

INFORMATION-PROCESSING, SUPPORT AND COPING: BREAST CANCER  
PATIENTS AND THEIR EXPERIENCES WITH A MENTOR AND CHESS

by  
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A Thesis submitted in Partial Fulfillment of the requirements for The Master of Science  
in Communication Degree

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THE UNIVERSITY OF WISCONSIN-WHITEWATER  
August 6, 2012

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## Acknowledgements

This thesis would not have been possible without the assistance of many individuals who provided support for the completion of this research. I would like to thank the following:

Dr. Edward Frederick, for serving as the chair of my thesis committee and exhibiting outstanding leadership;

Dr. Ray Baus and Dr. Mary K. Casey for being on my committee and sharing their knowledge throughout the entire process;

The faculty in the Communication Department at the University of Wisconsin-Whitewater for teaching the graduate-level courses necessary to prepare me for writing a Master's thesis and understanding in-depth concepts of communication;

Dr. Robert P. Hawkins, Fiona McTavish and the rest of the faculty and researchers at the Center for Health Enhancement Systems Studies (CHESS), for conducting research and allowing me to utilize their resources for the purpose of this study;

Finally, my family, for supporting me as I worked toward receiving my Master's degree, and especially my mother, whose breast cancer survival reiterated to me the importance of conducting research such as this thesis.

## Table of Contents

Title Page	i
Acknowledgements	iii
Table of Contents	iv
Abstract	v
Introduction	1
Literature Review	2
Research Questions	31
Method	36
Results	43
Discussion	90
Implications of Findings	105
Bibliography	112

Abstract of Thesis

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Communication (Corporate Emphasis)

Information-Processing, Support and Coping: Breast Cancer Patients and Their  
Experiences with a Mentor and CHES

August 6, 2012

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## Information-Processing, Support and Coping: Breast Cancer Patients and Their Experiences with a Mentor and CHESS

After a positive cancer diagnosis, the methods used to seek information, support, cope, and process one's illness can heavily impact one's outlook on the treatment/recovery process. Improving the quality of doctor-patient interaction and easing anxiety during treatment are two prominent goals within the medical industry. The rise of technology in healthcare has seen the development of electronic health communication sites serving as portals of information and sources of support for patients as they battle diseases.

The goal of this study was to compare information-processing behavior, recall of information, and coping techniques of breast cancer patients assigned a mentor, with that of breast cancer patients assigned to a mentor and granted access to an interactive cancer communication website known as CHESS.

This study utilized data by Hawkins et al. (2011), in which breast cancer patients were split into either a mentor-only group, or a mentor and CHESS group. Participants were recruited from three U.S. medical centers. A total of 211 women participated in the study; 106 of them were assigned to the mentor-only condition, while the remaining 105 women received a mentor and access to CHESS (Hawkins et al., 2011). The mentor had 10 scheduled calls over six months with participants in both groups. She also utilized email if it was more convenient for the women. Patients were free to write or call her as frequently (or infrequently) as they desired.

Each time the mentor emailed or called a participant, she recorded the

conversation and took notes on what was discussed. The notes were analyzed for this study; several of the key topics identified were spirituality and religiosity, coping, support, depression, information-seeking behavior and death.

The CHESS/Mentor combination provided action-facilitating and nurturing support for its users. There was no firm support for differences in coping abilities between the two groups. There was no evidence to suggest differences in information-seeking behavior by the groups. Several women in either group practiced avoidance behavior when it came to support and information-seeking techniques. Healthcare providers must take into account that patients may desire to pace themselves when receiving traumatizing information about a disease.

## **Information-Processing, Support and Coping: Breast Cancer Patients and Their Experiences with a Mentor and CHES**

The diagnosis of a serious and potentially fatal disease can be a traumatic experience for many people. Uncertainty about its outcome, as well as a lack of information about the disease itself and appropriate treatments, can turn the words, “you have cancer,” into one of the most stressful situations an individual will ever encounter. Following a positive cancer diagnosis, the methods used to seek information, support, cope, and process one’s illness can heavily impact one’s outlook on the entire treatment and recovery process.

Technology saturates many facets of life today, including education, business and commerce, and entertainment. Healthcare is no exception. Researchers are continuously analyzing how to integrate technology into the health field so that doctors and medical practitioners can provide better care and support to patients. Improving the quality of doctor-patient interaction and easing the anxiety during treatment are two of the prominent goals when it comes to changes in the medical industry. The rise of technology in healthcare has seen the development of electronic health communication sites designed to serve as portals of information and sources of support for patients as they battle various illnesses and diseases, such as cancer.

The goal of this study was to compare information-processing behavior, recall of information, and coping techniques of breast cancer patients assigned a mentor they could contact over the course of six months, with that of breast cancer patients assigned

to a mentor and granted access to an electronic health communication website known as CHESS.

## **Literature Review**

### **Interactive Cancer Communication Systems**

The rise of the Internet as a portal of data and information has allowed healthcare to be provided in an online manner. This has led to the rise of interactive cancer communication services (ICCSs). ICCSs are programs defined as “computer-based, usually Web-based, providing information about cancer and its treatment, and also other services such as social support services, decision-making support, and/or behavior change or emotional coping support” (Baker, Hawkins, Pingree, Roberts, McDowell, Shaw, Serlin, Dillenburg, Swoboda, Han, Stewart, Carmack-Taylor, Salner, Schlam, McTavish, and Gustafson, 2011, p. 134). One study found that 42-49% of breast cancer patients had utilized an online cancer communication system (Bash, Thaler, Shi, Yakren, & Schrag, 2004). Research indicates that people with cancer frequently seek information and that this trend continues over a long period of time (Hesse, Arora, Burke, Beckjord, & Finney Rutten, 2008). Consistent with this data, 49% of breast cancer patients participating in a different study sought information and support via the Internet, with 40% of these women using these services for as long as 16 months (Sattlerland, McCaul, & Sandgren, 2003).

Han, Wise, Kim, Pingree, Hawkins, Pingree, McTavish, and Gustafson (2010) argued that when equipped with mere Internet access, the computer is a passive participant in the communication of information between the patient and the health care system. The computer is user-driven and he or she determines the direction of the

information search. There is no coaching, guidance, or direction from the computer. This could be problematic if the user is overwhelmed by a potentially fatal diagnosis or does not know how to even begin the task of researching a health condition. In contrast, ICCSs allow the computer to play a more active role alongside the user in which it “makes suggestions, offers feedback, identifies deficits, and may encourage the user’s behavior” (p. 371). Thus, the computer becomes a sort of teacher for the user, helping weave through the amount of information and finding the most useful data based on the individual’s needs.

Strecher (2007) suggested that electronic health communication modules (eHealth) could improve patient outcomes several different ways. These modules could function as a library, providing easy access to a large amount of information. Furthermore, eHealth may serve as a channel for communication and support by linking people together (i.e., online discussion boards between users). Lastly, eHealth would be an interactive coach to users, providing feedback to individuals based on analysis of their past search history or data input, giving a person prompts that fit his or her characteristics or problems.

Mair and Kierans (2007) assessed the effectiveness of an information and communication technology program called Mihealth, a service offered to breast cancer patients out of the Royal Liverpool Hospital. Patients who acquired information used it in a variety of ways (e.g., sharing it with family members, sharing it with doctors, or even choosing to ignore some of the knowledge altogether). Using the Mihealth program, users individualized their searches; they could broaden or narrow the scope of the text in t

the search engines to tailor the data retrieved in any way they desired. The electronic health site was a valuable tool for breast cancer patients because it gave them an opportunity to develop their information-seeking processes to suit personal taste, and gave them control in how they managed any information acquired. Furthermore, the researchers noted that breast cancer patients tended to tailor their methods of information-seeking to match that of the Mihealth system. Information that participants could not print, transcribe, or record using an audio device was typically regarded as useless. The need to preserve the information in a written or recorded manner illustrates patients' desire to keep the information they initially read or hear for future use after they have processed and begun coping with their stressful diagnosis.

### **Information-Seeking Behavior**

One of the first topics a patient diagnosed with a serious illness may find himself or herself seeking is information about the disease. Understanding the trauma, treatment options, symptoms, side effects, etc. gives the patient a sense of control and may make recovery seem less daunting, whether information is obtained from a mentor or through computer assistance.

Buunk, Gibbons, and Visser (2002) noted that patients cope with uncertainty by looking to and reaching out to others in similar situations or predicaments. This allows patients to learn and gain clues as to how to act, feel, behave, or think. For example, a newly diagnosed cancer patient may learn to cope with terrible news by finding others who have been newly diagnosed as well, or possibly just other cancer patients in the area

that might have some knowledge and insight into how to handle a positive cancer diagnosis.

Geller, Zapka, Hofvind, Scharpantgen, Giordano, Ohuchi, and Ballard-Barbash, (2007) argued that the Internet provided a huge advantage to cancer patients following their diagnoses. Internet-based communication allowed patients to access information that could be updated frequently with ease. The web also gave individuals the ability to control how they formatted their searches during the information-seeking process, and ultimately allowed them to regulate the content and amount of knowledge they found. Cancer online communication technology enabled patients to look up information or even interact with other patients (depending on the program or study in which they were engaged). Geller et al. (2007) pointed out that the Internet went beyond a basic doctor's visit when it came to knowledge-seeking and communication because the web contained videos and audio pieces for individuals who were visually impaired, had lower reading skills. These forms of technology also aided patients who may have forgotten what their doctor said or what was discussed the first time they watched or listened to a clip—people could simply go back and consume the video or audio feed again (Geller et al., 2007).

Khanna (2008) analyzed how patients utilize the web to help answer questions, determine treatment options, and even shape their opinions and outlook on the process of fighting the disease. Hesse (2009) points out that a site called “Patients Like Me” poses an opportunity for individuals to share their own state of well-being (physical or mental) with others and to compare these characteristics to those of other individuals who may be

experiencing similar traits and feelings. These sites can also serve as immediate portals for information if a patient has a question or concern at a time when it is inconvenient to contact a doctor or healthcare provider. Regardless of the time of day or night, people can log onto the Internet and perhaps find an answer or tip instead of waiting several hours or days to call a clinic.

Implementing a computer-based breast cancer education tool has demonstrated utility for patients as they seek information during cancer treatments. A study found that computer-based education did not diminish the clinical encounter (Pruthi, Rausch, Hathaway, & Vickers Douglas, 2010). No statistical significance was found in patient understanding or distress between people who had access to the cyber option and people who only went to their doctor appointments. Furthermore, the computer-based education tool improved participants' breast cancer understanding and did not cause additional distress compared to their counterparts who did not have access to the computer information. Physicians reported that patients who utilized the computer-based approach had an increase in the quality and quantity of questions asked during appointments. Physicians could spend more or less time on topics during their time with the patients as necessary, improving the overall satisfaction of the doctor-patient interaction. Plus, traditional methods of information-sharing involved packets, brochures, and pages of information that were bulky and difficult to navigate through when quickly seeking information on a particular topic.

## **Mentors and Peer-Based Support Groups**

While information-seeking behavior may involve Internet research, another form of guidance and support arises in breast cancer groups such as the American Cancer Society's Reach for Recovery program (Coreil & Behal, 1999). Redfearn (2002) noted that in these groups, a newly diagnosed breast cancer patient is coupled with a cancer survivor who guides and coaches the patient, in addition to providing information and support as needed. The mentor symbolizes success and cancer survival, and is able to share personal experiences from the diagnosis, treatment, support, and reassurance for breast cancer patients suddenly placed in an unfamiliar situation; this continued contact and support is one of the major strengths of such a peer-based program (Hawkins et al., 2011). However, Hawkins et al. 2011 argued that while these mentors were knowledgeable because of their own experience with cancer diagnosis and treatment, they often lacked medical and scientific expertise consistent with that of a trained medical professional. Thus when it came to the mentor used in this study, CHESS made sure that the mentor used had worked with the Cancer Information Service and served as the expert for the Ask an Expert feature on CHESS for six years (Hawkins et al., 2011). The mentor had extensive training and knowledge of patient information needs, as well as the medical background in breast cancer information.

## **Coping**

When an individual experiences a stressful event or situation, he or she may be inclined to employ methods of coping in order to process the event and work through it. Coping is defined as an attempt to manage and overcome situations or events that

challenge, threaten, harm, or provide a loss or benefit to an individual (Lazarus, 1991).

When a stressful situation occurs, coping strategies are often sorted based on whether one chooses to face or avoid the stressor (Suls & Fletcher, 1985). Utilizing approach-oriented coping measures is often related to a decrease in cancer patients' distress (Stanton, Danoff-Burg, Cameron, Bishop, Collins, Kirk, Sworowski, & Twillman, 2000). In contrast, implementing avoidance techniques in coping has been shown to predict increased distress levels among cancer patients (Hack & Degner, 2004; Stanton, Danoff-Burg, & Huggins, 2002).

Berghuis and Stanton (2002) proposed three models of coping that serve as predictors of adjustment to stressful circumstances. The individual model notes that one's adjustment to a situation is determined by his or her coping tendencies. The second model, partner main-effects, argues that patients are influenced by their partner's coping strategies (either alone or in conjunction with their own coping methods). Finally, the patient interaction model claims that the relation between a partner's coping to adjustment varies as a function of how similar or different the partner's coping decisions are to the patient's coping strategies.

Support from a partner or spouse has demonstrated an influence on how patients cope with their disease (Bodenmann, 1997; Clark & Stephens, 1996; Coyne & Fiske, 1992; Coyne & Smith, 1991). Kraemer, Stanton, Rowland, Meyerowitz, and Gantz (2011) examined coping strategies of women with breast cancer and their male partners as it related to a change in the women's adjustment to the disease following treatment. They found that women who implemented approach-oriented coping strategies (e.g.

attempting to solve problems or understand and express emotions) showed an improvement in their depression symptoms, while men who employed avoidant coping methods was related to a decline in satisfaction for their wives. When breast cancer patients and their partners engaged in similar coping strategies, there was generally better adaptation to the disease than couples who enacted dissimilar coping methods.

Similarly, Luszczynska, Gerstorf, Boehmer, Knoll, and Schwarzer (2007) studied patient coping strategies and their relation to the amount of support provided by the patients' partners. They found that following cancer surgery, the level of support patients received from their partners varied, depending on how the patients coped with their illness and situation. It appeared better coping on the patient's part led to more support from the partner. These results are supported by earlier studies conducted by Schwarzer and Weiner (1991) and Silver, Wortman, and Crofton (1990). Patients who practiced Assimilative Coping (e.g., reframing situation in a positive light and active coping) compared to Accommodative Coping (e.g., lower levels of active coping) were more likely to process their situation (Urcuyo, Boyers, Carver, & Antoni, 2005). Luszczynska et al. (2007) also found that partners provided the most support to patients who exhibited Assimilative Coping methods and least support to those who practiced Accommodative Coping. They suggested this occurred because partners who realized their loved ones were expending considerable energy to cope were more likely to give additional support. However, when partners perceived the patients were only putting forth a small effort to cope, they did not seem to understand why, and thus did not provide extensive support or assistance, a finding also supported by Schwarzer and Weiner (1991).

## **Religiosity and Spirituality**

One way an individual may cope with an event and rationalize why it happened is by drawing on his or her religiosity or spirituality. Attending religious services, meeting with others and engaging in prayer, or meditating alone are all examples of people invoking spirituality in a time of crisis.

Spirituality can be defined as one's well-being derived from a combination of religious and existential (related to meaning or purpose in life) factors (Paloutzian & Ellison, 1982; Laubmeier, Zakowski, & Bair, 2004; Frick, Riedner, Fegg, Hoff, & Borasio, 2006). Religiosity is a subset of spirituality. Frick et al. (2004) defined religion as occupying "the borders of institutional belonging, belief systems, traditions and practical commitments" (p. 238). Religious involvement, such as how frequently one attends church, has been linked to social interaction, including lower levels of social isolation, higher social integration, and better social support (Ellison and Levin, 1998; Koenig, McCullough, & Larson, 2001; O'Brien, 1982). Furthermore, these elevated levels of social interaction and support assist in buffering stressful situations. Pargament (1997) argued that religion and spirituality help people reframe negative events so that they have meaning and even shed a positive light on them. A study by Mickley, Soeken, and Belcher (1992) showed that religiosity was linked to greater hope for survival, regardless of one's disease stage. Additionally, another study demonstrated that cancer patients who incorporated an element of spirituality or religiosity in their coping measures reported higher levels of acceptance, a more positive attitude, and elevated levels of confidence when it came to seeking support (Nairn & Merluzzi, 2003).

