded together in such a way as to make it difficult to distinguish one from the other.

7.1 Information Behavior

Information seeking and use among members of the List encompass elements of multiple information theories and models. Participants engage in various aspects of sense-making and the information search process as they try to deal with uncertainty and bridge gaps in their understanding of their worlds. This information behavior occurs during participants' breast cancer journeys as they try to figure out complex treatment options, but also as they navigate other situations in their lives. Using Savolainen's (1995, 2004) model of everyday life information seeking, List information behavior illustrates the ways that individuals traverse through their everyday lives, dealing with the stable aspects of daily life (way of life), as well as activities that are related to challenges or larger projects requiring more attention (mastery of life). As participants accumulate medical information from others on the List, they use this information to talk with their medical providers, to clarify treatment or to influence the trajectory of their treatment.

Members reported being engaged with the List in diverse ways, ranging from active participation on a daily basis to very sporadic contact. Members also noted different aspects of information exchange that were important to them. Some individuals found that the emotional content of messages was crucial to their well-being, especially as they were undergoing breast cancer treatment, whereas others were more interested in scientific material. Several participants reported that they derived great benefit from reading messages of all sorts, but were disinclined

to participate themselves. In addition, participants described accessing information from the List that they could use to help others who were not members.

Based on my observations and interviews, participants acquire considerable amounts of information related to aspects of health other than breast cancer treatment. Many participants share new health problems that develop, relying upon other members of the List as valuable resources for a comprehensive array of health information. In addition, health problems related to friends and family members often appear as topics of conversation. Although there are some members well beyond breast cancer treatment who do not share their health information with other List members, they still offer encouragement and advice to anyone who needs them.

List participants also share information about aspects of their lives that are unrelated to breast cancer or other health problems. At times there have been discussions about off-topic conversations and the potential effect they might have on newcomers unaware of this aspect of the List—there are concerns that these postings could cause potential participants to look elsewhere. However, these conversations lend a quality to the List that many other health forums lack—that of a third place, where people know that they can just drop in and talk about anything. Off-topic conversations and informal chatting add a social element that helps to build relationships.

7.2 Social Support

Social support on the List encompasses multiple layers and types of interactions. I drew on Lin (1986) and Gottlieb's (1985) conceptualizations of three layers of social relationships to inform my understanding of social support relationships among members of the List. The three layers comprise a continuum consisting of an outer layer (belonging/macrolevel), a bonding

layer (middle/mezzolevel), and a binding layer (inner/microlevel). Where individuals fit into the continuum offers insights into their social integration in the community, and as a "microcosm of life," List members span all three layers, depending upon their emotional attachment and levels of activity with others on the List. Where participants are situated within the continuum also gives indications of their social support involvement.

Participants' experiences of social support include both enacted support (comprising emotional, informational, and tangible support) and perceived support. Participants show emotional support through their compassionate responses, conveying the information that they care. Through exchanges of information, participants are also expressing emotional support. In addition, although in many online communities tangible support rarely occurs due to members being dispersed geographically, there are frequent instances of it among members of the List. Members raise money to help other members in financial difficulty, members send each other gifts, accompany others to medical appointments, and several participants recounted visiting dying members to help out in some way. Instances of tangible support are expressions of caring, which translate into both emotional and informational support.

Enactments of support among List members also nourish perceptions of support, leading the receivers to believe that support is available to them. Although some participants described instances of feeling unsupported at various times, most of them indicated, either specifically or implicitly, their belief that others on the List were there for them. For some participants, their perceptions of support were closely aligned with having experienced enacted support from other List members. However, members who posted rarely also perceived support—the act of reading the messages led these participants to feel comforted and believe that if they needed to ask for support, they would receive it.

7.3 Interconnections

Online health communities cultivate socially supportive atmospheres in which patients are able to access health information from sympathetic peers. Patients share personal stories that help them to understand their own health experiences, and exchange social support and information. Prior to beginning my study, I anticipated that interactions on the List would have some similar features to other groups, but I was curious to learn more about the inner workings of how social support and information exchange occurred.

I found that the List comprises a combination of social support and information, but as I began to delineate each of these elements to form a clearer understanding of how they impacted individuals and the community, I discovered how tightly intertwined they are. Together they form the foundation of the community, giving many participants the feeling that they are among friends whom they can approach for any reason. A feeling of community permeates the List, arising from multiple intersections of information and social support. Elements of communities of practice, in particular, tacit knowledge and informal, collaborative narrative practices have evolved through participants' shared understandings of the breast cancer experiences they have been through as well as other life events.

