“Things My Doctor Never Told Me”: Bridging Information Gaps in an Online Community

Ellen L. Rubenstein
University of Oklahoma
School of Library and Information Studies
Room 120, Bizzell Library; 401 W. Brooks
Norman, OK 73019-6032
erubenstein@ou.edu

ABSTRACT
In a medical climate where doctors are usually pressed for time, patients commonly leave their appointments feeling confused, unable to recall what was discussed, or simply missing information. These communication difficulties result in gaps in patients’ knowledge about their conditions and their potential treatments. One response to this problem has been that patients join online health communities as a way to access more information and obtain social support. Research shows that participating in these communities has important benefits, including decreased depression, better ability to cope, and increased social networks that can aid in accessing needed information. However, little research addresses the specific information gaps patients experience, how they fill these gaps through online communication, and how online health information behavior interacts with medical decisions and patient-provider communication. Drawing on data from 31 semi-structured, in-depth interviews, participant observation, and online archives analysis, this paper examines the health information interactions that participants in an online breast cancer community experienced as they progressed through breast cancer and survivorship. The findings reveal an extensive array of information that, from the patients’ perspectives, was either not communicated or was inadequately communicated during patient-provider interactions. This research highlights patients’ perceptions of information gaps, how patients navigated through their information gaps with the help of the community, and the significance of peer interaction in the comprehension of medical information and medical decision-making.

INTRODUCTION
Receiving a diagnosis of breast cancer is a frightening experience for everyone involved. Those diagnosed immediately face multiple treatment options, prognoses, and future life choices. Patients 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 (Radin, 2006; Sales, Schulz, & Biegel, 1992). 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, Koczwar, & Wade, 2008; Gustafson et al., 2001; Shaw et al., 2006).

The American Cancer Society (2012) predicts the diagnosis of 226,870 new cases of invasive breast cancer in 2012, with an additional 63,330 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 (American Cancer Society, 2009). 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). However, despite its prevalence and visibility, patients often feel isolated and lonely—close relationships often become strained due to fear and reluctance to engage in conversations about outcome possibilities, and breast cancer brings questions that friends and family might not be able to answer (Fogel, Albert, Schnabel, Ditkoff, & Neugut, 2002; Shaw, McTavish, Hawkins, Gustafson, & Pingree, 2000). Even long after treatment, survivors continue to face ongoing concerns, necessitating access to information and social support (Allen, Savadatti, & Levy, 2009; American Cancer Society, 2009).
concerns, and by two years are more related to family members’ risk of disease (Rees & Bath, 2000).

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 (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 (Fogel et al., 2002; 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.

**Patient-Provider Communication**

Interactions with medical providers often comprise multiple challenges for patients. Souden and Durrance (2011) note the disconnect encountered between patients’ “lived experience[s]” (p. 2) and providers’ seemingly objective and “top-down” (p. 9) communication with their patients. 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). Furthermore, many physicians do not necessarily know how to talk to patients, offering information that is not well matched patient needs (Duggan, 2006; Souden, 2008; Williams et al., 2002).

Patients often feel uncomfortable asking too many questions or, alternatively, do not know what to ask, resulting in information deficits about myriad topics including treatments, side effects, genetics, and spread of the disease (Beaver, Twomey, Witham, Foy, & Luker, 2006; Mournjid et al., 2009). Medical information takes time to process and patients are unsure how to respond at the time they are receiving it.

Breast cancer patients’ information needs often exceed what is offered by their physicians, and many patients report being unsatisfied with the extent and level of information they receive (Mournjid et al., 2009; Rees & Bath, 2000). Even years post-diagnosis and treatment, many breast cancer patients still have questions that they are reluctant to ask their medical providers (Vogel, Bengel, & Helmes, 2008).

Although in recent years patient-provider interactions have been evolving from a transmission culture to a more collaborative one (Anderson, Rainey, & Eysenbach, 2003) this brings an environment where patients must assume more responsibility than ever for their own care. In this context, patient-provider communication is even important in order for patients to contribute to their own care. Communication difficulties leave gaps in patients’ knowledge about their conditions and how to proceed. Without adequate information, patients find it difficult to make treatment decisions or to know what they should expect when they are undergoing certain procedures.