However, other studies found no correlation between one's religion and coping or optimism following a breast cancer diagnosis (Carver, Pozo, Harris, Noriega, Scheier, Robinson, Ketcham, Moffat, & Clark, 1993). This led to the conclusion that rather than religion or spirituality directly influencing one's optimism about cancer survival, they impact one's illusions regarding an event (Dull & Skokan, 1995). In essence, "such beliefs might engender an attitude of optimism, an experience of control, and a sense of event meaning that would in turn affect the level of stress experienced and ultimately one's physical health" (Gall, Kristjansson, Charbonneau, & Florack, 2008, p. 176). This model also acknowledges that believing in a higher power may regulate one's perception of a stressful event (Gall et al., 2008).

Religion and spirituality were categorized into five major themes: beliefs, community, transformation, coping, and practices (Alcorn, Balboni, Prigerson, Reynolds, Phelps, Wright, Block, Peteet, Kachnic, & Balboni, 2010). They argued, "the frequency by which patients spontaneously reported these themes suggests that multiple themes play a meaningful role for the majority of patients with advanced cancer (p. 586).

Schneider (2007) proposed a set of practical implications and suggestions for medical providers when it comes to spirituality and religion. First, doctors need to recognize that their patients are multi-denominational or non-denominational. Thus, it is essential for medical professionals to be open to views that may differ from their own. Furthermore, healthcare providers must be aware that their patient may have different religious views than other family members, and should be respectful of these situations. In the case of a mentor, he or she must be sensitive to the fact that patients may or may

not possess religious beliefs, which could affect how they seek information, support, or cope with their diagnoses. The same can be said for computer-assisted channels; users with or without religious beliefs may seek information or support and those in charge of the computer programs must be aware of the content they post; material should not be derogatory because patients may be seeking information regardless of whether or not they are spiritual. Computer-assisted programs and mentoring approaches aid in coping by assisting spiritual individuals in finding groups and support networks with people who share their beliefs. Not only can one's religion become a way to cope with a positive diagnosis, he or she may be among others with similar beliefs and practices, which provides additional support and methods of processing the stressful situation.

### **Social-Cognitive Theory**

The manner in which an individual responds to traumatic news, such as a positive cancer diagnosis, is not always dependent upon a single factor or circumstance. Various aspects of the environment, one's behavior, and other outside experiences all help shape how a person responds in a particular situation.

The social-cognitive theory was developed to argue that people do not simply react to environmental or personal changes, rather, they are proactive, self-regulating, self-reflecting, and self-organizing (Bandura, 1986). Thus, a social structure both produces and is a product of one's personal agency (Bandura, 2001). Bandura also argued that people's adaptations, development, and changes are entrenched in their social systems (2001). Personal determinants, behavioral determinants, and environmental determinants are all linked and are codependent in terms of how a person processes and

works through a situation.

Bandura's (2001) theory of social-cognition postulates that communications systems function through two different pathways. The first, known as the direct pathway, contains change that occurs through "informing, enabling, motivating and guiding participants" (p. 265). In contrast, the socially mediated pathway occurs when participants are linked to social networks and communities, for incentives and personalized guidance, to achieve changes (Bandura, 2001). The theory examines new behavioral styles in terms of the factors that brought about such changes in behavior and how these changes spread.

The social-cognitive theory is relevant to research about mentors and CHES because it examines how different pathways of communication and a combination of factors come together to determine how a breast cancer patient may react and behave during the treatment and recovery process.

### **Social-Cognitive Processing Model**

Encountering a stressful situation requires that a person respond and work to cognitively process the events that took place. However, the degree to which a person acknowledges and works through an event varies.

Patients address a difficult situation through cognitive processing, defined as the following:

"mental activities that help people to interpret traumatic events in personally meaningful terms, integrate threatening or confusing aspects of the experience into a coherent and nonthreatening conceptual framework, and reach a state of emotional acceptance" (Lepore & Helgeson, 1998, p. 90-91).

Talking about a traumatic experience, such as a breast cancer diagnosis, can help people

face the challenges associated with the situation and aid in psychologically processing everything that happened. In a mentoring approach, a patient can discuss his or her problems, as well as seek information and support that facilitates and enhances the coping process. In a similar sense, a computer-assisted approach, particularly one with a support group or chat feature, allows the user to discuss his or her trauma with others in a similar situation, which might help one's coping and cognitive processing of the event.

Cognitive processing theories assume that prior to a traumatic event (such as a cancer diagnosis), people have preconceived notions made up of information about themselves and their surroundings (Lepore, Silver, Wortman, & Wayment, 1996). These schemas can range from thoughts of invulnerability to ideas of how and why people are punished (Perloff, 1983). When a traumatic or stressful situation occurs, it challenges these preconceived notions by demonstrating to an individual that he or she is vulnerable and helpless (Lepore et al., 1996). People cope with these situations by discussing the trauma and memories surrounding the painful incident as a step in the recovery process. Thus, for breast cancer patients, talking about their diagnosis and treatment is helpful in the long run by forcing them to confront and deal with the situation at hand. However, social constraints on expressions of thoughts and feelings related to a painful incident may force patients to suppress these expressions altogether, which ultimately increases their emotional distress (Lepore et al., 1996). For example, if breast cancer patients do not have an adequate support network or the proper social groups where they can discuss their disease and treatments, they lack the opportunity to address the traumatic situation and may feel as though they are battling the illness alone. They have no chance to

discuss the experience, which can prove to be a setback as far as processing and coping with breast cancer itself. Research has also shown that people who are not able to discuss a painful situation have trouble attaching meaning to it or understand how to resolve it, compared to those who do disclose this information to others (Tait & Silver, 1989; Clark, 1993).

While it has been shown that cognitive processing of difficult or challenging situations is improved through discussion and disclosure, social constraints may exist for people that limit or completely block them from talking about problems with others. Lepore and Ituarte (1999) define a social constraint as: “any social condition that causes trauma survivors to feel unsupported, misunderstood, or otherwise alienated from their social network when they are seeking social support or attempting to discuss their trauma” (p. 168).

A lack of people in one’s life who are willing to listen, sympathize, assist, or offer words of comfort is a major constraint (Lepore et al., 1996). A second social constraint may be a person with a network, in which people say or do things they believe to be helpful, but are actually insensitive or inappropriate as perceived by the patient (Wortman & Lehman, 1985). For example, this could be an attempt to minimize the disease or the treatment’s toll on breast cancer patients. To avoid these painful, unhelpful, or awkward situations, patients choose to keep their thoughts and emotions to themselves (Lepore et al., 1996). A third social constraint for victims of trauma is due to experiencing negativity from others. As Wortman and Lehman (1985) pointed out, a terminal illness may cause members of one’s social network to practice abandonment or avoidance

techniques because they feel helpless. If they are unable to undo the trauma a loved one is experiencing, they feel they can do nothing to provide assistance. Breast cancer patients may experience this phenomenon from their friends or even their partners; those that should be there to listen and provide support remain distant and aloof. Thus, when any of these social constraints exist, victims of painful incidents may be forced to refrain from discussing their thoughts and emotions, and ultimately unable to process and emotionally heal from these experiences.

However, with a mentor or computer-assisted approach, these constraints and their effects on the patient may be reduced or eliminated. The mentor is most likely trained to provide information and support in a manner that will benefit an individual who has recently learned of a positive cancer diagnosis; the mentor's feedback will probably be delivered based on training he or she has received about how to effectively communicate with people coping with a stressful event. In terms of information received from a computer program or website, the user has the power to filter his or her searches and limit the amount of data exposure and intake at any given time. Therefore, they have better control of their processing and coping. Additionally, access to online support groups with people facing the same challenges may be beneficial because the individual knows the other participants can empathize with his or her situation, perhaps alleviating some of the awkward and frustrating constraints provided by friends and loved ones who have never experienced the same trauma or illness.

A social-cognitive processing (SCP) model was developed to assess how interpersonal interactions affect recovery (Lepore, et al., 1996). In breast and colon

cancer patients, those with high social constraints showed more of a negative affect compared to those with lower social constraints (Lepore, 1997). In a similar study by Manne (1999), patients with higher levels of spouse criticism showed elevated levels of distress compared to those with supportive spouses. Furthermore, emotional processing was related to a better quality of life in breast cancer patients with positive and supportive social groups (Stanton et al., 2000).

If a patient does not receive adequate support to cognitively process a traumatic event, he or she might find it beneficial to turn to a human mentor or an online support program with others encountering the same hardships to provide advice and reduce any obstructions to dealing with the stressor and confronting the challenge.

### **Social Support Theory**

Social support is another key component for an individual when it comes to cognitively processing a traumatic event, such as a cancer diagnosis. Support and coping are closely related; both involve processing a stressful situation and adjusting to it with the help of other people. The amount of support a person receives from others can shape his or her confidence while handling the situation, as well as assist in the coping and recovery process.

People battling an illness who received support have been shown to heal quicker, undergo a reduction in symptoms and stress levels, decrease pain, and establish self-esteem (Cohen & Wills, 1985; Metts & Manns, 1996). Query and Wright (2003) found that individuals who were more competent in their communication and received social support were significantly less distressed during their cancer treatment and recovery.

Cutrona and Suhr (1994) argued that social support could be divided into two categories: action-facilitating support or nurturing support. Action-facilitating support occurs when an individual performs tasks to gather information about a subject, while nurturing support takes place through expressing emotions, building self-esteem, and providing companionship.

Action-facilitating support can be broken down further into two groups: instrumental support and informational support (Cutrona & Suhr, 1994). Instrumental support refers to performing tasks and favors for an individual. Informational support occurs when an individual shares knowledge with another. For example, passing along information derived from an Internet search or giving an individual a list of suggested books to read all fall under providing informational support.

Nurturing support can also be divided into smaller categories: esteem support, emotional support, and social network support (Cutrona & Suhr, 1994). Esteem support revolves around making a person feel encouraged at a time when they are anxious and distressed. Wills (1985) noted that offering encouraging words eases feelings of despair and hopelessness for individuals experiencing a traumatic event. Emotional support involves empathizing and understanding the stress of another person (Cutrona & Suhr, 1994). Such support is useful when people cannot change their situation, such as a serious or terminal illness (Albrecht & Adelman, 1987). A lack of emotional support has been linked to moodiness and depression symptoms among people facing difficult situations (Metts & Manns, 1996). Emotional support involves an individual willing to listen to the plights of others (Brady & Cella, 1995). In other studies, distressed

individuals preferred to talk and be heard by another person without necessarily receiving advice or input about their problems (Lehman, Ellard, & Wortman, 1986). Lastly, a social support network is created out of relationships that last even during times when there is no crisis (Cutrona & Suhr, 1994). Thus, people undergoing similar stressful events may remain in contact long after they overcome their struggles. They may feel that their network is an example of support readily available to them for future traumatic experiences (Barnes & Duck, 1994). A study by Grissett and Norvell (1992) showed that the support in social networks was dependent on the number of people involved, frequency of interaction, conflict level during interactions, and the communication skills of those within the network. If the networks were comprised of a number of people who possessed quality communication skills, were respectful of each other, and frequently interacted, they were the most beneficial for the people involved.

Relating the concept of action-facilitating support and nurturing support back to CHESS, a breast cancer patient would be practicing action-facilitating support by passing along information from websites, a mentor, or other CHESS users to another individual. In comparison, the patient would be taking advantage of nurturing support techniques by having others empathize with her situation, receiving encouragement, or seeking to build a network of contacts with other women also afflicted with breast cancer.

Social support is not only beneficial for the person receiving assistance, but also for the caregiver administering support. According to Ferguson (1997), people providing supportive communication reported an increased sense of worth. Thus, in the case of mentoring patients, the mentor may also benefit from providing information and support

to others because he or she might feel a sense of accomplishment about having done a “good deed” through assisting others.

### **Dual-Coding Hypothesis**

The dual-coding hypothesis attempts to decrease cognitive overload when it comes to the intake and processing of information. The theory’s overarching assumption is that memory and cognition are made of separate systems; one processes verbal information and the other deals with nonverbal information (Paivio & Lambert, 1981). This allows for more information to be stored overall in short-term memory because of the two channels, versus one simple channel of processing data (Hui-Ya & Heng-Yu, 2011). Such an approach is relevant when it comes to mentoring and computer-assisted approaches; cancer patients receiving information via both channels should be able to store more overall data in their short-term memory, leading to better recall and understanding of their diagnoses, compared to patients only utilizing verbal information from the mentor and visual information from the computer.

The dual-coding hypothesis has not generally been utilized in healthcare, though the approach holds promise for examining issues where subjects with multiple channels of information access are analyzed.

### **Paired-Learning**

Paivio (1986) argued that successful dual-coding results are more likely to occur when the content is imaginable, versus a subject that is abstract. Paivio, Smythe, and Yuille (1968) studied imagery and meaningfulness of nouns in paired-associate learning. Utilizing a study-recall procedure, they found that the image of a noun resulted in

positive effects on learning, compared to a noun's meaningfulness. This is consistent with studies by Clark, AbuSabha, von Eye, and Achterberg (1999) and Mayer (2008), which indicated that people learn better when an image is coupled with audio, compared to on-screen text.

### **Emotional Perception**

Applying the dual-coding hypothesis to health, Peelen, Atkinson, and Vuilleumier (2010) noted that emotional information is processed via multiple channels more efficiently than through a single method. They found that individuals assessed people's emotions based on visuals of facial and body expressions, coupled with audio depictions of anger, disgust, fear, sadness, etc. at a faster rate than participants who were exposed to only visual or audio samples. Peelen et al. (2010) argued that visual and audio exposure led to quicker information processing in the medial prefrontal and superior temporal cortex of the brain. Thus, two methods of exposure to information processing were better than one form. The same concept relates to mentoring and computer-assisted approaches; patients exposed to both the visual form of information (on the computer) and an audio format (talking to a mentor on the telephone) would be better for a patient compared to receiving feedback through only one of these channels.

### **Short-Term Memory**

Paivio and Begg (1971) found that concrete words (e.g., bar, library, dollar) were recalled better than abstract words (e.g., virtue, situation, interest) when it came to short-term memory.

Pellegrino, Siegel, and Dhawan (1975) argued that pictorial stimuli are encoded both in visual and acoustic stores of one's memory, while words are typically only acoustically stored. Similar to the results of Parkinson (1972), experiments indicated that one's visual storage and short-memory system retain information for at least 15 seconds. One may question how short-term memory can be so durable, given both visual and acoustic components. Craik and Lockhart (1972) suggested that the visual portion of the system may involve quick access to information pertaining to the picture's meaning, creating a more rapid transition to much deeper levels of processing the visual stimuli.

Understanding the procedure in which humans receive information and keep it within their short-term memory for rapid recall impacts fields that depend on people processing information quickly. Implementing a dual-coding approach, David (1998) found that adding a visual component that was representative of the news story improved viewers' recall of that particular story. This finding is applicable to CHESS; the program allowed users to see the information on message boards and from the expert medical provider, rather than just hearing the data in an audio format. Talking to the mentor on the telephone provided the information in that audio format, so patients could potentially recall information faster if their mentor said it and they read it on the CHESS site. Second, the study showed that concrete news items were recalled better than stories dealing with abstract news. Similarly, concrete news saw higher results of recall when paired with an image, compared to the recall results of abstract stories. Finally, news concreteness was related to image attributes, such as verbal-visual overlap, possibly

explaining the gap between recall success after adding visuals to both concrete and abstract news stories.

The relationship between language acquisition and the dual-coding hypothesis is another area that adds to the theory's heuristic value.

Lambert and Paivio (1956) found that learning nouns in second languages, followed by adjectives, led to words being learned easier than people who were exposed to the adjective first, and then the noun. Paivio (1963) concluded that this is due to nouns serving as better overall conceptual frames than adjectives, because nouns elicit images to mediate response retrieval at a much higher rate than most adjectives. This hypothesis was congruent with the results by Yuille, Paivio, and Lambert (1969), who found that English and French subjects had higher levels of recall when taught in a noun-adjective process, compared to those who were exposed to an adjective-noun approach.

Lomicka (1998) examined how second language acquisition was aided by annotations and descriptions. College students in a second-semester French class were asked to read a narration. The students were split into three groups; the first group had full explanations in the margins, the second group received limited annotations, and the final group was given the text without any kind of annotations or additional information in the margins. Students who received the full set of annotations and descriptions comprehended the text faster and had a deeper degree of understanding, compared to students in the two other groups. This is relevant to CHESS, in which patients received access to both a discussion board where they could communicate with other cancer patients, and a drop box where they could submit questions for a doctor and receive an

answer within 24 hours. The concept was the same as with the students in the aforementioned studies—by receiving access to multiple avenues, people comprehend information better compared to when they have limited access to it.

Studies have also reiterated that students had better retention rates of text and vocabulary when presented with verbal and visual information to study (Miller, 1956; Plass, Chun, Mayer, and Leutner, 2003; Kuo and Hooper, 2004; Ko, 2005; Hui-Ya and Heng-Yu, 2011).