The formation of community also evolves through participants' roles, both formal and informal, built upon List members' shared information and social support practices. Whether members serve on the board of the Friends of the List, post welcome messages, or act as providers or receivers of information and social support, the enactment of these roles develops because of similar values among List participants, most of whom try to contribute however they can to others there. In addition, there is an undercurrent of friendship, evidenced by social

practices such as postings of jokes and birthday messages as well as the Gathering, all of which help participants to get to know others in roles outside of breast cancer.

The shared understandings, shared practices, and roles of members contribute to the building of a web of networks that gives participants access to other individuals who can provide information and social support. Participants take advantage of these opportunities to varying degrees—some are deeply embedded within all aspects of the List, while others have particular interests in the List that are more important to them. Having access to networks of others results in the ability to garner social capital, which connects individuals to various types of resources. Through a mix of bridging and bonding social capital, List members are able to reap multiple benefits. Within this one online space there are dense, close networks that comprise strong ties, but there are also weaker ties that bridge List members to new resources. Individuals within the strong tie networks on the List also have network ties outside the List, and members who are less connected to other List members also bring outside resources. In addition, there are former members who maintain close ties with current members, which casts them as both insiders and outsiders, with special knowledge about the List that other outsiders do not have. As several members noted, someone on the List is likely to know something related to a wide variety of questions, or know where to obtain the information, or, in some cases, take on the task of finding resources.

While at its core the List is a breast cancer forum, it is also a place where intersections of lives occur, offering access to a network of people, knowledge, and an extensive collection of resources related to other health issues and daily life experiences. This happens, first, because there is a general acceptance of a variety of conversation topics, which makes it possible for participants to know each other in ways other than breast cancer. Having the opportunity to learn

more about others on the List opens up avenues to mine the collective assets of this one group of people. In addition, being able to get to know one other and to interact in different ways helps participants become comfortable with each other and to develop relationships.

The information exchange and social support that form the basis for community on the list not only occur in conjunction with each other, they are often inseparable, and both evoke emotional responses. Information content on the List is often highly infused with emotion, and social support interactions, which often have emotional content in any context, also offer information. There is a recursive quality to the way that this happens. When participants exchange information, they are also indicating that they care about each other—the act of offering information is an expression of social support. Conversely, offering social support to someone is a form of information that tells the receiver she is cared for. In each case, there is an expression and recognition of caring, both of which have emotional and informational qualities. These intersections are prevalent among List members, encouraging an environment that produces webs of relationships, webs of information and social support, which in turn provide webs of connections to resources.

7.4 Implications

It is important to recognize the richness and complexity of relationships that are possible through online health forums. As I have continued to read List messages throughout the writing of this dissertation, I have seen some people become quieter, others more active, and quite a few new or returned participants. The jokes still occur while words of wisdom and care remain frequent and consistent. Although as time progresses participation may change, the warmth continues, as does the interest in the Gathering and getting to know each other better.

Most of the research about online health forums concentrates on the informational or social support components of these sites, which are extremely important for patients and others interested in understanding various health conditions. However, my research also reveals the potential for deep relationships on such forums, indicating extensive resources available to individuals who wish to take advantage of them. It is difficult to know how much this occurs among members of other sites because it is not reported. This study offers insights into how relationships develop, how participants' feelings about each other contribute to a sense of others being there for them, and how, by being part of the List, participants are able to access an abundance of resources that extend beyond information and social support related to one particular health condition. For example, through the jokes, stories and other off-topic conversations members offer glimpses into their lives that entice others to know them in multi-dimensional ways, promoting trust and the formation of relationships that encompass more than breast cancer.

A significant finding of this study is the extensive social interaction of participants through their communication practices, their face-to-face meetings, and the lengths they go to when helping each other. Participants whose membership spans multiple years encounter many opportunities to form deep connections that evolve into remarkable gestures of help, and those same participants offer that to newcomers. This research speaks to the importance of the social aspects of health information exchange as well as the critical nature of social support in health information behavior. In doing this research I have illuminated the possibilities for patients to expand their knowledge and their social networks to obtain a rich source of information and social support as they are navigating through illness as well as their everyday lives. In addition, recognizing the intertwined connection between information and social support is important to

understanding the impact of the messages that individuals give and receive as they progress through life's challenges.

7.5 Future Research

Information behavior research has noted that, in general, people prefer to go to easily accessible sources for information, in particular, people who are similar to them in some way (Harris & Dewdney, 1994; Savolainen, 2004). This is true for health information, as well (Johnson, 1997). The List provides these attributes—participants have similarities in terms of illness experiences and they are easy to access if one has an Internet connection. Being able to access online communities, like the List, can have far ranging consequences for anyone able to do so. In my introduction I noted that a Pew Internet and American Life Project report stated that 18% of all Internet users have sought health information from peers online, and 23% of Internet users with chronic health conditions have done so as well (Fox, 2011b). These are encouraging statistics in terms of percentages of people availing themselves of such opportunities, but clearly there are many who are not. In addition, several of my interviewees noted that other people looked at them strangely when they spoke about participating in an online breast cancer group. The experience of participants on the List indicates that this is an important area to continue to research as well as disseminate information about.