**BACKGROUND**

**Breast Cancer Patients’ Information Needs**

Breast cancer patients experience information needs that are complex and variable. They include 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. Patients seek information about physicians, the disease, how to combat fear and uncertainty, and how to prepare for the future (Mournjid 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 (O’Leary, Estabrooks, Olson, & Cumming, 2007; Talosig-Garcia & Davis, 2005). Patients’ needs vary widely and are dependent both on individual preferences and personal styles as well as the stage and progression of the disease (Rees & Bath, 2001; Williamson, 2005). 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 (Rees & Bath, 2000).

Research has shown that participation in online health communities helps patients cope with their illnesses in important ways including reducing depression and stress, combating loneliness, and having access to extended social networks that offer information not available from face-to-face relationships (Gustafson et al., 2001; Höybye et al., 2005; Lieberman et al., 2003; Winzelberg et al., 2003). However, despite the many benefits of online social support that previous studies have identified, there is little research that addresses the specific information gaps patients experience, how patients fill these gaps through online communication, and how online health information behavior interacts with medical decisions and patient-provider communication. To better understand the ways that online participation impacts individuals’ ability to navigate illness, this paper, which is part of a larger study (Rubenstein, 2011), examined participants’ use of an online breast cancer community, particularly focusing on participants’ perceptions of their medical encounters with their physicians as well as the ways in which the community contributed to their understanding of medical information, their interactions with healthcare providers, and their subsequent treatment decisions.

2002; Williams, Davis, Parker, & Weiss, 2002). These communication difficulties result in patients having to deal with information gaps about breast cancer and how to address them. Because of the complexities in treating breast cancer, treatment options are not clear-cut, leaving patients unsure about how to proceed. One way that patients respond to this problem is to engage with online breast cancer groups, where they can access breast cancer information and obtain social support from others who have had similar experiences (Lieberman & Goldstein, 2005).
Sharing Health Experiences Online

According to a Pew Internet and American Life Project report on peer-to-peer health care, 18% of all Internet users and 23% of Internet users with chronic health conditions such as cancer, lung and heart conditions, diabetes, and high blood pressure have sought health information from peers online (Fox, 2011). Studies describing why patients seek health information on the Internet cite several reasons: 1) unhappiness in regard to the information they received from their health providers; 2) concern that they may not have obtained complete information; and 3) to understand better the information they did receive (Boyer, Provost, & Baujard, 2002; Chen & Siu, 2001; Jenkins, Fallowfield, & Saul, 2001; McMullan, 2006).

Online communities offer opportunities for people to transcend geography and access others with similar conditions, promoting interactions that socialize patients into the discourse and language of particular health issues while at the same time fostering a positive environment where individuals can develop trusting relationships (Kraut et al., 2002; Preece, 1999; Orgad, 2005). Participants are able to enhance their understanding of their health issues by reading about others’ experiences and by writing about their own experiences with the prospect of receiving support and information from knowledgeable peers (Lieberman & Goldstein, 2006; Maloney-Krichmar & Preece, 2005; Shaw et al., 2000). Patient-to-patient interactions offer perspectives and information from personal experiences, which both fills gaps left by patient-provider communication, and expands on the knowledge patients have acquired (Hartzler & Pratt, 2011; Neal & McKenzie, 2011; Veinot, 2010).

Study Context

This study examined the interactions of participants in an online breast cancer community, which, to preserve anonymity, I have designated as “the List.” I chose the List after reviewing the archives of several breast cancer forums because, unlike other groups that consisted of questions and answers separated by topic (e.g., “Just Diagnosed,” or “Chemo”), List postings comprised interwoven conversations encompassing both breast cancer issues and everyday life events. This integration of multiple topics provided rich layers of communicative discourse that indicated the formation of a community and merited further investigation (Rubenstein, 2009, 2011).

The goals of this study were to obtain insight into the ways that the List functions to provide information, social support, and community to people dealing with breast cancer (Rubenstein, 2011). Several areas of interest included the information behavior of participants, how participation influenced health decisions and practices, why participants sought online help for breast cancer, and what kinds of meaning the group had for its participants. This paper focuses specifically on the ways that the online information interactions enacted among participants informed and influenced their medical treatment decisions.

In existence since 1994, the List is an unmoderated, English-language forum that 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 archive, which can be accessed through the website. Although the List primarily comprises female breast cancer patients and survivors, others who participate include men with breast cancer, spouses and other family members, and researchers. The archive is freely available on the Internet, making it possible for non-subscribers to lurk and gain benefit by reading messages. However, if someone wants to post a message, she needs to subscribe. During the time of this study, there were between 120-130 subscribers, most of whom were based in the United States, although members also reside in other countries including Canada, the U.K., The Netherlands, South Africa, and Australia.