The dual-coding hypothesis has also served useful in the classroom beyond second language acquisition. Sadoski and Paivio (2001) concluded that visual representations in learning and teaching materials lead to increased gains in learning, compared to the same materials without any kind of imagery. For example, a breast cancer patient may not know how to discuss the illness, treatments, and concerns with her loved ones; CHESS experts give her advice and even direct her to sites that illustrate how to facilitate these discussions.

Price (2007) argued that lecturers must understand the differences between their perceptions of the accessibility of the materials, and the perceptions of their students. They need to realize that students prefer instructional material with some sort of visual display and text, compared to text-only versions on the same topic. Thus, CHESS advisors and overseers must bear in mind that users prefer to receive information and advice with visuals interspersed throughout the text, rather than text-only instructional material.

Shalmani and Sabet (2010) created a study to look at reading comprehension with verbal or visual cues. Participants were split into three groups: one received a passage with pictorial and textual descriptions and associations, while the other two groups either received the text with either textual descriptions or pictures, but not both. Results indicated that the group who received both textual and visual annotations with their passage scored higher in recall and comprehensive tests compared to the other two groups. Furthermore, the group who received visuals to supplement their reading outperformed the group that was given textual descriptions with their passage.

Given the research done on the dual-coding hypothesis and paired-learning, one should expect to find examples of breast cancer patients with access to CHESS comprehending information better and processing information related to cancer at a better rate during interactions with the mentor compared to the patients who were not allowed to utilize CHESS.

### **Combining Social Support and Dual-Coding**

The concepts of social support and dual-coding, while separate theories in the past, were combined into a hybrid theory for the purpose of this study. People searching for information may combine the two concepts as well. For example, someone who seeks information may later recall it while providing support for another individual. In that case, the support recipient evolves to become the support provider.

## **Buffering Effects**

Individuals processing traumatic events often rely on some form of support to diminish their shock. These methods of coping, also known as buffers, serve to make the stressful situation seem less daunting and easier to process.

Horowitz (1986) believed that individuals process distressing information (such as a cancer diagnosis) by responding with coping behaviors, such as thought suppression. Lepore, Silver, Wortman, and Wayment (1996) noted that a supportive environment facilitates discussion of trauma (like a positive cancer diagnosis), rather than the patient suppressing thoughts about the experience. Lepore (2002) argued that in contrast, cancer patients with low levels of support were more likely to regress and suppress thoughts, inhibiting any development of skills for adjusting to a lifestyle of battling cancer.

Carpenter, Fowler, Maxwell, and Anderson (2010) found that among gynecologic cancer patients, those with higher levels of social support and fewer physical symptoms had lower levels of depressive symptoms. Patients with less social support and more physical symptoms exhibited more depressive symptoms. Carpenter et al. (2010) pointed out that this might be due to social support serving as a buffer for traumatic news, such as a cancer diagnosis and coping with the disease. Without the buffer of support from others, these individuals had no means to cope with the trauma of their cancer.

## **Patient Satisfaction**

The level of patient satisfaction regarding interaction with doctors and medical professionals also affects how individuals deal with their diagnoses and treatments.

Scott and Vick (1999) examined the doctor-patient relationship from the perspective of patient expectations when it comes to interaction, specifically transferring information and involvement in decision making. They found that patients prefer more information through easy explanations, and for the physician to listen to them when they talk or express concern. The most important point was doctors listening to the patients, and patients feeling that they could openly talk to the doctor during their visits. Patients desired to be part of the decision making process when it came to treatments; the people who preferred to be most involved tended to be female, young, and had been involved in decision making in previous visits with doctors.

Thorne, Kuo, Armstrong, McPherson, Harris, and Hislop (2005) looked at cancer patients' perspectives on the dynamics of communication with their doctors. Two hundred patients were interviewed regarding the degree of anonymity they felt they endured when they received treatments. Patients reported that they often felt like objects within the hospital or medical facility; they received little or no emotional support and their doctors were very systematic in treatments and conversing with them as patients. These people felt they had no place to turn for any help regarding emotional support or mental stability; they were "known" in the hospital by their cancer type and nothing more. To the participants, hospitals were impersonal and unsupportive places whose only purpose was to administer treatments.

Bylund, Gueguen, D'Agostino, Imes, and Sonet, (2009) noted the importance of the Internet when it came to patients discussing information with their healthcare providers. A study found that patients frequently reported discussing information

because they wanted to be involved in their treatments and health decisions. Patients sought information via the Internet and then brought up their findings with their doctors during their next visit. This method served a variety of functions, such as wanting to appear or be more educated on a health issue, appealing to the doctor as an authority figure to justify or clarify Internet knowledge, psychologically coping with a diagnosis by seeking out information online and having a doctor reassure them the information was valid, or testing a doctor's expertise. The study demonstrated patients have a host of reasons for sharing information they acquired on the Internet with their healthcare providers.

### **Implications of Theories on Mentor and Computer-Assisted Approaches**

All of these theories describe how people react and adjust to a traumatic situation, such as a positive breast cancer diagnosis. Social-cognitive processing is essential to begin successfully coping with a stress inducer. By acknowledging one has breast cancer, a patient can then begin to cope with the problem. Coping with the trauma could include talking to the mentor about the fear of treatments or seeking information on treatments by searching for information on the computer. The amount of social support a breast cancer patient receives from a mentor or online community can also help the individual overcome the traumatic experience. A high degree of social support from a mentor or online group may serve as a buffer to a positive breast cancer diagnosis. The presence of social support as a buffer following the news that one has cancer influences how well a person copes with this troubling news. After receiving a positive diagnosis and during the coping process, people tend to seek information about their disease to help

them understand and prepare for the treatment process. They may also seek out social support and rely on religiosity and spirituality to calm them during this difficult period.

Within the context of this study, the social-cognitive theory would say that the mentor-only group relied more on the direct pathway of communication; the mentor served as the source to inform, motivate, and guide breast cancer patients through their treatment and recovery process. However, the group assigned both the mentor and CHESS utilized the socially mediated pathway; CHESS served as a way to quickly link the women to others within the study through the message boards, and provided a sense of community. Furthermore, CHESS provides extra personalized guidance; users choose what elements of the program prove beneficial, whether it is the message boards, searching for and reading through information, asking a medical expert or a combination of the three options.

Together, these theories show the merits of both a human mentor and computer-assisted interventions during the recovery process. A mentor is a source of information and support, and helps the patient by providing him or her with valuable information (or even other sources) to alleviate stress and reduce uncertainty. Likewise, a computer-mediated approach also gives patients the opportunity to seek out information, control the methods in which they search for the data, and grant access to online support groups, allowing users to build networks and relationships with others troubled by the same illness. If granted access to both a computer program or website and a human mentor, theoretically the two different methods of obtaining support and information ought to enhance a patient's experience and aid in information recall and memory.

When it comes to emotional perception, people perceive emotions through both audio and visual exposure, rather than just seeing facial expressions or hearing one's voice. Depending on whether the mentor only converses with patients via the telephone or email, as opposed to meeting them in person, the patients may not have access to the mentor's visual stimuli, such as facial expressions, body posture, etc. They might only be able to judge the mentor's emotions from his or her voice, or inferring tone from an email. Therefore, the mentor must be aware of his or her voice and how things are communicated if the conversation is not face-to-face with the patient (since the patient does not get the benefit of processing the situation faster by receiving visual cues from the mentor). Having a mentor may also be positive because during face-to-face interactions with one's doctor, he or she may speak plainly about the diagnosis or treatment, while looking concerned or matter-of-fact. Thus, the tone of the doctor may not contain supportive emotion; yet the patient can speak to the mentor later on and be reassured regarding information about the illness or treatments.

These interventions should help breast cancer patients in uncertainty reduction, satisfaction, comfort and coping with an illness during what may be perhaps the biggest obstacle they have faced up to this point in their lives.

### **Comprehensive Health Enhancement Support System (CHESS)**

The initiative entitled the Comprehensive Health Enhancement Support System (CHESS) is an example of an ICCS. The idea began in 1987, when Dr. David Gustafson brought a team of medical experts together to identify a method that could help people facing illnesses to take control of their treatment, become educated about their condition,

and help them cope more effectively (CHESS, 2011). Since its inception, CHESS has conducted numerous studies related to cancer, communication, information-seeking behavior, and support.

Han et al. (2010) noted earlier that ICCSs were more beneficial for patients seeking online information because the computer took on the role of coach and guide. In the case of CHESS, its communication services allow patients to communicate with each other or interact privately with medical experts. This illustrates how the computer links people together and enhances “interpersonal processes such as social support, teaching, and conversation” (p. 372).

CHESS’ components have been shown to be beneficial for patients on a variety of levels. These advantages include improving quality and longevity of life, encouraging higher levels of participation in healthcare decisions, producing more positive perceptions of competence/self-efficacy, and developing more effective use of healthcare services (Gustafson, McTavish, Hawkins, Pingree, Arora, & Mendenhall, 1998; Gustafson, McTavish, Boberg, Owens, Sherbeck, & Wise, 1999; Gustafson, Hawkins, Pingree, McTavish, Arora, & Mendenhall, 2001; Gustafson, Hawkins, Boberg, McTavish, Owens, & Wise, 2002; Gustafson, McTavish, Stengle, Ballard, Hawkins, & Shaw, 2005; Shaw, Han, Baker, Witherly, Hawkins, McTavish, & Gustafson, 2007; Wise, Han, Shaw, McTavish, & Gustafson, 2008).

Lu, Shaw, and Gustafson (2011) examined CHESS’ utility for low-income women with breast cancer. They found that greater use of the program was associated with an improvement in the women’s perceptions of their own competence, as well as

their participation in the doctor-patient relationship. Thus, these patients felt higher levels of confidence when it came to actively seeking out information. They were more involved in treatment decisions, and CHESS enhanced their interactions with doctors.

Comparisons have also been made between CHESS and other forms of information-seeking opportunities. A study by Hawkins, Pingree, Baker, Roberts, Shaw, McDowell, Serlin, Dillenburg, Swoboda, Han, Stewart, Carmack, Salner, Schlam, McTavish, and Gustafson (2011) randomly assigned breast cancer patient subjects to one of four experiment groups: a control group whose members received a computer and internet access, a group which interacted with a human mentor, a group which was given access to CHESS, and a group which received both interventions. They found that those with a human mentor and CHESS access displayed the greatest improvement in health information competence and the most ability to emotionally process their situations. Thus, the integration of computer-based and human-based sources of information and support for breast cancer patients was more beneficial than the Internet, CHESS, or a human mentor alone.

The purpose of the Hawkins et al. (2011) CHESS study was to explore the benefits of an ICCS, as well as the advantages a patient gained when granted access to a human mentor through random assignment of participants. Notes that the mentor took through telephone and email conversations provided a wealth of data, which made the research possible for this study to compare and contrast what was discussed during the conversations between patients granted access to the CHESS website and a mentor, versus patients assigned only a mentor. This study hopes to move the audience's

understanding of CHESS beyond Hawkins et al. (2011) to identify themes addressed in the women's narratives, as well as the types of support, coping strategies and information-seeking habits of women in each of the groups.

### **Research Questions**

This study examined breast cancer patients who were randomly assigned to one of two groups: one group had access to a mentor, while the other group had access to a mentor and could log on to a CHESS website. Through the CHESS website, group members could interact with other patients, submit questions to a medical expert, and read through various topics related to breast cancer. The following research questions were developed to examine data collected between participants and their mentor:

*RQ1: What themes are addressed in women's cancer narratives, as reported by a CHESS Mentor?*

Since the CHESS/Mentor and Mentor-Only conditions were similar in that they both contained access to a mentor, every breast cancer patient had notes about her conversation recorded. A conversation in which the patient and mentor discussed information served as a unit of analysis and provided a source of data to identify common themes among all the participants. This question was also derived from the possibility of examining what common topics are discussed between breast cancer patients and a human mentor. From there, comparisons and contrasts can be made to see if different themes emerge when patients are granted access to CHESS.

*RQ2: To what extent is there evidence that the CHESS/Mentor combination provides both action-facilitating and nurturing support?*

Cutrona and Suhr (1994) identified two main types of support—action-facilitating and nurturing. It seemed only natural to examine the degree to which both a computer-aided and mentor condition and a mentor-only condition would serve as sources of support for breast cancer patients.

*RQ3: Is there evidence to suggest differences in coping ability for women using CHESS/Mentor versus women using Mentor-Only?*

Suls and Fletcher (1985) noted that in stressful situations, people either face the challenge or avoid it. Confronting the source of trauma often leads to quicker social-cognitive processing of the event, thus facilitating and improving the coping process. Within the framework of the social-cognitive theory, women in the CHESS/Mentor group have access to support both from the mentor and from the socially mediated pathway of CHESS discussion boards. Women in the Mentor-Only condition would have to be more proactive in seeking out their own support groups (in-person or online) since they were not granted CHESS access. While both groups received the benefit of the mentor speaking knowledgeably to them (which could give women a sense of support), those with CHESS access might look up extra information on the site that reinforces what information the mentor provided. Possessing another source that verifies the information received from the mentor might make the women in the CHESS/Mentor group see view the mentor as more supportive. They may develop a higher level of trust that the mentor is qualified and knowledgeable enough to provide cancer information and support if data from their mentor interactions is congruent with what they read on the CHESS site.

Not only might a woman feel more support from her mentor if the information aligns with what she finds on the CHESS site, but the same could also be true during a

doctor's visit. If the medical provider offers information during a visit, and the woman has already gathered or later on reads the same information on the CHESSE site, she may feel a better sense of comfort that the doctor genuinely cares and is committed to providing the most relevant and helpful information possible. Similarly, if the woman comes across the same information via the mentor and CHESSE as delivered by her doctor, she may feel even more support, because she has three different avenues that have a consensus as far as information that may assist her during treatment and recovery. Therefore, this research question addresses the possibility of either CHESSE/Mentor or the Mentor-Only condition fostering a better method of coping than the other approach.

*RQ4: Is there evidence to suggest differences in information-recall for women using CHESSE/Mentor versus women using Mentor-Only?*

Based on evidence from studies on the dual-coding hypothesis (Paivio & Lambert, 1981), in which two forms of information availability (e.g., audio and visual) led to better instances of recall by people compared to only one channel, this study looks at whether or not evidence exists that coupling CHESSE and a mentor was more effective in information-recall for breast cancer patients compared to a Mentor-Only approach.

## Method

This study utilized the data by Hawkins et al. (2011), a design in which breast cancer patients were split into either a mentor-only group, or a mentor and CHESS group. The study was conducted from April 1, 2005 through May 31, 2007 (Baker et al., 2011). Participants were recruited from one of three medical centers: the University of Wisconsin Paul P. Carbone Comprehensive Cancer Center (UWCCC), Hartford Hospital's Helen and Harry Gray Cancer Center, and the University of Texas M.D. Anderson Cancer Center. Women were asked to participate in the study through a predetermined, random system. At each site, staff approached an eligible patient and asked if she would be interested in learning more about this study. The requirements a patient had to satisfy in order to be approached were: greater than 17 years old, could read and understand English, and were inside of two months of a diagnosis of breast cancer for the first time or as a recurrence. A woman who said yes was briefed as far as informed consent and HIPAA guidelines, had her questions answered, was described the nature of the study, gave her written consent, submitted her contact information and computer access information, and filled out a questionnaire in which she gave demographic information and evaluated herself in terms of computer and web-based literacy. Then, a computer randomly assigned them to either the mentor or mentor and CHESS group.

A total of 211 women participated in the study; 106 of them were assigned to the mentor-only condition, while the remaining 105 women received a mentor and access to CHESS (Hawkins et al., 2011). The average age of women in the mentor-only group was

53.9 years, while the average age in the mentor and CHESS group was 52.7 years. The average level of education completed for the mentor-only group was some college (4.9 out of 7) as opposed to a Bachelor's degree for women in the mentor and CHESS condition (5 out of 7). The mean income of participants in both groups was between \$60,000 and \$80,000. Two percent of the mentor-only group did not have insurance, compared to one percent in the mentor and CHESS group. The number of women living alone in the mentor-only class was 16%, compared to 10% in the mentor and CHESS class, which was not statistically significant. Women with access to a mentor reported feeling quite comfortable using both a computer and the Internet (3.1 and 3.0 out of 5), compared to a slightly lower rating of being somewhat comfortable in the mentor and CHESS group (2.9 out of 5 for both categories). The difference between the two groups was not statistically significant. The original study noted that the average number of days since a positive breast cancer diagnosis for the mentor-only women was 48.2 days, compared to 44 days for the women with a mentor and CHESS. Again, this difference was not statistically significant.