This study brought up questions for further research that would contribute to the understanding of issues that people face as they seek and cope with health information. In particular, doing this research illuminated several issues in relation to online health information access. Participants on the List obviously have access to computers and the Internet, and are computer literate. In addition, the List is not a diverse environment, and although research on one

online community does not indicate the diversity of other online communities, demographic information indicates that there are still disparities in levels of Internet use as well as Internet use for health information among African-American and Hispanic populations (Fox, 2011a). Also, disadvantaged populations experience disparities in access to health care information and health care treatment (Bohland, Puckett, & Plymale, 2006). Given that there are positive benefits from participating in online health forums, it is important to understand the relationship between various populations' use of technology and health care with a goal toward finding ways to provide avenues that enhance access to health information, health literacy, and health care.

In addition, I learned that List members are embracing social networking sites as well as other technological innovations—many participants are using Facebook and mobile technologies, and some are blogging as well. Several aspects of this are interesting in relation to technology adoption among older adults including how, when, and why they decide to learn about and use new technologies. Doing research that investigates the impact and meanings of using new technologies in older adults' lives can also help in thinking about what tools can offer easier access to these technologies.

This study offers insights about the interactions that occur in an online breast cancer forum as well as insights into the potential of online health communities. This particular community offers its participants the opportunity to engage with others about breast cancer, other health issues, and the day-to-day aspects of everyday life. List participants have built a web of relationships through conversations interwoven with information and social support, constructing an atmosphere that is helpful, supportive, and meaningful, and which often expands beyond the scope of an online community.

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APPENDIX A

INTERVIEW GUIDE

BASICS

1. Year of birth, occupation, education, where live, married? Kids?
2. When were you diagnosed?
3. Tell me what that was like.
4. When did you first join the List?
5. How did you find the List?
6. Where were you in treatment?
7. Do you remember if you lurked for a while, or did you join right in?

SPECIFICS

1. Tell me about your history with the List
2. Tell me about your initial experiences on the List. What kinds of things were you looking for?
3. Tell me how being on the List helped or didn't help you.
4. Have you been on it continually?
5. What made you leave? (If appropriate)
6. If you left, how did that feel? (If appropriate)
7. Tell me what brought you back to the List. (If appropriate)
8. Tell me what it's been like to be on the List as time has progressed. How has your use of the List changed as you progressed through treatment and/or are further from diagnosis?
9. How would you describe your current participation on the List?
10. Can you tell me how you use the List? (E.g., an information source, a social source, a support source?)
11. How often do you read messages?
12. How do you read the List – do you read it through the archives, or do you get it sent twice a day through the digest?
13. Can you tell me about specific information you went to the List for, and what kinds of answers you received?
14. How would you compare what you get from the List to what you get from doctors/nurses/etc.?
15. What about non-breast cancer information?
16. What about social support?
17. Tell me what you think your role is on the List.

18. Tell me about your relationships with people on the list.
    a. How have they evolved?
    b. How do you communicate with people off the List?
    c. How often? What about seeing them in person?
    d. Many people on the List have become very good friends with each other, and you are someone who seems to have gained a lot of friendships through the List. Can you tell me about how that evolved, and how some of the other people have become part of your life? (If appropriate)
19. What about newer people? Have you become good friends with newer people?
20. Have you recommended the List to anyone? Have people that you know joined?
21. Tell me about being on the List as a European? Did you belong to any other groups? Why this group? (If appropriate)
22. What is it like for you when people die?
23. How do you decide to send personal messages to people as opposed to on-list?
24. Tell me how the List has changed since you first became a member. (If appropriate)
25. Why do you stay?
    a. Do you ever think about leaving?
    b. What has kept you here?
    c. What do you get out of it?
26. Are there other places that you go to or have gone to in the past to access similar kinds of things you get from the List?
27. Tell me how you would compare being on the List with other sources or places of support and information you use?
    a. What about your family/ non-online friends?
28. I've heard some people talk about how there are fewer people on the List than there used to be? What is your perception? How do people know this? Why do you think this is?
29. What are your thoughts on why people leave?
30. Have you had other health issues over the years that you've brought to the List? Tell me about what those interactions were like. Why come to the List with them?
31. What about issues not related to health?
32. What about some of the other things going on with your family? Why bring them to the List? What does that do for you? (If appropriate)
33. Aside from discussions about personal health problems, there seems to be a number of other topics that people talk about, other types of discussions: other personal issues, political issues, lots of OT things. What do you think that's about? What are your thoughts about them?
34. I've also been struck by the frequency of humor/joking that occurs here. I'm curious as to why this occurs, even when things might seem very dire for someone. Tell me your thoughts about that. (Squirt guns & chocolate, being there in the OR…Friday funny…your status line…jokes about memory…)