Participants on the List exchanged a wide range of information. In addition to posts specifically about breast cancer, participants discussed other health problems, as well as non-health related topics such as social events, news stories, pets, and family news (Rubenstein, 2009). The number of postings ranged from approximately 500-1200 per month, with between 65-85 participants posting in a given month. According to Google Analytics, a program designed to track website visits, the List also drew approximately 200 visitors per month to its web-based archives.

Research Design and Methods

Using an ethnographic approach, I used archives analysis, participant-observation, and conducted 31 interviews over a period of two years, much of which occurred concurrently and iteratively through theoretical sampling (Corbin & Strauss, 2008).

Archives analysis

The online archives were an essential resource in framing this research in that they provided background information as well as up-to-the-minute information on conversations among members of the community. Reading the archives occurred concurrently with participant-observation and interviewing, and continued throughout the duration of the study. Three months of the archives were coded to generate emerging themes and concepts (Charmaz, 2006; Corbin & Strauss, 2008), which informed the formulation of interview questions and selection of interviewees.

Participant-observation

When I began the participant-observation process, I identified myself to group members, explained my research, and asked them if it would be possible for me to participate. I spent several weeks answering questions publicly through the forum and privately through email. Although there were a few participants who expressed discomfort at my being there and others who were not sure how they felt, after interacting with them during the first few weeks, a level of acceptance evolved.
Membership in the forum is not static—although there is a core of participants, there are also newcomers who were not aware of my research. Because of this, I posted a monthly message to remind current participants of my research as well as to apprise newcomers of it, signed with my full contact information. In addition to my online participation, I met some participants at an annual meeting that the group holds each fall, which contributed further to their understanding of my work, and my understanding of their community.

My online participation comprised interacting with participants on a daily basis, reading each day’s postings and contributing my own comments, suggestions, and words of support. My daily monitoring of conversations and participation made it possible to experience unfolding events as they occurred. Each day I wrote field notes and memos to record the experiences, coding them based on the emerging themes generated through analysis of the archives, as well as generating additional themes (Corbin & Strauss, 2008; Emerson, Fretz & Shaw, 1995).

**Interviews**

I conducted 31 semi-structured, open-ended interviews lasting from 30 to 90 minutes. Interview respondents were selected based on themes that emerged through archives analysis and participant-observation, as well as through the interviews themselves. Thirty of the interviews were done by phone, and one was done face-to-face. I electronically recorded 30 interviews; one person did not wish to be recorded and I took notes while we spoke.

My interview guides consisted of a number of questions I wished to ask informants—for example, I asked all participants to describe their experiences with breast cancer and with the List—but the progress of each interview proceeded based on where the conversation went. Most of the interviews started out exactly the same, but due to their open-ended nature, they did not always follow the same path.

I transcribed and coded the interviews using initial coding that comprised analysis of the data as individual sentences, paragraphs, and larger segments, using *in vivo* coding when possible, (Charmaz, 2006; Corbin & Strauss, 2008). As concepts emerged, I began focused coding, synthesizing the initial codes into recurring theoretical themes. 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.

Interview respondents’ ages were between late 40s and mid-70s, a typical range for breast cancer patients and survivors. Thirty were female; one was male. One respondent was African-American. The length of time of participation in the group ranged from a few months to 14 years. Interviewees were mostly college educated, with over half having obtained an advanced degree. One interviewee had not pursued higher education after high school and five had “some college.” Two participants identified themselves as housewives; one was unemployed, and 10 were retired or on disability. Overall this group comprised individuals who knew how to use computers and the Internet, and how to use them to access information. Most respondents were well spoken and able to express their experiences with breast cancer and the group in a thoughtful manner.

**FINDINGS**

In this paper I examine how participation in an online breast cancer community interacted with patients’ understanding of medical information, patients’ medical decision-making, and patient-provider communication. Within this context, the List proved to be a significant resource where participants obtained new information from other patients and survivors that affected their information interactions with their providers as well as the course of their treatment. Being a member of the List meant that not only were participants able to obtain and provide support to each other, but that in sharing experiential information, they were able to make sense of their medical concerns and more easily discuss information with their healthcare providers, ultimately taking charge of the course of their treatment.