Women who landed in the mentor and CHESS group were trained on how to operate the CHESS system (Hawkins et al., 2011). Training lasted about half an hour and was generally done over the telephone. All participants were given access to the Internet free of charge.

As previously mentioned, the mentor used in this study was a female named Elaine (all names have been altered to protect the anonymity of participants) who had past experience as the expert for CHESS' Ask an Expert feature and served as a specialist

for the Cancer Information Service (Hawkins et al., 2011). During calls with breast cancer patients, Elaine had Internet access and could consult numerous online resources from the National Cancer Institute (NCI) and the American Cancer Society (ACS); she also had printed versions of materials that were frequently consulted. She served to interpret information the women disclosed to her, as well as referring the patients to other sources (including ones found on the Internet). Elaine described her duties, writing that “women use the mentor service in many ways. I can provide information, do some research, listen and give support, make referrals, etc. Some women spend more time on the phone with me than others, depending on their needs.” The CHESS software was equipped with a feature that took care of call scheduling and allowed Elaine to record conversation topics, her own responses and information-seeking recommendations for the participants, and her assessment of patient preparedness and overall satisfaction. This feature allowed Elaine to readily access and evaluate a breast cancer patient’s previous conversation, thereby focusing the upcoming call on any issues or concerns expressed in the past. Each call’s audio was recorded; Elaine also took notes during each conversation on important points discussed and her assessment of the patient’s overall status.

For women who had access to a mentor and CHESS, the software also gave Elaine a summary of each participant’s CHESS use and concerns she reported (whether on the discussion board or through the Ask an Expert feature), which helped Elaine analyze each woman’s level of knowledge and information-seeking behavior (Hawkins et al., 2011). This aided Elaine in making recommendations specific to each patient and her

needs, as well as referring her to certain CHESS resources, since Elaine already knew which aspects of the program the woman had utilized.

Elaine telephoned each woman weekly during the first month of the study, twice during the second month, and once during each of the last four months of participation, for a total of 10 calls (Hawkins et al., 2011). Each upcoming call was scheduled either by telephone or email, depending on each woman's preference. Calls between the mentor and breast cancer patients ranged from five minutes to an hour, and averaged about 15 minutes in length. The first call was usually one of the longer conversations, as the mentor and patient had introductions and became familiar with one another. About 10-15% of participants initiated calls to Elaine for additional support, and about five percent of calls ended up occurring as email exchanges. The average number of complete calls or emails was 8.9 per woman, with the Mentor-only condition having 9.01 complete conversations and the CHESS + Mentor group having 8.77 complete conversations. This difference was not statistically significant. A complete conversation (which served as the unit of analysis) meant a phone or email exchange in which information was shared, or topics were discussed (i.e., not a missed call or a call or email to schedule a future conversation). There was no statistically significant difference between these two groups.

As far as emails between Elaine and the participants, Elaine could not initiate emails except for scheduling purposes, nor could she initiate phone calls except for scheduled conversations. However, patients were free to write or call her as frequently (or infrequently) as they desired.

Each time that Elaine emailed or called a participant, she recorded the conversation and took notes on what was discussed. The notes were analyzed for each woman to identify common themes and attempt to produce support for the research questions mentioned earlier. The key topics identified were spirituality and religiosity, coping, support, depression, information-seeking behavior, cancer and death, and a general heading of other topics discussed with Elaine. After each participant's name, whether or not they had access to CHESS or could only utilize the mentor is noted in parentheses by CM (Chess and Mentor) or MO (Mentor Only). While 211 participant exchanges were studied, testimony from 78 women were included in the result section; 45 subjects in the CHESS and mentor category, and 33 subjects in the mentor-only group.

### **Measurement**

The first research question examined themes addressed in the women's narratives during their talks with a mentor. A theme was conceptualized as a main idea that was reinforced in a number of CM and MO interactions. Inter-rater reliability was established by having three individuals examine complete conversations (including some phone and some email conversations) from the same 25 participants and take notes on recurring topics or ideas. The concepts, or themes identified by these outside coders were mostly similar or identical to the themes identified by the researcher for this study, such as support of family and friends, relationship with mentor, searching for information, anxiety and fear, and religion.

The second research question focused on action-facilitating and nurturing support. Action-facilitating support is defined as individuals performing tasks to gather

information about a subject (Cutrona & Suhr, 1994). This type of support can be further broken down into two categories: instrumental support and informational support.

Instrumental support occurs when tasks and favors are performed for an individual, such as a person who performs job searches on the Internet for a friend, or a student who agrees to search for books for a classmate in the campus library. Informational support refers to people sharing knowledge with others, e.g., a doctor sharing information with a patient, or a professor teaching a group of students.

Nurturing support occurs through the expression of emotions, building self-esteem, and providing companionship to others (Cutrona & Suhr, 1994). This type of support can also be divided into sub-groups: esteem support, emotional support, and social network support. Esteem support makes a person feel encouraged at a time when they are anxious and distressed. A newly-graduated college student stressed out about moving to a different part of the country to start a job might desire esteem support from family, encouraging him or her that adjustments can be made and professional success is in the future. Emotional support means understanding the stress of another person. If a person experiences the sudden loss of a family member, he or she might benefit from receiving emotional support from other family members, friends, and coworkers. Lastly, a social support network is created out of relationships that last even during times when there is no crisis. An example of a social support network would be a person who attends an intervention group for alcoholism, overcomes this crisis, and still maintains contact with the other people in his or her group long after they no longer meet.

Inter-rater reliability was also implemented using the same three individuals to determine whether their assessment of the types of support utilized by participants, loved ones, and the mentor matched those identified by the researcher.

The third research question in the study dealt with coping mechanisms of women afflicted by breast cancer. While the word “cope” can be a broad term, examples of coping include phrases such as “managed,” “felt better,” “took it one day at a time,” “came to terms with it.” In these cases, an individual cognitively processed a traumatic ordeal and tried to gain a sense of control over the situation.

Finally, the fourth research question explored evidence of information recall among breast cancer patients. Signs of people recalling information included remembering facts, conversations, or passages they read (on the Internet, in a brochure, in a book, etc.). Information recall also involved situations reminding people of past experiences, or advice they received in the past from doctors, family, friends, or coworkers. Retention of these facts suggests successful information recall.

## Results

### Spirituality and Religiosity

The first concept that was uncovered frequently within the data was spirituality and religiosity. Whether a patient explicitly mentioned her religion or just claimed that she was “spiritual,” relying on faith was a coping mechanism for over half the women in the study. In some instances, a positive breast cancer diagnosis even drove women to bring prayer and religion back into their lives after a hiatus from their faith.

Darlene (CM) leaned on spirituality during her cancer experience, as well as the support she received from others at church. Elaine wrote, “she is Catholic and believes in prayer, especially group prayer. She is getting cards telling her that people are praying for her.” Cora (MO) described herself as possessing “a very positive attitude which she attributes to her connection with God. She is very involved in her church as well.” Cora (MO) even turned down Elaine’s invitation for additional support because she was so confident of her spiritual and familial support: “I asked her if she might be interested in a support group, but she feels she has lots of support and might go in order to help other women. I encouraged her to allow herself some space in there to feel her feelings and to remember that it's a gift to others to let them help.” Misty (CM) also mentioned the support network she received due to her spirituality. She belonged to a “Mennonite church and (had) lots of friends and family support.”

As Elaine noted when talking about this topic with Blanche (MO),

I asked her about church/spirituality and she said she’s gone to church once when she borrowed a dress from someone. [...] Wants to go every Sunday to the Catholic Church she grew up in, as well as when no one is there so she can pray

alone. I asked if she prays at home and she said yes. I also suggested making an appointment with a priest for spiritual counseling.

Prior to her cancer, it appears Blanche was not an avid churchgoer in adulthood; however, she now has the desire to attend a place of worship again, as well as engaging in prayer alone at home. Yvette (MO), another study participant, also started attending Catholic ceremonies again and told Elaine she was “very happy about this.”

Olivia (CM) relied on prayer as a coping strategy, repeatedly asking Elaine to pray for her at the end of their conversations. Not only did she pray to be cancer-free, but to also aid her medical providers in their quest to help her beat the disease. She told Elaine,

I put my trust in Dr. Green's care. I have to believe in her care. I pray for her often that God will bless her with only His best Wisdom, knowledge, and understanding and so far He has not disappointed me! Not only for her but as well as all the other doctors and patients. I know that this road is rough, and can get worse, but I'm trying to give it all I have and not give up. I determined to see myself through this with the Lord carrying me through most of the time, if not all. I know that He is the greatest of all Physicians. He is what keeps me going!! I must admit that there are times that I tell myself what have I gotten myself into, but I'm quick to tell myself, there is no turning back. I have to keep focused and keep looking ahead.

Hannah (MO) credited her spirituality as the cause for any good news she received while battling cancer. Elaine described her exuberance: “Hannah's tumor has shrunk by half after only one treatment! Doctor says this is very unusual and Hannah chalks it up to the power of prayer. She had her second chemo yesterday and is doing well today.” Leticia (CM) told Elaine she “believed in God and the healing power of prayer.” She firmly felt that “God had saved her” as far as her discovering her breast cancer before it was too late and she was terminally ill.

Another patient, Kara (MO), was also deeply rooted in a spiritual lifestyle, including being “on track to become a certified healing touch practitioner and is into integrative meds like acupuncture.” She also attended a shaman class and participated in a group healing ceremony because she was open to any form of alternative healing practices. Closely linked to her spirituality was an extremely positive attitude toward her cancer diagnosis. Elaine noted that she “has a positive attitude, but is struggling with all of the unknowns. Views this like road construction where during the construction you have to take detours, go over bumpy roads, etc., but when it's finished, you get to drive on smooth, clean pavement.”

Other women considered themselves spiritual, but did not attend public gatherings. Krista (MO) remarked that she was “very spiritual but it's on a personal level—not organized religion. However, she has many friends who belong to churches who have her on prayer chains and she's grateful for that.”

Simply being cured from cancer was not the only topic the women incorporated into their prayers. One patient, Myra (CM), wanted to “go on a retreat with a friend so she can pray about her choices and then decide what to do.” She believed that spirituality would give her clarity as far as the appropriate treatment plan. During one trip she stayed in a cabin by herself and experienced health problems not related to her cancer improve. She remarked that she hoped “that God (was) also working miracles inside her body.”

Estelle (CM) rationalized her positive breast cancer diagnosis as something she could deal with, because she believed God does not give people more problems than they

can handle. She remarked, “the Lord knows what we can bare. I have to remember that. I need everyone's prayers right now.”

Muriel (MO) attributed the success of her treatment plan to her religiosity. She emailed Elaine:

The left hip was totally clear of cancer and my liver, kidneys, spleen, pancreas, adrenal glands and lungs are clear. And the tumors in my right breast have all gotten smaller and nodes under both arms are looking good. The doctors told me I am a unique metastatic cancer patient and have recommended that I have both breast removed in hopes that this could prolong my life. Is this not fantastic! I am still trying to come down out of the clouds. Thanks to God and everyone that I have had praying for me I am going to be around for a while.

Sophie (CM) referenced religion at the end of her involvement in the study while showing gratitude for Elaine as a mentor: “may God richly bless you and all who work with you because you give of yourselves to help those of us who don't have a clue what to expect.”

### **Coping**

The next theme that was illuminated in Elaine’s notes was behavior revolving around methods of coping. Nearly all 211 participants discussed coping mechanisms with Elaine in some capacity. This does not seem unreasonable; since all the women had been diagnosed with breast cancer, they were most likely going to have to cope in some form while undergoing treatment.

Sonja (CM) was angry and frustrated with her breast cancer diagnosis. In her first email to Elaine, she wrote:

I'm scared silly, very nervous and anxious. This is my 2nd (time having) breast cancer in nine years and I'm so mad. Two cancers before I'm 50 (years old) have deflated my resolve. I deal with it one day at a time. I don't want a phone call before surgery, so will wait till I feel better after to visit. I'm hoping to get a hold

on this after the final pathology report. I have a lot to say and lots of feelings, just too anxious and nervous right now. This new cancer is just that; a new cancer, not a reoccurrence. I just want to get on with a normal life. I'm sick and tired of major bumps in my road, but will fight like a warrior for myself, family and friends. If you know anyone who can email me that has had a bilateral mastectomy with lat flap reconstruction, I'd appreciate hearing from them. Right now I'm more scared of the surgery than the cancer, but I want to look and feel like a woman, so (I) must have reconstruction. I feel like I'm outside my body, looking in and that this isn't really happening again to me. Pretty pathetic, huh?

Sonja (CM) experienced shock, anger, and detachment during her second bout with cancer. Even though she had dealt with the disease in the past, being diagnosed again was the same as being diagnosed with a completely new form of cancer. She still feared surgery and undergoing the treatment process. Participating in the CHESS discussion group appeared to help Sonja. One of the other women said, "I can be angry and scared every day, but it will ruin every day." Sonja adopted this philosophy as a way to overcome the anger and frustration she felt in her own situation during the treatment process.

Kerri (MO) was also baffled as to why she was afflicted with the disease. Elaine recorded her first impressions and conversation with Kerri:

Kerri describes a very healthy lifestyle where she walks miles a day, lifts weights, eats very, very well. She cannot understand why she got this disease. I explained that we don't know what causes cancer, but believe that there are many factors involved that work together to allow cancer to grow. Empathized with how difficult it is to not know why. Gave support.

Corinne (CM) struggled with receiving a positive cancer diagnosis as a young, single mother. "I have a hard time with being 33-year-old and having this, I expected in my later years in life that I would have to worry about such things." Brittney (MO) also

questioned why she of all people had to have breast cancer. Elaine wrote, “she says she's had more anger and ‘why me?’ lately. Cried and let herself have a pity party.”

Lorna (CM) was another younger patient, as well as a mother, who had to confront her diagnosis. She confessed “that it has finally hit her that she has cancer. She's had a couple of days of ‘crying jags.’” Elaine described Lorna’s situation:

Her hair is falling out and her head hurts as a result. She had her kids cut her hair to two inches all over—this helped them with the transition. She thought she was more prepared for this, but isn't sure you can fully prepare. Part of her wants to shave it all off, but part wants to wait and see how much actually falls out.

Ingrid (MO) had to cope with the fact that cancer limited her number of daily activities. She remarked that she “is a type A personality and ‘burns the candle at both ends,’ and cried about how hard it is to slow down.” She also described feeling weary and how cancer controlled everything in her life at that point.

In a similar vein, Betsy (CM) struggled with cancer preventing her from parenting and being involved in activities at home. As Elaine noted, “she described what she calls a blue day on Saturday where she is so fatigued that she can't do anything and as she watches her husband take care of everything she feels useless and helpless.”

The physical change in one’s body due to undergoing cancer treatments was another element women had to come to grips with and cognitively process. Deena (CM) developed lymphedema and swelling in her hand, so she was sometimes forced to wear a glove and sleeve, which frustrated her. “She'd rather not have this public reminder of her breast cancer because that's not all she is,” recalled Elaine. “However, people always ask questions about it and this bothers her.”

Hair loss was a source of frustration and disappointment for many women who participated in chemotherapy treatments. Hannah (MO) was embarrassed by her hair loss as a result of chemotherapy. Despite shopping for a wig, she confessed to Elaine that she wanted “to get flights to Florida for this weekend—her husband's aunt is a hairdresser and she'd like to lose her hair down there where no one knows her. I gave support.”

Ingrid (MO) admitted that she hated hair loss from chemotherapy because she “has always had long hair and took pride in it.” Though she wore wigs and hats, it took her over a month before she started to become comfortable with her hair loss. Even then, weeks of chemotherapy, and a mastectomy/breast reduction robbed her of her physical appearance. “You just lose everything, hair, body parts, your whole image,” she said. Ingrid cried on nearly every call while Elaine gave support. She would cry when discussing a frustrating or discouraging aspect of the cancer process, such as hair loss.

Fay (CM) not only dealt with her own despair over how her body changed, but also how upset her family members were upon seeing her physical differences. Elaine wrote:

She was somewhat emotional. She'd seen herself for the first time and this was hard. She wonders how her wonderful husband will want to make love to her. She also feels badly that she let her mom see her body in the hospital because mom cried a lot and continues to have trouble. Wishes she hadn't.

Leigh (MO) was frustrated with the amount of time her body took to recover between rounds of chemotherapy. She remarked that she “just doesn't have the stamina she had before.”