35. Have you been to any Gatherings?
      a.   What were they like for you?
36. This last Gathering was your first. Why hadn't you gone before? (If appropriate)
37. Does it make a difference in meeting people? Would you go again?
38. Tell me about the Gatherings. What do they mean to you?
39. Tell me about your first Gathering.
40. What do you think they mean for the List? Why do you think people go?
41. How many Gatherings have you attended?
42. Had you ever met anyone in person?
      a.   What about phone calls or chats, emails?
43. Is there something about meeting someone in person that makes a difference to you?
44. Tell me about some of the smaller, local gatherings.
45. What made you decide to go or not to go?
46. Do you use Facebook to communicate with people? How is it different?
47. Have you ever been on the FL? What is your perception of it? What do you see as its function?
48. Tell me about being on the FL. What is your role there? How long have you been on it? You also referred to "list cops." Can you tell me more about that? (If appropriate)
49. Is there anything you don't like about the List? And are there particular things you don't like?
50. Tell me what the List means to you? Tell me what you like about the List, and don't like about it.
51. Tell me about why you use your real name on the List.
52. Who runs the show?
53. How would you say the List fits into your life?
54. Is there anything that I've missed? Anything else you might want to say?
55. Is there anything else you might want to say about being a member of the List?

IRB CONSENT MATERIALS

An Ethnographic Study of an Online Breast Cancer Support Group
Consent Form for Telephone Interview
Acknowledgment of Participation

(This consent form will be read over the phone, and participants' verbal consent will be within the transcription.)

I am invited to take part in a research study examining how online breast cancer support groups provide information and support to participants. The purpose of this research study is to learn how being part of an online breast cancer support group can help breast cancer patients with medical decisions and coping ability. This research study is being conducted by Ellen Rubenstein, PhD student at the University of Illinois at Urbana-Champaign under the supervision of Dr. Lori Kendall at the Graduate School of Library and Information Science at the University of Illinois, Urbana-Champaign.

While there is no direct benefit to participants in this study, this project is a needed contribution to the literature to better understand the mechanisms involved in the area of online social support and illness. The hope is that the results will lead to future opportunities for other breast cancer patients to obtain similar social support, information, and help with coping strategies.

Participants must be 18 years or older to participate in this study.

This interview will take no more than 90 minutes.

I give permission for Ellen Rubenstein to use my responses to interview questions to prepare articles, presentations and a dissertation with the understanding that there will be no identifying personal information included in the final report.

Further, I understand:

- My participation is voluntary, and I can opt out of this study at any point with no penalty.
- I do not have to answer every question asked by the interviewer.
- My responses will be confidential.
- There are no risks associated with my participation in this research beyond those I encounter in everyday life.
- The researcher will digitally record my interview with my permission.
- The researcher may contact me at a later date with brief follow-up questions.

☐**By checking this box, I give my permission to the researcher to use my verbatim interview responses. I further understand that my personal information (including my name) will not be attached to the quotations, but that a pseudonym will be used in referencing my interview.** (If this box is left unchecked, summaries of your interview responses will be used instead of verbatim quotations.)

☐By checking this box, I indicate that I understand that although a pseudonym will be used in all references to the interviews, it may be possible for my identity to be discovered due to the open, public nature of the Breast Cancer Mailing List and its ability to be searched through key words by anyone accessing the list through the Internet.

☐By checking this box, I indicate that I agree to have my interview digitally recorded. (If this box is left unchecked, the interviewer will take notes rather than record the interview.)

I have read and understand the consent document above and voluntarily agree to participate in this study.

_____   _____
Name   Signature

_____   A copy of this agreement will be provided
Date   for your records

Questions about the rights of research participants can be directed to the University of Illinois's Institutional Review Board. Phone: (217) 333-2670 (collect calls accepted). E-mail: irb@illinois.edu

If you are interested in the results of this study or if you have any questions about this study, please direct your inquiry to Ellen Rubenstein [erubens3@illinois.edu], or Professor Lori Kendall [loriken@illinois.edu], (217) 244-8829.

IRB PROTOCOL NUMBER: 09589
Approved May 5, 2009

An Ethnographic Study of an Online Breast Cancer Support Group
Consent Form for In-Person Interview
Acknowledgment of Participation

I am invited to take part in a research study examining how online breast cancer support groups provide information and support to participants. The purpose of this research study is to learn how being part of an online breast cancer support group can help breast cancer patients with medical decisions and coping ability. This research study is being conducted by Ellen Rubenstein, PhD student at the University of Illinois at Urbana-Champaign under the supervision of Dr. Lori Kendall at the Graduate School of Library and Information Science at the University of Illinois, Urbana-Champaign.