**Making Sense of Medical Concerns**

Participants often described their initial contact with the List as being steeped in information gaps, uncertainty, and confusion. While some participants found the List soon after diagnosis and others further into their treatment, all reported a need to understand their illness and treatment better. Despite having had discussions with their physicians, there was a compelling desire to communicate with others who were undergoing similar experiences. Participants cited several reasons why they sought online interaction. Some noted that they did not know anyone in their face-to-face environments who had had breast cancer. Others stated that although their family members and friends tried to be helpful, they needed something more. Participants also talked about dissatisfaction with face-to-face support groups, due to either scheduling or health issues, or simply not feeling helped by them. In addition, there was a need to have people to talk to who could help participants interpret their medical experiences in ways that their providers had not.

Participants also noted that each stage of breast cancer treatment brought new questions about procedures, side effects, and recovery. After treatment, many continued their association with the List to be able to discuss post-treatment life with other survivors as well as having support “just in case” there were recurrences. Participants who remained on the List did so because of strong emotional attachments to List members who had helped them through difficult times as well as a commitment to help new breast cancer patients.

**Communication issues with providers**

Although many study participants indicated that their perceptions of their physicians were generally positive,
They also recounted a variety of scenarios where their interactions were unsatisfactory, leaving them overwhelmed, confused, or distressed. Initial difficulties in comprehending information from providers occurred due to the newness of the diagnosis as well as unfamiliarity with technical medical information, often exacerbated by little time with providers:

*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.*

Participants recognized that the time set aside for a typical medical appointment was inadequate for conveying highly specialized information; however, despite this recognition, not receiving enough information was difficult to contend with. Lack of information was a common complaint among List participants.

Even when participants were further into their treatment, they often felt that their doctors did not give them enough information to make informed decisions. There frequently appeared to be mismatches between patients’ needs and expectations and what their providers were telling them, leaving participants with an incomplete picture. For example,

*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...[but] he just basically focuses on what’s happening right now with me. So I don’t get much information from him.*

Participants also recounted becoming aware of information they had not received from their physicians and wished they would have. For example, one interviewee stated that she would have liked to participate in a support group, but her physician never mentioned the possibility. She had not asked about support groups because it had not occurred to her, but in retrospect she was sorry she had not known that they were an option. Others indicated that they did not receive complete information about adjuvant therapy options (e.g., chemotherapy or drug options) and several noted that they hadn’t been informed about the full spectrum of breast reconstruction options:

*They never tell you things about...what kind of reconstruction you can have, what’s available...*

Among participants, there was an expectation that providers should offer comprehensive information, and many felt their providers were falling short, leaving it to them to find their own information.

**Use of List resources**

Engaging with the List offered participants a way to supplement the information they were receiving from providers. Participants often compared the information their physicians told them, treatments they were undergoing, decisions others had made, and even differences in radiation facilities. In many cases, participants also discussed medical articles, both scholarly and popular, that provided evidence for information they were sharing. Interacting with other patients helped with coping as well as the ability to attend to the practical aspects of navigating a serious illness.

Participants made sense of their experiences through both purposeful information seeking and information encountering. Purposeful information seeking consisted of participants “trying to figure out what to do,” or trying to understand information they obtained from providers. They were aware of information gaps that prompted them to request information from others on the List or to read the archives. In bridging these information gaps participants engaged the List for both clarification and confirmation of information.

**Clarification of information** occurred when a participant had been to see her provider but needed better explanations or expansion of the information she had been given. Often questions came up after an appointment was over, making it inconvenient to pursue clarification by contacting a provider’s office. Usually a participant had basic information, but needed more to make sense of it. For example, one woman described bringing her pathology report to the List for explanation:

*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.*

In this instance the participant had not understood the medical terminology and brought it to the List for an explanation. Since most List members had had to decipher their own pathology reports at some point, they were able to help her interpret it. In other cases, participants stated that they had obtained additional information from the List regarding recommended anti-nausea medication, or explanations of various side effects for different chemotherapy “cocktails.”

**Confirmation of information** comprised hearing information from providers and tapping List resources to see if they agreed with the information or considered it reasonable. In this scenario, participants needed to hear about their peers’ experiences to feel assured that the information they had was complete. According to one woman,

*[The List] confirmed that what was going on was okay and that I didn’t have to worry about, “Oh, is there some other treatment for this? Is there some other, you know, prescription you could get for mouth sores...that I’m not getting?” So it was more like confirming what was happening to me....*
clarification, it might mean everything was fine, or it might instead spur more anxiety and a need for more information and discussion with providers.

Information encountering occurred when participants found unsought information while browsing the archives or participating in discussions. In these instances there was no awareness of a particular information need, but finding information subsequently prompted purposeful information seeking or discussion.