Polly (CM) struggled with processing the fact that she had cancer when she experienced fatigue and pain following her mastectomy. She craved the form of

nurturing support known as emotional support—someone to understand that she was encountering a difficult and frightening situation. She wrote to Elaine, “I AM HAVING A HARD TIME WITH REALIZING THAT THIS IS TRUELY HAPPENING. [...] I YELLED AT MY MOM. THIS IS REALLY A BUMMER. HELP!” She experienced even more frustration several weeks later:

I went to the doctor (today), ready for more chemo. HE EXAMINED ME AND FOUND CANCER TUMOR ON MY SCAR LINE. I WAS SENT TO MY SURGEON AND NOW I START ALL OVER AGAIN. NOW I'M IN THE WAITING GAME. WAITING AND WAITING.

Rosetta (MO) employed approach-oriented coping strategies to deal with her diagnosis. Elaine noted, “she's recruiting people to walk with her in the 5 mile breast cancer walk in October. A friend who had an almost life-ending stroke is now able to walk and will be walking with her.” Rosetta used her cancer diagnosis as a way to unite people in the cause to find a cure; she chose to partake in a walk to celebrate her struggle. The fact that she was able to recruit willing friends and coworkers to participate with her speaks to the network of support she had, especially the one who had suffered a stroke. In a similar vein, Brittney (MO) and a team of 63 family and friends participated in a Susan G. Komen Race for the Cure event, so she felt “very supported.”

Rosetta (MO) also turned her positive breast cancer diagnosis into a beneficial experience by volunteering and providing support to other women afflicted by the disease. She told Elaine that she “signed on to the ACS' Cancer Survivor Network where she's created her own webpage, and can go to chat rooms and email with others in similar situation. She's already received a couple of emails from women.”

Olivia (CM) experienced a social constraint when she attempted to talk to a relative about her anxiety and fear about upcoming chemotherapy treatments. Elaine noted:

The father of her son's girlfriend had cancer back in 1983 and had chemotherapy. Every time she talks to him, he tells her how horrible his chemo experience was. He's to the point of being abusive in my mind. On Sunday she refused to talk with him and I applauded her for taking such good care of herself!

Daphne (MO) also dealt with the social constraint of friends who were unsure of how to react about her cancer, and thus made her uncomfortable or dread being in contact with them. Elaine noted, “there are others in her life with whom she is friends (though not close) who are pitying her, or crying when she talks to them or giving advice and this is not helpful to her. Daphne is trying to avoid the friends who are not helpful and is setting good boundaries, but she feels guilty.”

Although Isabelle (CM) suffered from bouts of anxiety during her six months in the study, she was able to see her diagnosis in a beneficial light. She went to the doctor for her three-month follow-up and was told she was cancer-free. Plus, during her treatments, she kept herself busy by writing a book, which was picked up by an agent in the hopes of getting published. Isabelle described what she had been through: “she feels like this has been a big transitional year for her and that breast cancer prepared her for waiting and putting things in perspective.” Similarly, Shana (CM) told Elaine she “credits her breast cancer for bringing people together.”

Marta (CM) developed an interesting way to rationalize and cope with her breast cancer. She told Elaine, “I have a very positive attitude and have taken to saying that I

had breast cancer as it has been removed and I just need to complete the preventative treatments.”

Another woman able to put a beneficial spin on breast cancer was Clarice (CM).

She told Elaine:

Ironic that you wrote today—just a few hours before receiving your message, I received a telephone call from a long-time friend. She had just had an ultrasound that showed a lump, was awaiting an appointment with a surgeon, biopsy, etc.—and said I was the first person she thought to call, as she saw me as knowledgeable and a ‘survivor.’ It certainly brought back memories of my first, uncertain days. And while my future is not certain, I feel secure enough to be able to help another with this journey.

Margo’s (MO) positivity made an impression on Elaine. She described Margo:

She has an amazingly positive attitude and refuses to let herself think negatively about her situation. She uses phrases like ‘I’m ready to rock and roll’; ‘I don’t have time to be sick, get depressed or have a pity party’; ‘this is just another obstacle in my life and I will be okay.’

Even during her treatment when she experienced pain and fatigue during chemotherapy, Margo continued to maintain a positive attitude, even encouraging her husband and four children to avoid thinking in negative terms or getting upset about her having breast cancer. She remarked that her kids did extremely well during her treatment “because of her attitude.” Deena (CM) was another woman who displayed a high degree of positivity upon learning she had breast cancer. She said, "I've got cancer but it doesn't have me."

### **Support**

Seeking support, whether exclusively through Elaine, through other CHESS users in the support group, or from friends and loved ones was another common theme in the data. Over half the participants discussed support in some capacity with Elaine, whether it was seeking some form of action-facilitating or nurturing support from her directly or

from CHESS. In some cases, women sought emotional and esteem support by noting the lack of these forms of nurturing support they received from family and friends.

Lydia (CM) admitted that by being diagnosed with breast cancer, “this experience has made her realize how great all of her friends are.” She was a special education teacher assistant, and her coworkers arranged to bring her meals around Christmastime. Furthermore, Lydia acknowledged that her husband was very supportive and recognized how difficult it was for her to endure the cancer ordeal.

Janelle (MO) had a strong network of friends, community members, and others who checked in with her regularly and tried to ease her fears. She wrote to Elaine:

Tomorrow I am seeing a patient who had this surgery 2 years ago. She is willing to show me the results. I am so lucky to have so much support! I seem to get a card or two in the mail each day from various friends as they find out and this has been going on for weeks! I told you we live in a small town. A florist called me and asked if I was OK after he got an order for a "cheerful bouquet" for me. Then he offered to cook a meal or wash my windows, whatever I need! People have been awesome. (Esteem Support)

Felicia (MO) was fortunate enough to have an incredible support network around her. A wife and mother of three children (ages eight, 10, and 11), she told Elaine that the “kids are doing well; they ask a lot of questions and are being honest and open. Her husband is very supportive and is keeping the household together. She also has many friends and family who are helping. In fact, two of her friends organized the delivery of two meals per week until next April!”

In Noelle’s (CM) case, her spouse was not comfortable with the medical process; Elaine wrote, “she told her husband only that she had to get a ct scan, but since he’s very afraid of medical things, she’s waiting to get the results before she tells him any more.

And, he's not asking for more information." Noelle's husband did not choose to be an involved and informed caretaker; she "described how he still hasn't asked any questions, but she thinks he knows she's okay because he overheard her talking to her sister-in-law on the phone about it." However, he attempted to show support in other ways to compensate for his fear of medical intervention. Noelle said, "he's helping her more around the house, which is a big change from before and she feels grateful for the support." This was initiated after she wrote him a letter outlining all of her medical problems for him [...] (and he became) much more kind and attentive." (Action-Facilitating and Nurturing Support)

Helga (CM) described how her husband did not take an interest or was extremely involved in her experience as a cancer patient: "my husband came with me and although he was bored (ran through his Sports Illustrated and had to turn to their Peoples), I think it was good for him to see what goes on. I think I will let him stay home next time as it is an easy drive and I feel fine."

Hannah (MO) struggled with a decrease in support and understanding from her husband. She sought nurturing support, specifically esteem and emotional support.

Elaine recounted one very difficult call she had with Hannah:

Hannah cried for the first time with me today. She's 'tired of being sick and tired.' Her husband is tired of it and she's not getting the support like she did before. This morning he was sarcastic when he said, 'are you sick again?' She says that problems used to bring them closer together, but this is pushing them apart. He's also having to do things at the shop that she usually does so he's more stressed out.

Ingrid (MO) experienced the social constraint of having a family member practice avoidance techniques. Her family was visiting her for Thanksgiving, and Elaine noted

that this included the brother “who has not kept in touch very well. She's angry with him for disappearing on her and doesn't know how it will go when they finally see each other on Thursday. She plans to keep her head bare and be open and honest about her experience, even if it's hard for him. I mentioned that we all respond differently in a crisis and I realize how much it must hurt that he couldn't be there for her. She agreed.”

Adrian (MO) dealt with a similar situation in which “her coworkers seemed uncomfortable around her and this was difficult.” Likewise, Signe (MO) recalled attending a party “and was uncomfortable with the way people treated her—too much focus on her cancer.”

Michelle (MO) also had to deal with a family member who seemed to disappear when she was most vulnerable. She told Elaine:

My brother and his wife haven't been there for us. Steve, my husband, is particularly bothered by this. I try not to get dragged with negativity and try to appreciate all the people who have been there in amazing ways, its just that when people we didn't expect to be helpful with meals, rides, cards, calls have been so amazing, its hard to not feel let down by a brother who hasn't done the same. I really thought he would be there and be helpful, when my father was dying of cancer, I do remember that my brother had a hard time dealing with that and he avoided him also. His wife is not the most supportive person and historically has not put herself out to help our family either. (Emotional Support)

Hallie (MO) struggled with being the focus of people's concern and pity. Elaine described the situation:

She's uncomfortable with people coming over or feeling pity for her. Her parents are having a hard time and she doesn't want to be around them much. [...] It sounds like if anyone shows compassion or caring or their own feelings about this, she gets really uncomfortable. She really wants to focus on getting better and she's basically eating well, doing her exercises and sleeping in order for this to happen. However, she feels bad if she doesn't respond to people. I suggested a mass email thanking people for their concern, cards, messages, etc. with a little

update about how she's doing. She liked this idea. I gave her lots of support and encouraged her to let herself feel sad or whatever at least a little bit each day.

Cora (MO) echoed Hallie's desire to avoid being the subject of other people's attention. She thought of herself as "a caretaker, and isn't used to others caring for her." Reyna (CM) shared the same sentiment; she described herself as being the family's "air traffic controller, and when she's down, planes crash." Similarly, another woman, Isabelle (CM), found it difficult to grieve and cope with her breast cancer diagnosis because she was so used to worrying about everybody else. She told Elaine, "everyone around her has cried about her diagnosis except her. She's able to cry about others, but not for herself. Her fear is that other loved ones will get sick and not for herself."

While social factors proved to be a limitation when it came to support (e.g., family and friends unwilling to discuss cancer diagnosis or listen, or people being too willing to help and not giving the patient adequate space), other situations also restricted the amount of support the women received. Myra (CM) felt as though she had family and friends to provide support and assistance, but geography proved to be an outside constraint. She lived in a small town in Wisconsin, and told Elaine she felt isolated because of her rural location.

Torrie (CM) found substantial social network support through a group of friends willing to accompany her to treatments. Elaine noted, "her friends have signed up to take her to radiation each day and she's really enjoying the few hours she gets to spend with each of them. They often go out to eat or go shopping." In this case, it appears Torrie found a benefit and made her situation positive—despite dealing with cancer and undergoing treatment, she was able to spend time with friends and do activities other than

just traveling to and from the medical facility. This became such an important routine for her throughout the treatment process that she said she was “anxious about treatment ending. [...] Will also miss driving to and from Madison with various friends and eating out, shopping, etc.” However, she was fortunate enough that her friends and other family members continued to be a strong support system for her and assisted her in cooking and cleaning at home. In Torrie’s case, she did not experience social constraints that limited her ability to receive support from a group of friends and family whom she trusted.

Savannah’s (CM) colleagues, neighbors, and friends provided a strong support network for her. Neighbors repeatedly brought her food so she wouldn’t have to spend time and energy cooking. She was the center of attention at a “pink” party, and was taken to listen to a speaker discuss her experience with breast cancer. Afterward, everyone had dinner together. She told Elaine that she was not inclined to go on the CHESS discussion group or join a support group because “she corresponds with a couple of friends who've been through this and feels this is sufficient.”

Aisha (CM) was another patient fortunate enough to have a strong social network of friends willing to assist her through the cancer process. She and her partner often had to figure out tasks for them to accomplish, which included taking Aisha to treatments, cleaning the house, and walking the dog. Her friends were so eager to help that Aisha ended up utilizing Elaine to brainstorm projects for them to accomplish. In addition to its physical toll, cancer tested her personality. She thought of herself “as an analytical person who is pretty in touch with feelings, but approaches this (cancer diagnosis) intellectually rather than emotionally.”

Aisha was also reluctant to utilize the technology at hand, acknowledging, “she needs to talk more about her feelings, but isn't into support groups and the CHESS discussion group just makes her sad. She is used to being very self-reliant and looks after her own emotional well-being.” Aisha confided to Elaine that she tried to live a “normal” life during the week and thus would avoid logging onto CHESS because she needed to take a break from thinking about breast cancer. She also admitted she was “informed and assertive where surgery were concerned, and is informed about chemo, but just kind of went along with what doctor suggested.” She compared herself to coworkers who had undergone chemotherapy, and would wake up during the night obsessing about her cancer. Her positive diagnosis with cancer forced her to confront not only the disease, but also the importance of discussing it with others, whether it be family, friends, or Elaine. Despite this independence, she told Elaine she was grateful for the access to the CHESS module and a mentor.

As she progressed through her chemotherapy treatments, Aisha’s emotions were tested repeatedly. She worried that she was genetically at risk for contracting ovarian cancer, given that she had breast cancer and her body was continuously undergoing hormone changes. She also confided that she was scared since she was not used to being “emotionally out of control.” Furthermore, she became so anxious that she experienced anticipatory nausea, a condition in which a cancer patient feels sick prior to receiving a chemotherapy treatment. She fought this by engaging in positive self-talk, relaxation techniques, and using a portion of CHESS entitled “Easing Distress” at the recommendation of Elaine.

Toward the end of her participation in the study, Aisha mentioned that she routinely confronted her breast cancer diagnosis, its impact on her life, and allowed to actually experience her feelings. In fact, by the end of the study, Aisha welcomed outside support; she wanted to keep participating in a support group and counseling. Consistent with Lepore et al. (1996), her preconceived notions of herself were disrupted upon a positive breast cancer diagnosis. Prior to the situation, Aisha felt independent and in control of her emotions. She suddenly became vulnerable and relied on others (her doctors, friends, her partner, and Elaine) to provide her with support and information for survival.

Friends not only offered emotional support, but also served as additional sources of information and medical recommendations during participants' time in the study. Jaime (CM) was fortunate enough to have a close friend who was a doctor or nurse; thus, this person went with her to most appointments and was "wonderful in helping her understand what's going on and who asks the right questions." She also explored CHESS and found the discussion group helpful, even participating in it on several occasions.

Winifred (CM) was very grateful for the opportunity to talk on a consistent basis for six months with a mentor. She told Elaine:

Because of your wisdom, I was able to gain all the support I needed from family and friends. Being able to talk so openly with you gave me the courage to address any issues that I was facing. And as you know, I have a family that greatly encouraged me through my treatments, but you helped me understand how to effectively communicate my needs and limitations. (Esteem Support)

Daphne (MO) became very attached to Elaine during her time in the study. "At the end of the call I reminded her that this was our 8th call and that we would only have

two more,” Elaine said. “She began to cry then and said she hadn't realized we were nearing the end. I sat with her while she cried.” Daphne told her, “I have enjoyed our relationship and obviously am sad to see it come to an end. You have been very supportive and helpful. I will enjoy the next two calls and will be more prepared to say good-bye.” Tonya (CM) referred to Elaine as “my very own angel of hope!” Daphne relied on Elaine as her source for action-facilitating and nurturing support; the prospect of losing this foundation was aggravating and deeply upsetting.

Alexa (MO) relied heavily on Elaine as a constant line of support during her six months of participation in the study. She was a widow upon joining, and her children were spread out around the country. She also lost a close friend to pneumonia and who had suffered from some of the same health problems as Alexa. Alexa was very emotional upon learning this news. In this particular instance, the bad news even affected Elaine in terms of her relationship with Alexa as a mentor. “I had to mention that our next call would be our last and she took it in stride, but I could tell that this is a very rough time to lose another support person. I encouraged her to call me before our next scheduled call if she needs to talk.” While it is hard to infer in most cases how much having to say goodbye to the patients affected Elaine, it appears because of the information Alexa disclosed about losing her family and friends one by one made Elaine realize how important her work and role was in Alexa’s life. It also showed Elaine the extent to which ending Alexa’s study participation and mentor access might affect her emotional and mental well-being.

Reyna (CM) was also very grateful to Elaine for being her mentor, as well as having access to CHESS during her time in the study. She told Elaine:

I wanted to thank you, again, for all of your kind support during the past months. I feel very fortunate to have benefited from what CHESS offered. Your compassion, willingness to listen, and laughing with me have been a significant part of my ability to cope with my diagnosis. I look forward to a future that hopefully will be cancer-free while gathering inner strength from exceptional people like you. (Esteem Support)

Tabitha (MO) echoed Reyna's sentiments when she said, "I want to thank you for being able to talk to because I do enjoy and feel I need someone and you are great." She confessed that she was "sad that we only have one more phone call."