While there is no direct benefit to participants in this study, this project is a needed contribution to the literature to better understand the mechanisms involved in the area of online social support and illness. The hope is that the results will lead to future opportunities for other breast cancer patients to obtain similar social support, information, and help with coping strategies.

Participants must be 18 years or older to participate in this study.

This interview will take no more than 90 minutes.

I give permission for Ellen Rubenstein to use my responses to interview questions to prepare articles, presentations and a dissertation with the understanding that there will be no identifying personal information included in the final report.

Further, I understand:

- My participation is voluntary, and I can opt out of this study at any point with no penalty.
- I do not have to answer every question asked by the interviewer.
- My responses will be confidential.
- There are no risks associated with my participation in this research beyond those I encounter in everyday life.
- The researcher will digitally record my interview with my permission.
- The researcher may contact me at a later date with brief follow-up questions.

☐**By checking this box, I give my permission to the researcher to use my verbatim interview responses. I further understand that my personal information (including my name) will not be attached to the quotations, but that a pseudonym will be used in referencing my interview.** (If this box is left unchecked, summaries of your interview responses will be used instead of verbatim quotations.)

☐**By checking this box, I indicate that I understand that although a pseudonym will be used in all references to the interviews, it may be possible for my identity to be discovered due to the open, public nature of the Breast Cancer Mailing List and its ability to be searched through key words by anyone accessing the list through the Internet.**

☐**By checking this box, I indicate that I agree to have my interview digitally recorded.** (If this box is left unchecked, the interviewer will take notes rather than record the interview.)

I have read and understand the consent document above and voluntarily agree to participate in this study.

_____   _____
Name   Signature

_____   A copy of this agreement will be provided
Date   for your records

Questions about the rights of research participants can be directed to the University of Illinois's Institutional Review Board. Phone: (217) 333-2670 (collect calls accepted). E-mail: irb@illinois.edu

If you are interested in the results of this study or if you have any questions about this study, please direct your inquiry to Ellen Rubenstein [erubens3@illinois.edu], or Professor Lori Kendall [loriken@illinois.edu], (217) 244-8829.

IRB PROTOCOL NUMBER: 09589
Approved May 5, 2009

An Ethnographic Study of an Online Breast Cancer Support Group
Consent Form for Email Interview
Acknowledgment of Participation

I am invited to take part in a research study examining how online breast cancer support groups provide information and support to participants. The purpose of this research study is to learn how being part of an online breast cancer support group can help breast cancer patients with medical decisions and coping ability. This research study is being conducted by Ellen Rubenstein, PhD student at the University of Illinois at Urbana-Champaign under the supervision of Dr. Lori Kendall at the Graduate School of Library and Information Science at the University of Illinois, Urbana-Champaign.

While there is no direct benefit to participants in this study, this project is a needed contribution to the literature to better understand the mechanisms involved in the area of online social support and illness. The hope is that the results will lead to future opportunities for other breast cancer patients to obtain similar social support, information, and help with coping strategies.

Participants must be 18 years or older to participate in this study.

This interview will take no more than 90 minutes.

I give permission for Ellen Rubenstein to use my responses to interview questions to prepare articles, presentations and a dissertation with the understanding that there will be no identifying personal information included in the final report.

Further, I understand:

- My participation is voluntary, and I can opt out of this study at any point with no penalty.
- I do not have to answer every question asked by the interviewer.
- My responses will be confidential.
- There are no risks associated with my participation in this research beyond those I encounter in everyday life.
- The researcher will digitally record my interview with my permission.
- The researcher may contact me at a later date with brief follow-up questions.

☐**By checking this box, I give my permission to the researcher to use my verbatim interview responses. I further understand that my personal information (including my name) will not be attached to the quotations, but that a pseudonym will be used in referencing my interview.** (If this box is left unchecked, summaries of your interview responses will be used instead of verbatim quotations.)

☐**By checking this box, I indicate that I understand that although a pseudonym will be used in all references to the interviews, it may be possible for my identity to be discovered due to the open, public nature of the Breast Cancer Mailing List and its ability to be searched through key words by anyone accessing the list through the Internet.**

☐**By checking this box, I indicate that I agree to have my interview digitally recorded.** (If this box is left unchecked, the interviewer will take notes rather than record the interview.)

I have read and understand the consent document above and voluntarily agree to participate in this study.