[M]y doctors had never said anything to me about lymphedema [arm swelling]. There was never one word ...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 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!

Lymphedema, a swelling of the arm, occurs when lymph nodes have been removed during surgery or as a result of radiation. Through this participant’s monitoring of List discussions, she discovered that she had a condition that she had not known existed. Learning about lymphedema gave her both clarification about what was occurring as well as confirmation that the swelling she was experiencing was real and treatable. This participant 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.

Both active and passive information behavior were interwoven in participants’ engagement with the List. Asking questions and purposefully seeking information in the archives signified conscious efforts to quell fears, anxieties, and desire to understand, but unexpectedly learning about procedures or conditions garnered as much benefit as intentional information seeking. In both situations, List participants were able to obtain information that would serve them well as they interacted further with medical professionals.

Bringing Information to Providers

Participating on the List contributed to a variety of interactions with providers. Whether participants were unsure of how to proceed with their care or unhappy with care, having other breast cancer patients’ experiential knowledge stimulated them to approach their medical care more collaboratively with providers. Typically participants engaged in back-and-forth movement between doctors and the List; for example, acquiring information from the List, bringing it to physicians, then vetting physician responses with the List in multiple repetitions until participants were satisfied with the results.

Information gathering from the List served to generate new knowledge that spurred participants to have conversations with providers about issues they would not have discussed without exposure to the List. Participants used List information in several ways, including building confidence, confronting physicians, and questioning and influencing treatment.

Building confidence

Building confidence was a cumulative process. As individuals participated in List discussions, they learned to understand medical terminology and how to approach doctors. List members offered each other encouragement and validation in addressing fears, questions, and treatments, resulting in the ability to approach providers with assurance:

I found it empowering, and I could use the same techniques I learned on the List...how you speak to doctors and how you present yourself.

Having contact with List members gave this participant the opportunity to meet others with similar experiences and become confident in her ability to use the language of breast cancer. For List participants, building confidence was a gateway to better communication and collaboration with providers, often resulting in more satisfaction with treatment.

Confronting physicians

Confrontations were based on frustration stemming from unexplained symptoms or side effects for which participants had no frame of reference, not even realizing that they were related to breast cancer. Participants noted many occasions where they learned new information from the List that their physicians had not provided them. One participant recounted feeling anger at her physician and urging him to make sure that other patients learned about the potential of 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 this example the participant was able to obtain appropriate treatment for her condition, as well as voice her opinions about this lapse, paving the way for future patients to obtain more comprehensive information than she had.

Questioning and influencing treatment

Participants described a range of information obtained from the List that caused them to question the treatment they were currently getting. Obtaining multiple perspectives on breast cancer and its treatment spurred participants to approach providers for discussion of current treatment and other options. Participants described a range of information they brought to their providers because of the List, including questions about vitamins, altering medications, chemotherapy percentages, and breast reconstruction procedures.
In bringing new information to their physicians, participants also influenced the course of their treatment:

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] explained...the pros and cons....So I went [to the oncologist] and we discussed it [and] we decided to just do a test drive to start....

When this participant learned about a different course of treatment, she asked the List for clarification, learning enough to be able to then approach her physicians, resulting in a change of treatment. Through participation on the List, she was able to access tools that allowed her to engage more fully with her doctors.

The conversations that occurred on the List opened participants up to the experiences of others who had lived through similar circumstances, and offered them information that was lacking in their interactions with physicians. Participants noted that the List was a “trusted source” of information, and because of their experiences with the List, they were able to channel questions, confusion, and frustration into positive action that benefited their own treatment as well paving the way for other patients.

**DISCUSSION and IMPLICATIONS**

This research presents several significant findings about how participation in a particular online breast cancer community contributed to provider interactions and healthcare decisions. Being part of the List was crucial to participants’ ability to make sense of their illness by obtaining the experiential knowledge of other breast cancer patients. In doing so, participants used the List to acquire information that helped them understand breast cancer, as well as using it to question, augment, and appraise the health information they were receiving from providers.