Sophie (CM) expressed her gratitude for having the opportunity to talk to Elaine with a religious reference, as noted earlier. She also repeatedly reiterated her appreciation on several calls:

Thank you again so much for giving of yourself! I appreciate you taking the time to help me when I didn't know which end was up. You helped me get beyond being scared and see that when I needed it I could muster up the strength to do the things I needed to do. I will forever be grateful for that. I pray God will richly bless you for all that you have done and continue to do to help others (and me). I feel that you shared more of yourself than I ever could, so THANK YOU!!!! Please take care and be assured that you have been my angel for the past six months. I feel like a rose that has begun to open in the spring, it has thorns but it is still strong and full of character. Take care of yourself and enjoy the springtime. (Esteem Support)

Olivia (CM) sought emotional and esteem support from Elaine when she became frustrated with her oncologist. She complained, "she's been trying to talk with Dr. Green, but says that someone else always calls her back, never the doctor." Olivia felt Dr. Green's lack of calls or speaking to Olivia herself when she left messages with questions displayed Dr. Green's lack of interest. Olivia lamented, "I am beginning to think that she

doesn't care. I am just a number to her, and not a person! I am really disappointed in her.” Olivia went on to say, “I can't believe that this doctor can't make the time or rather take a few minutes of her time to talk to me. She is getting paid for her services, it's not like it's charity! I feel I deserve better than this.” Olivia described her next appointment with Dr. Green:

Dr. Green got her nose bent out of shape when I mentioned to her that I needed to hear from her and not others. She is supposed to be my doctor. I only wanted her to call me and explain the situation to me and reassure me. She said she only sees her patients in the hospital if she is on rotation at that time. She has her nurse call and relay her messages or the doctors that are on rotation in her group will see me. I told her I asked the nurse to get a hold of her and she said she wasn't aware, but to be honest with you, her body language was saying more than she knew. To me I saw another side of Dr. Green I had not noticed. She seemed very uncaring, cold and not very compassionate at all. Her nurse was a lot more caring and considerate. I guess I am only a medical number to Dr. Green instead of a human being. That is the way she made me feel. Dr. Green mentioned that I might want to get another physician. I totally agree with her, since her outlook STINKS. I'm just sorry that I had so high hopes and trusted her. I guess what really got her mad was that I stated that my trust was out the window for now. It seems that I cannot depend on Dr. Green to be there for me when I really need my doctor.

Olivia also became frustrated when she would tell Dr. Green about side effects and other health issues that occurred, but felt Dr. Green was not concerned. “You know, Dr. Green mentioned that the steroids they were giving me sometimes could cause esophagus (problems), but she didn't seem at all concerned when I told her I was hurting in breast bone area,” she said. “Lack of communication didn't get me the medical attention I needed. [...] If anything I've encountered more medical problems along the way that could have been avoided. If only someone would have listened!”

Tessa (CM) was relieved to have access to CHESS during the study because she felt it was “very reassuring.” Betina (CM) also told Elaine, “last Thursday she started

‘freaking out’ about chemo, thinking about all of the side effects and afraid that they would ALL happen. Posted her concerns on CHESS discussion group and got good support.”

Some women seemed to practice avoidance techniques when it came to cognitively processing the fact that they had breast cancer. When describing Trish (CM), Elaine noted, “at this point, Trish is not expressing any "feelings" about the extent of her cancer. Remains upbeat and I wasn't sure whether to probe this at all, so I didn't.”

Gilda (MO) also appeared to distance herself and limit her contact with her mentor. Elaine commented after one conversation, “another very short call. She doesn't seem to want to open up to me and keeps a ‘stiff upper lip.’ I suppose this is her way of coping.” Bailey (CM) participated in her first call with Elaine, and then requested to skip the next three calls and be contacted on a monthly basis, rather than weekly calls during the first month of the study. She told Elaine she “didn't think she needed a mentor.”

Larissa (MO) utilized other sites with a discussion group function to find support.

Elaine wrote:

She has now posted on [ibcsupport.org](http://ibcsupport.org) website—introduced herself and has received about 50 responses. Found some women in Kentucky who are beating this disease. Considering starting a support group with these women. Also heard from another woman in her 70's who has been surviving ibc for 11 years. She had only read stories about people not doing so well so this was a big deal to read about women who are making it. I gave her lots of kudos for putting herself out there. (Social Network Support)

Larissa continued to value this site for its utility; on her next two calls, she remarked that she was still participating on the [ibcsupport.org](http://ibcsupport.org) discussion site and getting a lot out of it in terms of communicating with other cancer patients and receiving support.

While many women embraced all the different advantages of being granted access to CHESS' services, several women did not prefer to participate in this opportunity. For example, Daphne (MO) told Elaine she "had full CHESS six years ago with her first (breast cancer) diagnosis and she didn't like the discussion group because she feels burdened by the plight of others. She's unsure if this would still be the case and may try out support groups later." Lorna (CM) "noticed that reading the discussion group was getting her down, so she stopped doing that."

Addie (CM) was another participant reluctant to engage in the discussion group on CHESS. Elaine recorded:

I shared a recent news article about radiation [...]; we discussed side effects and ways to deal with them and I suggested she write to her discussion group about their experiences with radiation. This led to a discussion about how she feels guilty about not being as sick as the other women and wondering what she has to offer them. I pointed out her compassion and empathy as well as her beginning experience as valuable to other women.

Likewise, Carissa (CM) confessed to Elaine, "I've got to spend a little while perusing the (CHESS) site to get my bearings to take advantage of this opportunity given to me. I do feel a bit guilty as I know other women are dealing with much more severe forms of breast cancer. I'm very lucky to have caught mine so early." Rosetta (MO) also expressed that "she feels guilty because her cancer was caught so early and she hasn't been through what others are going through." Elaine "reminded her that there would be newly diagnosed women that she could help and that just as a person she has things to offer to other women." Isabelle (CM) also needed coaxing from Elaine when it came to posting questions on the CHESS discussion group asking about side effects of tamoxifen:

She stated that the women on there are going through much more than she is and also that she feels compelled to offer them support if she starts writing. I (Elaine) assured her that it's okay to post a message to all, get feedback and then post another message to all thanking those who wrote back.

When Isabelle did participate in the discussion group, she seemed to experience negative results. She told Elaine:

She had a 'meltdown' yesterday. High anxiety after reading discussion group on CHESS. Began to doubt her treatment choices. Talked with her husband and started to feel better. Doing even better today—trusts her original decisions again. Many of the stories were from women who were told things were fine, then diagnosed with breast cancer.”

Isla (MO) was also hesitant to take advantage of the CHESS discussion groups

Elaine wrote:

She's been actively using the discussion group, but feels a little guilty because she's done with treatment and some of these women are nearing the end of their lives. Her therapist suggested that maybe there's a reason she's on the group such as giving support to others. I concurred and informed her that there are women in all phases of their cancer experience.

However, over the next month she admitted to Elaine that she was giving and receiving support via the CHESS discussion group, as well as looking up information on the site to deal with her concerns and questions as they surfaced. Isla did comment on how she was prone to depression and admitted that she cried frequently, so reading some of the sadder stories and posts on the discussion group was difficult at times.

## **Depression**

One of the more troublesome themes the participants dealt with was the feeling of depression about being diagnosed with breast cancer. Women in both the MO and CM groups experienced an array of emotions, including anxiety and helplessness, during the treatment and recovery process.

Felicia (MO) remarked that she felt “down and is wishing this could just be over.” Anastasia echoed these sentiments when she described feeling “severely depressed all week—not eating, exhausted, no enjoyment, and wishing she could go to sleep and not wake up until this is all over.” These feelings resurfaced during Anastasia’s (MO) participation in the study; a month later she still confided to Elaine that she “was in a bad funk” on certain days. Melinda (MO) expressed frustration because she could not sleep and was not interested in things like she used to be prior to her breast cancer diagnosis.

Cassandra (MO) was a minister and thus, her career meant she was a visible person in front of a congregation during her treatments. “She also describes how difficult it has been ‘having this happen in front my congregation,’” Elaine noted. “It’s very hard being on display and having to talk with people when all she wants to do is be alone.” She admitted to being “in a funk” and feeling restless. Plus, “things are tense at home because she really needs privacy and insulation and her husband doesn’t ‘get it.’”

Elaine played an important role as a mentor in the lives of some women battling depression. Augusta (CM) confided that she had “been feeling kind of depressed and she said she’d never go to counseling, but she liked talking to me (Elaine).”

Olivia (CM) experienced the desire to avoid talking about cancer in any capacity. She commented:

Sort of feeling a little down, don't know why, I tried to think as to what was making me feel like that, and don't know. I do know one thing, I really haven't been in the mood of discussing any topics regarding cancer, or have felt like reading up on any topics either. Guess I'm just going through a 'phase.' I try to avoid anything or subject regarding cancer. I just don't feel like talking about it.

Olivia also apologized to Elaine for not being talkative during several of their conversations because she did not want to talk to anybody and “enjoyed her quiet time.”

Eileen (CM) described how she felt like breast cancer robbed her of a sense of control over her life. She said, “I feel like my world is spinning off in another direction. I feel very alone even though I'm not.”

Marina (CM) experienced depressive symptoms following the end of her treatment process. She confided to Elaine during the eighth call that she “felt aimless” and was “pretty grumpy and not sure how to get out of this ‘funk.’” During the ninth call, Marina still admitted that she “may be a little bit depressed, doesn't really care about anything, doesn't feel right, but doesn't feel wrong.” Marina went on to say that she “feels as though her life is on hold until surgery complete,” which illustrates the weight of the situation on her mind and how the cancer diagnosis dictated her thoughts and actions throughout the recovery process.

Jaime (CM) also experienced detachment from her normal activities, and the desire to separate herself from others. She confided to Elaine:

I feel somewhat non-functioning. Don't want to do much of anything. Haven't really been able to go back to work and really don't want to talk about any of this. Just think it's been a lot of stuff in a short and long period of time. Haven't really slept through the night since I found out in April and haven't woken up once without that being the first thing on my mind. I have a lot of wonderful support from a large family and wonderful friends, but I'm sure everyone including me is sick of talking about it and not really having any set plan yet. (I hang around a lot of goal setters.) I like to have a PLAN. [...] My greatest peace has come from a couple of friends that have experienced similar cancer.

To cope with the unnerving situation she was experiencing, Jaime found that forcing herself to keep busy prevented her (at least for small periods of time) to avoid thinking

about her positive breast cancer diagnosis. For example, tasks such as going to work, spending time participating in the CHESS discussion group, and going out to dinner with friends were all ways Jaime avoided the constant weight of cancer on her mind. Jaime utilized CHESS more for its support opportunities and less as a portal for medical information. At the end of her treatments, Jaime described what she had endured as “a very confusing journey, lots of dark places, but lots of lights of hope as well.” She also felt that she “had incredible support and help” and hoped she could “be there for someone in the future to repay the kindness.” Her method of coping and cognitively processing her cancer experience led her to see things in a positive perspective and even how cancer benefitted her—she could now provide assistance to others who may experience breast cancer in the future.

### **Information-Seeking Behavior**

Another theme that emerged, perhaps unsurprisingly, was information-seeking behavior. Beyond merely coping by receiving emotional and social support, many women utilized Elaine and CHESS services to provide them with adequate data about cancer, treatment options, symptoms, and side effects. While some women were proactive in seeking informational support, others requested Elaine to do the bulk of the work in finding appropriate sources to answer questions or enhance data they received from their medical providers.

Many breast cancer patients asked Elaine about aspects of their treatment, such as the benefits and risks of taking Tamoxifen, a drug that interferes with estrogen within the body (Fisher, Constantino, Wickerham, Redmond, Kavanah, Cronin, Vogel, Robidoux,

Dimitrov, Atkins, Daly, Wieand, Tan-Chiu, Ford, Wolmark, 1998). Nearly every individual discussed the side effects of receiving treatment for breast cancer with Elaine at some point during their participation in this study. Some developed infections or surgical incisions that did not heal properly following surgery. Many women reported redness and swelling in their breasts following lumpectomies. They also experienced itchy skin while undergoing radiation. Overall, most participants reported nausea, dizziness, and fatigue, regardless of what treatment options they pursued.

Women also wanted to know the benefits versus risks of possible treatment options. For example, Anastasia (MO) talked with Elaine about different types of radiation, such as brachytherapy and tomotherapy in the hopes of acquiring information and making the best treatment decision for herself. And, after undergoing brachytherapy, Anastasia was still an engaged patient. She was prescribed tamoxifen, but was hesitant to take it because of the potential side effects it could cause. She even wanted to look over her own pathology report before she made up her mind. Carly (MO) requested correct terminology involving postmastectomy radiation therapy (PRT) and statistics on the success of getting rid of cancer when varying numbers of lymph nodes are involved in PRT. Gena (MO) had Elaine explain what decadron was to her, as well as describing the upcoming tests she would undergo following her lumpectomy. Gena also discussed aromatase inhibitors, herceptin, and her treatment options with Elaine. Other women asked Elaine about how to obtain wigs once their hair began to fall out, or how to get prostheses they could wear following mastectomies. The number of lymph nodes taken

in a sentinel node biopsy was a question women asked during their treatments when doctors needed to run tests to determine the extent of their cancer.

Another concern for women was being genetically predisposed to get breast cancer. Francine (MO) expressed the concern she and her daughters had “about the risk/heredity (of getting breast cancer). [...] I (Elaine) read some information from NCI's genetic testing booklet and then helped her find it online and make it a favorite so her daughters can read it.” Francine began taking arimidex but had to stop because of how much pain it caused her from head to toe. She was unsure of how beneficial tamoxifen or arimidex would be because “she'd like to take something, but not if it affects her quality of life so much.” Elaine discussed the advantages and risks of tamoxifen to help her make a decision. Francine then talked to her oncologist, and using this information, helped determine that she should take aromasin, a different drug that might not have caused so many negative side effects.

As one of the participants without access to CHESS, Naomi (MO) relied heavily on Elaine to prepare her for undergoing chemotherapy treatments. She asked Elaine to send her articles and websites on what to expect in terms of what happens during a chemotherapy treatment and the side effects that went along with it. Naomi also sought information about hormone therapy from Elaine prior to her doctor and oncologist appointments.

Estelle (CM) asked about specific pharmaceutical drugs for her treatment regimen. Elaine wrote, “she asked me about silver sulfadiazine and I read to her from

Medline Plus Drug Information. Will send link. She is using this now to prevent infection because the radiation really burned her skin.” Elaine noted in a later call:

She asked about side effects of herceptin and pain is listed as one of them, but the book doesn't describe the pain. I also tried to find some information on side effects from long-term use of herceptin since she'll be on it for a year. I will do some research and get back to her.

The amount of information she sought and the stress of dealing with breast cancer began to take its toll on Estelle. Elaine recalled, “she's not sure how much of this she can tolerate. I gave support and also looked up taxotere information. Pain is a less common so I suggested she at least speak with her doctor about it.”

Savannah (CM) made a large effort to gather information from a variety of people about which treatments she should receive and how she should formulate her plan for recovering from breast cancer. As Elaine noted:

Since last week, Savannah has seen Dr. Breslin to go over pathology report. She is node negative, grade 2, hormone positive and her tumor is 1.3 centimeters. Dr. Breslin says that chemotherapy is an option, but it'll be up to Savannah. Savannah then saw Dr. Van Ummersen who shared statistics, side effects, etc. and told her the decision was hers to make. Savannah has since spoken with various people in the field who have made suggestions and given their personal and professional opinions. One is a breast cancer researcher in public health and the other is an oncologist. She's also spoken with other women who are younger and have little knowledge about breast cancer and asked for their opinions. Most of them say they'd do whatever is available.

Savannah also consulted Elaine for her opinion on whether to do chemotherapy, tamoxifen, or ovarian ablation. Elaine gave her information from the National Cancer institute's website and helped her figure out what questions to ask her doctor at her next appointment. Plus, she confided to Elaine that she was “concerned about cognitive dysfunction with tamoxifen but hasn't found any information to suggest that this is a risk

factor.” Savannah actively pursued information and wanted a variety of opinions to make sure she had facts and clarification before making her decision. Furthermore, her doctors empowered her to make her own treatment decision, rather than simply telling her she would undergo chemotherapy, radiation, or take tamoxifen.

Kerri (MO) relied on Elaine to provide her with basic information about cancer and treatments. Thus, Elaine served as a source of informational support; Kerri relied on the mentor to share knowledge about medical terminology and the changes her body experienced while battling breast cancer. She asked Elaine:

How does radiation work? I don't mean what does it do inside the body, I mean what is going on inside the machine that makes it attack the cells in the body? What is inside the machine? What is happening with whatever is inside the machine?

Another participant in the mentor-only condition, Muriel (MO), asked in-depth questions to Elaine beyond merely data on treatment options or expected side effects. She had Elaine describe a bone tumor to her, define what a PET scan was, tell her what about the herbal remedy essiac, and give her information on the Cancer Treatment Centers of America.