_____   _____
Name   Signature

_____   A copy of this agreement will be provided
Date   for your records

Questions about the rights of research participants can be directed to the University of Illinois's Institutional Review Board. Phone: (217) 333-2670 (collect calls accepted). E-mail: irb@illinois.edu

If you are interested in the results of this study or if you have any questions about this study, please direct your inquiry to Ellen Rubenstein [erubens3@illinois.edu], or Professor Lori Kendall [loriken@illinois.edu], (217) 244-8829.

IRB PROTOCOL NUMBER: 09589
Approved May 5, 2009

An Ethnographic Study of an Online Breast Cancer Support Group
Consent Form for Using Quotes from Online Archives
Acknowledgment of Participation

(This consent form will be sent within an email, to be checked and sent back.)

I am invited to take part in a research study examining how online breast cancer support groups provide information and support to participants. The purpose of this research study is to learn how being part of an online breast cancer support group can help breast cancer patients with medical decisions and coping ability. This research study is being conducted by Ellen Rubenstein, PhD student at the University of Illinois at Urbana-Champaign under the supervision of Dr. Lori Kendall at the Graduate School of Library and Information Science at the University of Illinois, Urbana-Champaign.

Participants must be 18 years or older to participate in this study.

While there is no direct benefit to participants in this study, this project is a needed contribution to the literature to better understand the mechanisms involved in the area of online social support and illness. The hope is that the results will lead to future opportunities for other breast cancer patients to obtain similar social support, information, and help with coping strategies.

I give permission for Ellen Rubenstein to use my online quotations from the archives of The Breast Cancer Mailing List to prepare articles, presentations and a dissertation with the understanding that there will be no identifying personal information included in the final report. I also understand that although my real name will not be identified, that a pseudonym will be used in all references to these quotations.

Further, I understand:

- My participation is voluntary, and I can opt out of this study at any point with no penalty.
- My responses will be confidential.
- There are no risks associated with my participation in this research beyond those I encounter in everyday life.
- The researcher will digitally save my interview with my permission.
- The researcher may contact me at a later date with brief follow-up questions.

☐**By checking this box, I give my permission to the researcher to use my verbatim quotations. I further understand that my personal information (including my name) will not be attached to the quotations.** (If this box is left unchecked, summaries of your quotations will be used instead of verbatim quotations.)

☐**By checking this box, I indicate my understanding that although a pseudonym will be used in referencing my quotations, it may be possible for my identity to be discovered due to the open, public nature of the Breast Cancer Mailing List and its ability to be searched through key words by anyone accessing the list through the Internet.**

_____   _____
Name   Signature

_____   A copy of this agreement will be provided
Date   for your records

Questions about the rights of research participants can be directed to the University of Illinois's Institutional Review Board. Phone: (217) 333-2670 (collect calls accepted). E-mail: irb@illinois.edu

If you are interested in the results of this study or if you have any questions about this study, please direct your inquiry to Ellen Rubenstein [erubens3@illinois.edu], or Professor Lori Kendall [loriken@illinois.edu], (217) 244-8829.

IRB PROTOCOL NUMBER: 09589
Approved May 5, 2009

Ellen Rubenstein

929 Jona Kay Terrace
Norman, OK 73069

EDUCATION

University of Illinois, Urbana-Champaign   August 2011
Ph.D., Library and Information Science

Indiana University, Bloomington   May 2006
Master of Library Science

State University of New York, College at Fredonia   May 1978
Bachelor of Arts, English

DISSERTATION TOPIC

"It's a Microcosm of Life": Weaving a Web of Information and Support in an Online Breast Cancer Community
This ethnographic study used participant-observation, interviews, and archives analysis to understand
and investigate the ways that interpersonal communication in an online support group provides social
support, information exchange, and community for breast cancer patients, survivors, and significant
others, and how the community is integrated into participants' daily lives.

Committee Members: Lori Kendall, Linda Smith, W. John MacMullen, Caroline Haythornthwaite

SPECIAL INTERESTS

Online communities and communication; health information; health literacy; information behavior; social
capital; social networks; ethnography

RESEARCH

Publications

Rubenstein, E. (2012). From social hygiene to consumer health: Libraries, health information, and
the American public. Submitted to and accepted by *Library and Information History*.

Rubenstein, E. (2010). *Researcher subjects: Gaining access and building trust in an online breast cancer support
group.* Proceedings of the iConference, February 3-6, Champaign, IL.

Rubenstein, E. (2009). *Dimensions of information exchange in an online breast cancer support group.*
Proceedings of the annual meeting of the American Society for Information Science & Technology,
November 6-11, Vancouver, BC.

Rubenstein, E. (2008). *The intersection of information behavior and coping among women undergoing breast lump
diagnosis.* Proceedings of the annual meeting of the American Society for Information Science &
Technology, October 24-29, Columbus, OH.

Publications, cont.