One of the main findings of this research was that participants’ often felt that they were not getting the information they needed from their providers. In a highly charged atmosphere of dealing with a major illness, it can be difficult to process the information one is receiving from physicians. It is possible that in some cases, physicians were relaying appropriate information but that the patients did not hear it or understand it, resulting in perceptions of information gaps. However, even so, there are well-documented discussions of lapses in patient-provider communication for many reasons, including mismatches of language and physician disconnects from patients’ actual experiences (Duggan, 2006; Souden & Durrance, 2011). Patients are generally not experts in medicine and find health information to be confusing, putting them in the position of not knowing what questions to ask. In addition, patients are reluctant to ask their providers for information because they do not wish to inconvenience them, they do not want to sound “stupid,” or because waiting for callbacks produces anxiety. Being able to access a forum like the List, comprised of peers who have had similar experiences, gives participants 24-hour access to others who can help with questions and ease concerns.

Online communities offer alternative authority to that of traditional medical providers, giving voice and validity to patient expertise (Neal & McKenzie, 2011). Accessing peers as information sources in the process of navigating illness offers opportunities to assess one’s situation in relation to other patients (Veinot, 2010) and to use that information to make decisions with greater clarity than acting upon provider information alone. For example, lab reports are generally incomprehensible to laypeople, and upon receiving one, a patient might seek out someone else who could shed light on the language. In this study, that “someone else” was the List – a group of patients who were currently undergoing breast cancer or who had done so in the past.

List participants viewed their information exchanges differently from those with their providers due to the forum’s supportive environment, which resulted in participants feeling cared for by others. List interactions exhibited several social support conceptualizations including emotional support (caring, concern, empathy and reassurance of worth), informational support (information, advice, and new perspectives), and perceived support (belief that support is available) (Goldsmith, 2004; Lin 1986). The interactive nature of these various support elements interwoven within the online communication offered an ongoing flow of information not available between patients and physicians. Being able to connect with sympathetic individuals while coping with illness and other everyday life challenges formed the foundation for List interaction, and provided supportive information experiences that contrasted with the more clinical medical exchanges participants had with their providers.

This study extends other research about online health communities in that it highlights the disconnects between the information that physicians provide and what patients would like to know. It brings attention to the information gaps that patients commonly experience as they go through breast cancer. Most striking was the use of peer information not only to understand breast cancer, but as an impetus to approach doctors and influence treatment. As participants moved between List members and providers, their information behavior was consistent with research focusing on gap bridging (Dervin 1982, 2003), information encountering (Erdelez, 1999), and network-mediated information (Veinot, 2009). Participants engaged with their network members as a way to make sense of their illness and address their uncertainty, at times purposefully seeking to bridge gaps; at other times acquiring information unexpectedly. Regardless of how participants acquired information, they utilized it to improve their experiences,
bring information to their providers, and to effect changes in treatment.

Understanding more about patient-patient information exchange and how it impacts healthcare decisions is an area that needs more study. From this research it is clear that peer input played a significant role in participants’ experiences of their illness, treatment, and interactions with providers. For patients, having the ability to exchange information with other patients allows them to take charge of their healthcare as well as to cope better.

Information research has consistently shown that people prefer to obtain information from other people, typically informal sources (Case, 2007; Savolainen, 2008). Although providers may feel ill-equipped to deal with peer information obtained by patients, people will continue to seek information from others. In a traditionally top-down, expertise-driven field such as healthcare, clinicians need to have a framework for anticipating and responding to this productively and collaboratively.

CONCLUSION

Through this research I sought to understand how participating in an online breast cancer community interacted with health care information access, healthcare decisions, and patient-provider communication. The findings showed that being part of this community made a difference for participants in how they made sense of their illness and how they proceeded with their treatment. This research showed that there were multiple information disconnects between patient expectations and what providers offered them. List participants primarily noted that the amount of information they received from providers was inadequate both in amount and in clarity. As participants navigated their way through breast cancer with the help of other patients, they were able to fill in their information gaps, obtain a better understanding of their medical concerns, and though this, build the confidence they needed to address their physicians and optimize their treatment strategies.

LIMITATIONS AND FUTURE RESEARCH

This paper focused on the perspectives of breast cancer patients and how their participation in a particular online forum influenced and interacted with patient-provider communication, medical decisions, and their understanding of medical information. This research is limited in that it provides information only about one group, and also only from patients’ perceptions. Future research should investigate other online health communities as well as other health conditions to obtain a wider understanding of how patient-patient information sharing impacts their communication with physicians as well as health decision-making. In addition, research should be done that examines provider perspectives on both patient-provider communication as well as provider assessments of online patient communities.

ACKNOWLEDGMENTS

I thank Dr. Maria Souden of the School of Information & Library Studies at University College Dublin for her feedback on this paper.

REFERENCES