Karina (CM) liked to be informed and play an active role in how she lived during treatment. She often asked Elaine for information, such as side effects of treatments on organs (e.g. the heart and lungs), whether alternative forms of medicine were better than drugs such as tamoxifen, and had Elaine help her navigate through her pathology report. On one call, Elaine described Karina’s method of actively seeking out ways to deal with breast cancer: “she is really exploring alternative healing by changing her diet, bringing therapeutic touch back into her life, having a metatex blood test to find out what's

going on in all of her organs.” Karina even took on the role of distributing information to others, including her mentor. Elaine noted, “she's read more books about diet and continues to see her naturopath. Just found out a friend has ovarian cancer. Sent her an article about Dr. Nicholas Gonzalez and his nutritional treatments. Offered to send one to me and I accepted.”

The women found various sections of CHESS helpful during their treatment and recovery process. Because of her anxiety about her disease and the downtime between treatments, Elaine referred Bryn (CM) to the Mindfulness section that allowed users to participate in listening exercises. Bryn also concentrated on staying in shape as a way to keep her mind busy. She did yoga, swim exercises, arm exercises, and cycled every few days. She also enjoyed working every few days because, like exercising, it gave her something to concentrate on, rather than just thinking about breast cancer throughout the day. In addition to physical activity and work, Bryn spent the first four months of the study helping plan her son's wedding. She admitted because she was so busy, she did not spend much time thinking about cancer.

Elisa (CM) possessed the desire to learn as much information as possible about cancer and understand various facets of her diagnosis, such as side effects, risks versus benefits of treatments, and how breast cancer could increase her likelihood of developing other health problems. She was also very forward in describing herself in her first email to Elaine:

I am a physical therapist and have taken good care of myself so it is a surprise to have cancer. I am a Christian and really rely and trust in God to take care of me and my family. Lots of good friends and family and I am a positive person so I am coping as well as I think I can. Thank God I do not have a met because then I

would not be coping as well. I do worry about a future reoccurrence. I hear that herceptin is not effective in crossing the blood-brain barrier. I want to be proactive and if I had unlimited funds I would probably have a brain MRI every year as well as body MRI and PET scans. I'm not sure why I told you that but I have nothing to hide from you I guess. That's all for now.

Elisa utilized the “Ask an Expert” function of CHESS, attended the “Look Good, Feel Better” program through the American Cancer Society, and voiced her concern over one oncologist she saw because she “needs someone who is more direct with her” when it came to talking about what treatment she should follow, side effects, etc. She inquired about taking marijuana to curb her nausea and integrative medicine techniques (e.g., acupuncture). Elaine searched the web for information on vitamins B6 and B12 and neuropathy at Elisa’s request.

Addie (CM) relied on Elaine’s knowledge to put her at ease and pass along information to help her answer questions and determine whether or not to undergo chemotherapy. Regarding a brochure she was given by her doctor, she asked Elaine:

It said that more studies are suggesting that chemo be done even in small stage 1 tumors with no nodal involvement because cancer is a systemic disease. So, is that the norm? Should I be preparing myself for that? I thought I had dodged that bullet if the nodes were negative. Not true?

Addie was also extremely unnerved when her oncologist became unnerved that she was still using the pill for birth control, even after five weeks of knowing about her positive breast cancer diagnosis. She recounted the story to Elaine:

I had a disturbing thing happen yesterday. I went in for my history and physical and like I have done many times before recounted my meds. Well, I am on the pill, and once when I told another RN this she asked if my surgeon had taken me off of it. I told her not yet. Today when I had my H&P the RN took down my meds and asked me if I was still on the pill. When I said yes she called the oncologist who told her I should stop taking it IMMEDIATELY. I asked the nurse why and she said it was like putting fertilizer on the cancer since the cancer

is estrogen sensitive. Well, heck! I should have been taken off of that 5 weeks ago when the diagnosis was made! So now it seems that a scary situation is scarier. I have lost faith in.....I don't know who.....the surgeon?? She saw my meds list and should have known. I'm not certain what to do but it feels significant to me--like a loss of trust. I don't know if I am overreacting or not and wanted to get your thoughts.

Clarice (CM) relied on Elaine's knowledge to calm her fear of taking tamoxifen as part of her treatment regimen. She told Elaine, "I also appreciated your comments about tamoxifen—those were some of my major concerns. The more research I did, the more worried I became about side effects..." Like she did for other women, Elaine served as a source of support (in addition to a portal of information) as Juliet navigated through her treatment. She recalled:

I met with a medical oncologist for the first time today. And rather than feeling reassured, now feel even more confused, and depressed for the first time since the initial diagnosis! I was hoping for more information and clear answers, but didn't receive that, or the reassurance I'd wanted. In part, that was because the estrogen and progesterone receptor status studies were still not finished—so we don't know that status of the tumor. Then—I learned about even more worrisome side effects of tamoxifen—growth of fibroids (I have a huge one, with very, very heavy periods, and have refused a hysterectomy for the past three years), depression (I was treated for depression during and after my pregnancy, but have felt great for the past six years, and don't want to go there again!), hair loss, facial hair growth (my mom's family is Italian—need I say more?!). And then I was told that taking tamoxifen does not increase longevity—just reduces the rate of cancer recurrence. I feel doomed either way. Like everyone else, I want both the quality and quantity of life! And the fact that only the MRI showed my cancer (never seen on a mammogram) makes prevention even more important, as I will always doubt the detection again.

Yvette (MO) went straight to Elaine when she became upset and stressed out over a doctor's appointment. Elaine recounted their conversation:

Yvette is panicking about what the oncologist and gynecologist have told her. Medical oncologist told her that she can't take tamoxifen because she has too much estrogen and will either need an oophorectomy or hormone shot to put her into menopause. Her gynecologist wants to do a hysterectomy due to her clotting

and spotting. Yvette tried to see the medical oncologist at MDA since our last call to discuss options, but couldn't get an appointment until mid-November. She does not want to wait that long and thinks she will just go ahead and have the hysterectomy next week. She sees the medical oncologist tomorrow and I suggested she have him write down all of her options along with the reason that she can't take tamoxifen. If what she heard is what he said, then I told her that it didn't make sense to me because tamoxifen has been given to pre-menopausal women for years. I honestly can't tell if she's confused by what he said or if he really said this. That's why I asked her to have him write the reason down. She will email his response to me, but asked me to email her in case she forgets. I attempted to give her support, but I think I made things more difficult for her because she says she's getting opinions from all sorts of people.

Gilda (MO) was another participant who took a proactive role in acquiring information. As Elaine noted, “when I explained that I can be a resource for her, she said that her doctors are very good about answering her questions and she's also reading Dr. Susan Love's Breast Book, as well as another breast cancer book by a surgeon at Harvard.”

Misty (CM) pointed out the importance of understanding breast cancer, treatments, its effect on the body, and other topics associated with a positive diagnosis. “I later reminded Lynda (her partner) that going into the appointment prepared and participating in the treatment plan makes for a brief doctor's visit!”

Hallie (MO) sought information on how to lead a healthy lifestyle to reduce her chances of breast cancer recurrence. She participated in acupuncture, yoga, and discussed the benefits of meditation with Elaine. She also wanted Elaine to refer her to authors who wrote about meditation practices. All of this was done to help curb what Hallie described as depression—cyclical unhappiness that coincided with each round of chemotherapy.

However, some participants preferred to know information about their treatments, but remained more passive when it came to making decisions and selecting treatments. This is illustrated by Natalie (CM), whom Elaine described as “the kind of person who doesn't want to know too much about her disease and wants doctor to make treatment decisions for her. However, she does want to know the pros and cons of a treatment and then do whatever the doctor recommends.” Despite wanting her medical providers to ultimately choose her treatment plan, Natalie was very inquisitive and asked many questions, including about the procedures determined for her by doctors. For example, she mentioned that she had read about hormone therapy, and during radiation, questioned why her breast was not numbed a second time during needle placement and injection.

Natalie often emailed Elaine to ask multiple questions and allow Elaine time to look up the answers and return her messages. She inquired about the number of sentinel lymph nodes a person has, why having children decreases the risk of getting breast cancer, and the likelihood of other female relatives being diagnosed with breast cancer if one of them is afflicted with it. In another email, Natalie asked Elaine questions more specific to her own treatment and recovery process, such as if there was a link between consuming soy products and breast cancer, the possibility of getting a nutrition or dietician to assist in low-fat meal-planning, and whether radiation treatments would make her sick, and how long radiation treatments last. A third email revealed Natalie inquiring about whether drinking green tea reduced one's risk of getting cancer and for more information on environmental estrogens. She also wanted information on whether using flaxseed prevented cancer, if drinking water from plastic bottles gave off cancer-causing

toxins, and if cancer treatment centers were more beneficial than traditional hospitals for receiving treatments. Toward the end of her treatment process, she even second-guessed herself as far as asking the right questions (both to Elaine and her doctor); Elaine assured her that this was not true and she had sought the appropriate information from each medical provider during chemotherapy and radiation.

Natalie underwent a lumpectomy, radiation, and chemotherapy, but began to question this method of battling her cancer:

Wondering if I made the 'right' decision to have a lumpectomy versus a mastectomy. Before I had the surgery I asked Dr. Mack what most women chose. He told me a lumpectomy. Dr. Patel (the radiologist) told me the outcome is about the same whether you choose a Mastectomy or a Lumpectomy as long as the lumpectomy is followed by radiation. I think I made the 'right' decision for me for 'now,' but I wonder if I made the 'right' decision for the long haul. I'm talking 10, 15, 20, years down the road. I wonder if doing six weeks of radiation now is going to put me in greater danger years from now. My 'gut' feeling is telling me "yes." Common sense is telling me 'yes.' Why didn't I think about this sooner? Even if it had, I'm not sure I would have chosen a Mastectomy over lumpectomy. Though the treatment would have ended sooner—I don't know—I'm not sure. Sometimes, it's not good to be given choices. I'm curious to know why CVCTT chose mastectomy over lumpectomy. Most people I've spoken to--and those offering an opinion, say they would have chosen mastectomy over lumpectomy. I'm really beginning to question my choice. It's too late now to change course--but for future reference just in case I need it, please research radiation treatment/radiation exposure and how that might cause future cancers. Please level with me and tell me the whole 'truth.'

Elaine responded by assuring Natalie she still had time to make a change in her treatment process and gave her information from the National Cancer Institute that compared a lumpectomy and mastectomy. Though her doctors determined her treatment process, Natalie was not a passive patient. She spent a great deal of time reading about breast cancer on the Internet, talking to others about the disease, and making sure that she made sound decisions about nutrition that would not put her at a greater risk for being

diagnosed with cancer again. While Natalie did not want to make final decisions about her treatments, she clearly actively coped with her diagnosis by researching and seeking information on her own so that she was still well-informed about her options.

Helga (CM) also utilized CHESS as a source of information when wondering what the best course of action was for her treatment. She “sent an Expert question regarding taxol versus taxotere and why a doctor might choose one over the other. I (Elaine) shared some information from pubmed.gov as well as Dr. Susan Love's Breast Book.” Helga also sought information from her doctors with the encouragement of Elaine. On one particular call, she said, “I just got back from the radiation consult. I was there for almost two hours, meeting first with a nurse practitioner, then the doctor and finally a nurse. They were very thorough in their explanations and I liked them all very much. I think I will be happy with the location and the treating (of) people. [...] I mentioned the hot flashes to the radiation oncologist and he too thought that trying natural soy was a good step in addition to the herbs.”

Jaime (CM) found CHESS helpful as a resource for information on mastectomy and breast reduction operations. She became frustrated with her doctor because she felt like it was hard to get through to the office and talk to someone who could answer her questions. By looking at the information provided through CHESS, Jaime was able to talk to her surgeon's assistant and get all her questions answered. Likewise, Marta “expressed (the belief) that (having access to) CHESS and (the) mentor was very helpful, particularly in terms of what questions to ask (doctors) and knowing what's coming up.”

Betsy (CM) used CHESS to assist her in navigating through and making sense of her pathology report. Estelle relied on the Symptom Management section to learn what she could expect in terms of fatigue during her radiation treatments.

The CHESS site also served an alternative form of support when seeking information became too emotionally difficult for the study's participants. Elaine noted:

Eileen was reading about lymph node surgery and getting worried about the extent of hers. We talked about [...] the chances of anything being in the lymph nodes is very low. This confirmed what her doctor is telling her. I suggested that she stop reading things right now, but I did encourage her to use the CHESS discussion group for support.

Eileen (CM) asked many questions regarding recommendations for the day of her mastectomy, e.g., what type of clothing to wear that would not interfere with or restrict her. She received too much information before she had cognitively processed her disease; this led to feeling overwhelmed and an even greater amount of anxiety. She was directed to the CHESS discussion groups several times by Elaine, so that she could ask other women about their experiences with surgery, including practical tips following the operation, and how to relieve anxiety. Eileen confessed, "she feels like she doesn't have much to offer the other women because she only had DCIS and isn't going through what they are. Also that reading the discussion group makes her feel guilty." The name DCIS refers to ductal carcinoma in situ, "a noninvasive condition in which abnormal cells are found in the lining of a breast duct. The abnormal cells have not spread outside the duct to other tissues in the breast" (Yale Medical Group, 2012).

CHESS became an integral part of many women's lives over the course of the six months they utilized the program. Elaine noted that one patient, Helga (CM), "asked

about continued access to CHESS after the 6 months and I explained the study parameters to her. She wanted to know if she'd automatically have access again after 14 months or would she need to call.”

Some women were hesitant to take advantage of being granted access to CHESS resources. Maura (CM) was cautious about utilizing the site prior to her mastectomy. She told Elaine, “she's not interested in having too much information until after her surgery. She thinks she may have read too much in the beginning and now wants to pace herself.” Elaine described one patient in particular, Lydia, who needed encouragement when it came to utilizing CHESS services:

She asked me if this is about the time that most women start feeling pain and I suggested she ask the women in her discussion group about their experiences. She hesitates to get involved in the group because it is so time-consuming, but I told her that it's okay to post her question, get the feedback and decide not to respond if she wants. I don't think she'll do this, however. Feels guilty about not using parts of CHESS and not having much to talk about on our phone calls. I said that the study is not judging how much or how little one participates, but the service's impact on a woman's quality of life.

Lydia (CM) also valued information concerning cancer recurrence. She admitted to being worried about her prognosis, despite her doctors assuring her that the prognosis was good. She read materials and wanted to be prepared for her cancer's recurrence. Elaine attempted to alleviate these fears by discussing recurrence statistics with her giving her support about her prognosis to put her at ease. Elaine also referred Lydia to information on the CHESS site, because Lydia said “she does not feel ‘drawn’ to using the discussion group.” Rather than participating in the discussion section of CHESS to ease her anxiety about breast cancer recurrence, Lydia sought other means to give herself confidence. She told Elaine “she read about the success of the Women's Intervention

Nutrition Study and is adopting a low-fat diet so that she feels she's still doing something to keep this cancer from coming back.” Lydia also disclosed that “she saw a complementary and alternative medical practitioner at Group Health (Cooperative) and they assessed how she's doing in the areas of emotional, spiritual and physical well-being. Result—doing quite well.”

As someone who flat out refused to engage in the CHESS discussion group because of how depressed she got reading women's stories of cancer recurrence, Leticia (CM) turned to Elaine to answer questions she may have posed to other CHESS participants. She inquired about cancer recurrence rates, exercise and diet suggestions to prevent recurrence, environmental estrogens, natural ways to reduce estrogen, and contralateral breast cancer. At her request, Elaine sent her information on complementary and alternative forms of medicine, as well as side effects of arimidex (since she was trying to determine whether to take that route for treatment). Leticia also took the initiative to have her doctor and oncologist answer questions, often emailing them or the lab about her results without being prompted by Elaine.

In the case of Lacy (CM), a former nurse, Elaine knew that she was “very interested in research and knowing all that she can.” She sent Lacy links from CHESS without Lacy requesting them first, and rather than Lacy asking questions during their calls, they had discussions about her doctor appointments and how she felt about what her medical providers prescribed to her as far as drugs (arimidex) and additional hormone therapy. Lacy often took the initiative in answering her own concerns as well; she would

travel to the nearest health or medical library and conduct her own research to answer questions or calm her fears.

During her time in the study, Juliet (CM) actually provided Elaine with information at one point. Elaine recalled, “she also wanted to know about tamoxifen in someone who has allergic bronchopulmonary aspergillus. I found some info on the web, but not much. Suggested a pubmed (pubmed.com) search. She is going to email me some info about this disease, just so I understand it better.”