Shachaf, P. & Rubenstein, E. (2007). A comparative analysis of libraries' approaches to copyright: Israel, Russia, and the U.S. *Journal of Academic Librarianship, 33*(1), 94-105.

Rubenstein, E. (2006). *Montreal Jewish Public Library Sheet Music Collection Finding Aids.* Published on library's website, at http://www.jewishpubliclibrary.org/site/archives/isheetmusicaid.html

Chicago blues: From delta to world; E-reference services: What users tell us; Race/ethnicity, recruitment, retention; Bradbury chronicles his love for libraries. Contributions to coverage of 2005 ALA annual conference; appeared in *American Libraries,* August 2005; 68-69.

Presentations

Rubenstein, E. (2011). *Information and social support in an online breast cancer community.* Presented at the annual meeting of the Breast Cancer Mailing List, October 21-23, Philadelphia, PA.

Rubenstein, E. L. (2011). *"It's a microcosm of life": Weaving a web of information and support in an online breast cancer community.* Paper presented at a workshop of the Special Interest Group – Social Informatics at the annual meeting of the American Society for Information Science & Technology, October 9-12, 2011, New Orleans, LA.

Rubenstein, E. (2011). *Intersecting constructs in an online community.* White paper submitted to SIG-USE (Information Needs, Seeking, & Use) Symposium at the annual meeting of the American Society for Information Science & Technology, October 9-12, 2011, New Orleans, LA.

Rubenstein, E. L. (2011). *"It's a microcosm of life": Weaving a web of information and support in an online breast cancer community.* Poster presented at the University of Illinois Graduate School of Library and Information Science Research Showcase, April 8, 2011.

Rubenstein, E. L. (2011). *"It's a microcosm of life": Weaving a web of information and support in an online community.* Invited talk, University of Oklahoma, March 2, 2011.

Rubenstein, E. L. (2011). *"It's a microcosm of life": Weaving a web of information and support in an online breast cancer community.* Invited talk, Florida State University, February 24, 2011.

Rubenstein, E. L. (2011). *"It's a microcosm of life": Weaving a web of information and support in an online community.* Invited talk, University of Arizona, February 17, 2011.

Rubenstein, E. L. (2011). *"It's a microcosm of life": Weaving a web of information and support in an online breast cancer community.* Poster presented at the annual meeting of the Association for Library and Information Science Education, January 4-7, San Diego, CA.

Rubenstein, E. L. (2011). *Disease and social mission: Libraries, health information, and the American public.* Paper |presented at the annual meeting of the Association for Library and Information Science Education, January 4-7, San Diego, CA.

Souden, M., Rubenstein, E. L., Genuis, S. K., Hogan, T. P., & Veinot, T. C. E. (2010). *Listening to patients: How understanding health information use can contribute to health literacy constructs.* Panel presented at the annual meeting of the American Society for Information Science & Technology, October 22-27, Pittsburgh, PA.

Presentations, cont.

Rubenstein, E. (2010). *Role play: Gaining access and building trust in an online breast cancer support group.* Presented at the Sixth International Congress of Qualitative Inquiry, May 26-29, Champaign, IL.

Guest Lecturer, "Ethics in Online Research," MGMT5004: User Experience, School of Information Management, Dalhousie University, March 12, 2010.

Guest Lecturer, "Online Privacy and Security," INFO202: Social Aspects of Information Systems, Graduate School of Library and Information Science, University of Illinois, March 4, 2010, & April 20, 2009.

Rubenstein, E. (2010). *Researcher subjects: Gaining access and building trust in an online breast cancer support group.* Poster session presented at the iConference, February 3-6, Champaign, IL.

Rubenstein, E. (2009). *Dimensions of information exchange in an online breast cancer support group.* Poster session presented at the annual meeting of the American Society for Information Science & Technology, November 6-11, Vancouver, BC.

Rubenstein, E. (2009). *Dimensions of information exchange and health literacy in an online breast cancer support group.* Presented at the annual conference of the Association of Internet Researchers (AoIR 10), October 7-10, Milwaukee, WI.

Panel Chair, Online Social Support, Information, and Health Communication Session at International Communication Association, May 20-25, 2009, Chicago, IL.

Rubenstein, E. (2009). *Acquiring health literacy through participation in an online breast cancer support group.* Presented at the Ohio State University Expanding Literacy Conference, April 3-5, Columbus, OH.

Rubenstein, E. (2009). *Multidimensional facets of information exchange among members of an online breast cancer support group.* Work-in-Progress poster session at the annual meeting of the Association for Library and Information Science Education, January 20-23, Denver, CO.

Rubenstein, E. (2008). *The intersection of information behavior and coping among women undergoing breast lump diagnosis.* Poster session presented at the annual meeting of the American Society for Information Science and Technology, October 24-29, Columbus, OH.

Rubenstein, E. (2008). *Coping, communication, and information behavior among women undergoing breast lump diagnosis.* Presented at the Kentucky Conference on Health Communication, April 17-19, Lexington, KY.

Rubenstein, E. (2007). *Online breast cancer support groups: Interweaving folklore, learning and community.* Presented at the American Folklore Society Annual Meeting, October 17-21, 2007, Quebec City, Quebec.

Rubenstein, E. (2007). *The Monroe County Public Library: Its place in the community.* Presented at the School of Library and Information Science, Indiana University, as recipient of Beta Phi Mu Award and Scholarship, Bloomington, IN.

Research Work Experience

COPY EDITOR, *LIBRARY TRENDS*   Jan. 2010 – June 2010
Graduate School of Library and Information Science, University of Illinois

RESEARCH ASSISTANT TO PROFESSOR TERRY WEECH   May – July 2010
Graduate School of Library and Information Science, University of Illinois
Project: Research and writing related to paper about volunteers, librarianship, and digital libraries

RESEARCH ASSISTANT – DATA CURATION EDUCATION PROGRAM   Aug. 2007 – July 2008
Graduate School of Library and Information Science, University of Illinois
Projects: Interviewing research subjects, Grant preparation

RESEARCH ASSISTANT – LIBRARY RESEARCH CENTER   Jan. 2007 – July 2007
Graduate School of Library and Information Science, University of Illinois
Projects: Interviewing research subjects, Analysis of data

SCHOLARSHIPS AND HONORS

Eugene Garfield Doctoral Dissertation Fellowship (Beta Phi Mu), June 2010
Certificate of Merit, ASIS&T SIG-USE Poster Competition, November 2009
Teachers Ranked as Excellent List, University of Illinois, May 2009
Beta Phi Mu (Indiana University Chapter) Award and Scholarship, April 2007
ASIS&T SIG-USE PhD Student Conference Travel Award, November 2006
ALA-SC Scholarship to ALA Annual Conference, Spring 2005
Lois Eleanor Kidwell Scholarship, Indiana University, Fall, 2005

TEACHING EXPERIENCE

INFORMATION USERS IN THE KNOWLEDGE SOCIETY   Spring 2012
School of Library and Information Studies, University of Oklahoma

DIGITAL INFORMATION ETHICS   Spring 2012
School of Library and Information Studies, University of Oklahoma

ACQUIRING KNOWLEDGE IN THE DIGITAL AGE   Fall 2011
School of Library and Information Studies, University of Oklahoma

LIBRARIES, INFORMATION & SOCIETY   Spring 2011
Graduate School of Library and Information Science, University of Illinois

ETHICS IN CYBERSPACE   Spring 2009; Fall 2010
Graduate School of Library and Information Science, University of Illinois

INFORMATION ORGANIZATION AND ACCESS   Fall 2006; Fall 2008
Graduate School of Library and Information Science, University of Illinois

SERVICE

Undergraduate Studies Committee, School of Library and Information Studies, University of Oklahoma	2011-2012
Admissions Committee, School of Library and Information Studies, University of Oklahoma	2011-2012
Program Committee for American Society for Information Science &Technology, Information Use Track	2010
Reviewer, Library Student Journal	2009-2010
Reviewer, HICSS (Hawaiian International Conference on System Sciences) Mini-Track, Social Networking & Communities	2009, 2011
Ph.D. Student Representative to the Curriculum Committee	2009-2010
Ph.D. Student Representative to the Faculty	2008-2009
Ph.D. Student Representative to the Doctoral Studies Committee	2007-2008
Doctoral Research Showcase Committee	2008-2010
Organizer of New Ph.D. Student Orientation	2007-2009

MEMBERSHIPS

American Society for Information Science & Technology
American Library Association
Association of Library and Information Science Educators
Association of Internet Researchers
Medical Library Association

PROFESSIONAL DEVELOPMENT

Tenure Workshop, University of Oklahoma	February 2012
Journal Writing Workshop, University of Oklahoma	Spring 2012
New faculty seminars, University of Oklahoma	Fall 2011
Faculty writing group, University of Oklahoma	Fall 2011-Spring 2012

NON-ACADEMIC WORK EXPERIENCE

Library Experience

REFERENCE ASSISTANT	Sept. 2005 – May 2006

Business/School of Public Affairs and Environment Library
Indiana University-Bloomington

ARCHIVES INTERN	July - Aug. 2005

Montreal Jewish Public Library

ALA CONFERENCE INTERN/PRESS ASSOCIATE	June 2005

American Libraries Association Annual Conference, Chicago

LIBRARY ASSISTANT II	Sept. 2004 – May 2005

Technical Services, Indiana University