Other times, Elaine was proactive in finding information on websites or reading passages from books to the participants even before they asked her for data. In the case of Felicia (MO), Elaine emailed her a list of websites on discussing radiation treatments with doctors, as this was the option she was pursuing to dispel her cancer. Felicia was grateful, saying that she would take notes upon reading through the sites so that she would feel “a little more intelligent” at her next doctor’s appointment. Elaine often also followed up on discussions with women by emailing them excerpts from online articles off the National Cancer Institute or American Cancer Society’s websites, or sections from books she found on breast cancer.

The women in this study were not the only ones who took advantage of having access to an informative resource such as CHESS. One patient, Trish (CM), used the site to learn about side effects of her mastectomy, but also acknowledged that her husband was logging onto CHESS and giving her information. In one instance, Trish recalled how she and her husband watched some of the videos on the CHESS site together.

## **Cancer and Death**

A theme that was not as prevalent among participants as some of the themes previously discussed (e.g. coping, support, information-seeking behavior) was the issue of cancer and death. Some participants, especially ones it appeared who received very little nurturing support, often expressed concerns about dying from cancer. This led to a host of reactions, from preparation for death (family arrangements, creating wills) to panic to a sense of calm and resolve that the individual had already lived a long and fulfilling life.

When other constraints, such as stress and finances became problematic, some breast cancer patients underwent stark changes in their attitudes. For example, Natalie (CM) admitted, "I wish I had my life back the way it was." She also wondered if undergoing chemotherapy was worth it, because she had "lived a good life and has no regrets, so that if things don't work out (i.e., she dies), she's okay with that." Natalie questioned whether putting in all the effort to undergo treatment would benefit her in the end, and if the ends justified the means.

Reyna (CM) learned that her breast cancer had potentially turned into Inflammatory Breast Cancer (IBC), a rare aggressive form of cancer in which the cancerous cells blocked the lymphatic cells within the breast (National Cancer Institute). Between that appointment and her follow-up appointment, in which it turned out she did not have IBC, Reyna began to think about death. "She said that on Sunday she was with her grandchildren and looked at them and wondered if she'd see the youngest start

school,” Elaine noted. “She says she tries not to let her mind go there, but it did and she cried a lot.”

Lillian (CM) met another woman with breast cancer while undergoing treatment and told Elaine that “this opened her heart and also made her realize that having breast cancer can mean death and ‘this could be me.’” Lillian clarified that she did not say this “in a morbid way and she doesn't worry about what might happen in the future, but she'll do what she has to do to take good care of herself.”

Some women addressed the issue of dying relatively early in their treatments. During her first month in the study, Myra (CM) noted that she was not afraid of dying, though perhaps she should've been and this was the incorrect attitude. However, she framed this as positive since everyone would eventually pass away and not being overwhelmed with fear during an uncertain time in her life was one less factor to provide her with stress.

Leigh (MO) had a history of cancer in her family, which affected her outlook on her own diagnosis. Elaine commented,

She's not concerned about dying from this cancer, but has for years believed that she will die from some cancer since most of her family has. Is considering starting to journal since she's done this through difficult times before. I pointed out that now might be a good time since she's waiting or she might do so after surgery while she's recuperating. Encouraged her to simply have her process and not judge it too much. She actually sounds to me like she has a pretty good attitude about the whole thing.

Betsy (CM) experienced a social constraint when it came to her fear of death.

Elaine wrote:

She told me that every once in awhile a little voice will say to her, ‘I'm not gonna make it.’ She wonders if this is common. I assured her that it's a normal reaction

to cancer and supported her in her efforts to not indulge this thinking for too long. She hasn't told anyone else about these thoughts because she doesn't want to go there with them.

Related to the social constraint was the fact that Betsy's friends could not contain their fear about her death while in front of her. Elaine noted:

Betsy has been feeling sad and scared lately. Last Saturday night she was out to dinner with some friends and the one is her P.A. started crying and said, 'you know you're going to be okay.' This was difficult for Betsy to hear and she spoke with her friend later and asked if she knows something that Betsy doesn't know. We talked about prognosis and how uncertain things are.

### **Other Factors Discussed with Mentor**

Besides the main topics of religiosity, support, coping, information-seeking behavior, and death, the women took the opportunity to discuss additional concerns with the mentor. Many women disclosed information about spouses or children that had ailments or health concerns. Dixie (MO) dealt with her daughter's brain injury in an automobile accident. In these instances, the women were forced to be concerned about the well-being not only of themselves, but also others around them. Marta (CM) mentioned that her mother had been diagnosed with kidney cancer, and one of her sisters was battling breast cancer while Marta was dealing with her own breast cancer. Karina (CM) disclosed that "her husband has Parkinson's so she wants to be around to take care of him," and that she was "concerned about having to drive back and forth every day for 6 weeks in the winter." In addition to her own breast cancer, Holly (CM) had to deal with several other family members diagnosed with cancer during the same year. She told Elaine that not only was her sister also diagnosed with breast cancer, but her "maternal

aunt had a hysterectomy for uterine cancer yesterday. [...] She also has an uncle who's had melanoma for 10 years. [...] Her maternal grandmother also had uterine cancer.”

Daphne (MO) was another patient who faced health concerns for loved ones, besides her breast cancer. She had a tumultuous relationship with her mother and daughter. She described her situation:

Her own sister and mother tend to be more of an emotional drain on her and these are difficult for her. She is the primary caregiver for her 85-year-old mother who lives in an independent living complex about 10 minutes from her house. She is agoraphobic, truly neurotic and not the least bit nurturing. Her sister is extremely needy and can't be there for Daphne—cries or gets angry when they talk.

Reyna (CM) was undergoing treatments while her husband was also receiving medical attention for a heart condition. This affected her support system—she used humor to cope with her situation because she did not “feel like she could share the really rough stuff with him” for fear of aggravating and worsening his heart condition.

Numerous women not only had to face breast cancer, but other lingering health complications that existed prior to their diagnosis or as a result of radiation or chemotherapy treatments. Dixie (MO) had undergone a kidney transplant and took insulin because her pancreas was defective. Alexa (MO) admitted that she “gets frustrated and angry that she has to deal with her illness. Not breast cancer, but the bowel problems as a result of ovarian cancer treatment years ago.” Lolita (MO) reported she “has bi-polar disorder and is on meds and seeing a psychiatrist regularly. [...] Also has Cobbs syndrome, which she says is a misconnection between artery and vein. Has 4 of these, two were removed (leg and abdomen), but still has 2 in her spine.”

Elaine noted that Lorna (CM) “also has thalassemia minor, which means that she has more white blood cells than red blood cells for which no treatment helps. I explained that radiation may affect red blood cells, but to ask her doctor if this treatment is a problem.” Lorna experienced frustration later on because she had to wait to get tests from doctors to determine if she could have radiation, and was unable to find anybody in the CHESS group with same condition. This left her feeling isolated and further annoyed, since she had nobody else in the study to discuss her medical condition with and receive tips or support. Betsy (CM) not only learned that she had breast cancer, but was also diagnosed with colon cancer prior to her involvement in the CHESS study.

Polly (CM) was diagnosed with multiple sclerosis nearly twenty-five years earlier, which left her in a wheelchair. She had nurses and aides that visited her throughout the week to help care for her. Following through with her mastectomy was a concern because prior surgeries had set off MS attacks that left her paralyzed and blind for a week at a time. Furthermore, Polly’s mother had Alzheimer’s disease, so Colleen was her primary caretaker. Polly’s cancer diagnosis meant that her own nurses and aides had to care for her mother when Polly was too weak and ill following treatments. Francine was forced to undergo gallbladder surgery, and due to this recovery process, had to miss and reschedule three radiation treatments.

Another issue many of the women faced was the fear of the burden of medical costs or that their insurance companies would not cover their treatments or materials needed during the process. Dixie (MO) feared she and her husband would have to pay twenty percent of her health care costs. Despite having Medicare and being on her

husband's insurance plan, she was stressed because she did not have enough money to pay for the prescription drugs needed for her cancer and other health complications.

## Discussion

This study examined breast cancer patients who were randomly assigned to one of two groups during their treatment and recovery process: one group had access to a mentor, while the other group had access to a mentor and could log on to an interactive cancer communication website named CHESS to submit questions, read information, and interact with other breast cancer patients in the study. In both cases, the mentor took notes; units of analysis consisted of complete conversations in which the mentor and participant talked to one another via the phone or email (without merely scheduling a future call) and were studied to uncover themes discussed by participants in the CHESS group, as well as the mentor-only group. Furthermore, this study looked at the degree of support provided by CHESS, and whether or not there were differences in coping abilities and information-seeking behavior between the CHESS and mentor-only groups. The data revealed that the majority of ideas discussed by the participants with their mentor fell under the headings of spirituality and religiosity, coping, support, depression, information-seeking behavior, and cancer and death.

Women in both the mentor-only and mentor and CHESS conditions referenced their spirituality and religiosity when it came to coping and receiving support during the stressful time in their lives. Cora was an example of a woman who recognized that her positive attitude about her situation stemmed from her firm belief in God. Darlene and Misty remarked at the extensive and strong support network they were engulfed in at their churches. Some participants, such as Blanche and Yvette, renewed their faith and began regularly attending religious services again and praying in solitude following their

breast cancer diagnoses. They felt that practicing religion was a way to take their mind off their negative situations, as well as giving them a source of positive energy to remain calm during their treatment processes.

Kara implemented approach-oriented measures to cope with her breast cancer by facing it, rather than avoiding the situation. She saw breast cancer as a bump in the road that needed to be overcome, but once conquered, would lead to a smoother and more carefree life. Instead of avoiding her diagnosis, she participated in alternative healing practices and acknowledged that she had cancer and would have to survive treatment before her life would become easier.

As far as coping with a positive breast cancer diagnosis, the women in the study varied in terms of how their approach and how successful their approach and their success were in dealing with such a traumatic event. Sonja, a woman in the mentor and CHESS group, experienced a high degree of anger and frustration over having breast cancer. However, participation in the discussion group appeared to improve her mood by exposing her to the idea that being angry and scared every day can also ruin every day. Reading this idea from another woman in the study helped Sonja change her philosophy on breast cancer, which in turn improved her mood and outlook while treating her breast cancer.

Leigh, Kerri, and Brittney, all in the mentor-only group, questioned why they were afflicted with breast cancer. Similar to the social-cognitive processing model, Leigh experienced a loss of invincibility due to a source of trauma (breast cancer) that affected her outlook on life. Kerri's lifestyle views were also shattered by her cancer; she did not

understand why she got the disease, given the fact that she led a healthy lifestyle. Brittney echoed Kerri's frustration about having breast cancer, out of all the people that could be diagnosed with the disease. Seven women in the mentor-only condition referenced having "pity parties" and mentioned the "why me" question as far as why they got cancer as opposed to other people. Only two women who had access to CHESS and a mentor explicitly discussed the "why me" aspect in their conversations with Elaine. Comparing the Mentor-Only group to the CHESS/Mentor group, the number of women who referenced feeling pity was statistically significant (chi-square value = 6.153, p-value = .013). Such a difference in the number of women who expressed self-pity is unlikely to have happened by chance.

Hair loss and one's changing appearance were frequently mentioned as stressors and concerns by women, regardless of whether they were in the mentor-only group or had access to a mentor and CHESS. Women had to adjust to losing their hair, or getting shorter hairstyles and wigs to hide this fact. Many of them took pride in their hair, so losing it because of their treatment regimen was a huge obstacle to overcome. Linked to that was the fear of how others (family members, friends, coworkers, the general public) would adjust to these women's new appearance. Women in both the CHESS and mentor-only groups reported that people were supportive and understood hair loss was collateral damage in order to get rid of the breast cancer.

Participants in both groups experienced social constraints of family and friends practicing avoidance techniques or being too eager to provide assistance. This sometimes damaged or threatened some women's support networks and created animosity between

patients and their loved ones. In order to create a healthier mindset, some women were even forced to limit how much interaction they had with these people to prevent feeling uncomfortable and stressed out.

### **Support**

The extent and quality of support women received from family, friends, and coworkers was contingent on their individual situations, not whether they were assigned to the mentor-only or the mentor and CHESS group. Some women only given access to the mentor wanted additional support from other breast cancer patients. Elaine referred them to other cancer websites with online support groups similar to that of the CHESS discussion group. Another factor that affected the degree to which women desired support was their personality; several participants assigned to the mentor and CHESS condition believed they received enough support from their family, friends, and coworkers, and deemed the CHESS discussion group irrelevant. Some women in both groups also chose to skip phone calls with Elaine or did not elaborate on their treatments and concerns during conversations; again, this appeared to rest more on women's personality and support they received from others and not what group they were assigned for the study.

Several women mentioned that they enjoyed being able to talk to a person (i.e., Elaine) about their problems and concerns. Even women like Reyna, who had access to online support via CHESS, remarked that it was helpful to be able to talk to a person during the ordeal. While women may have enjoyed reading information about breast cancer or communicating with others through the CHESS discussion groups, these

methods lacked the human element patients received by having phone conversations with Elaine. Participants could talk at their own paces and hear immediate feedback from Elaine. Furthermore, communication aspects, such as tone and inflection, are lost through online discussion forums or reading information on the web or in books.

Hearing nurturing support, such as one-on-one conversations with esteem and emotional elements, might be more beneficial for women than merely interacting with others through a computer.

Perhaps the most notable phenomenon was a case in which one woman, Clarice, switched from being mentored to being a mentor. Because she was part of the group that utilized both CHESS and the mentor, Clarice received information and support through two methods—visual (e.g., reading information and suggestions on the CHESS website), and audio (e.g., conversing on the phone with Elaine). She sought support from Elaine, but then a friend diagnosed with cancer sought information from Clarice. Because Clarice was a survivor and had already experienced the uncertainty following the initial diagnosis, she was able to help a friend in desperate need of emotional and informational support. She received social and informational support, and then turned around and provided support to others. Thus, the individual in need of support progressed to become the person able to grant support to other people in need. She gathered information and support from CHESS access and a mentor, and was able to process and work through the stress of a positive breast cancer diagnosis—two methods of information and support, or a dual approach. Clarice learned enough and felt confident to provide assistance to a friend who needed support following her own breast cancer diagnosis. She took on the

same role in the social-cognitive theory as Elaine. CHESS and a mentor allowed Clarice to pass information on to others, thus becoming a sort of mentor herself.

Elaine juggled providing support and information for over two hundred women at different points in their cancer recovery for many months. Interestingly enough, CHESS may have relieved some of the stress and weight off of Elaine's shoulders; she could direct half of her patients to CHESS at various times for support and information (if they chose to utilize the opportunity). The computer-assisted method provided a backup to Elaine by serving as an alternative source of information, the ability to submit questions to a medical expert and receive an answer with 24 hours, and a simple connection to other women with breast cancer. Women could log onto CHESS at their convenience, day or night, possibly reducing the number of questions or constant flow of frantic and anxious emails or phone calls Elaine received. CHESS allowed Elaine to provide better support and information to all study participants because she was not the only source of comfort and data about cancer.

Failed support was a stressor several women experienced. Many times, women looked to their medical providers for support, whether it was informational or a form of nurture. Juliet illustrated an example of failed support; during one visit with the oncologist, she left the appointment feeling more stressed and anxious than when she arrived due to an overload of treatment side effects and information, without nurturing support. Yvette also did not feel calm and confident as a result of a lack of support from her medical provider.

Women in both the mentor-only and mentor and CHESS conditions also reported feeling depressed during their treatments. Many became disinterested in activities they once enjoyed, while others described feeling unhappy and in a bad mood. They felt like they were in a rut or funk and unable to shake their overwhelming sense of fatigue.

Concerning the topic of cancer and death, both women with access to a mentor or access to CHESS and a mentor seemed to discuss mortality.

### **Information-Seeking Behavior**

Perhaps the biggest topic of the study and the one that consumed the most time during conversations between Elaine and participants was the concept of information-seeking behavior. Anastasia, Carly, and Gena were all part of the mentor-only condition, and yet they went to great lengths to seek out information from Elaine through phone calls and emails. All three women desired correct terminology when it came to drugs for treatment and definitions related to their pathology reports. While women with or without access to CHESS asked questions and sought information, the women in the mentor-only group did not appear to have any significant gaps in knowledge compared to their mentor and CHESS counterparts. For example, at least 19 women in the Mentor-Only group referred to types of radiation and drugs by their correct names (compared to 25 in the CHESS/Mentor group), illustrating that they had processed information and were able to recall it when discussing breast cancer. Comparing the Mentor-Only group to the CHESS/Mentor group, the number of women who correctly referred to treatments and sought out this type of information from Elaine was not statistically significant (chi-square value = .080, p-value = .777). Thus, these results could have happened by chance.

There appeared to be no major differences between the ability to process and recall information between the two conditions. Regardless of having access to CHES or just a mentor, women took it upon themselves to conduct their own research on the Internet, read articles, and then ask Elaine questions. Participants in both groups also asked Elaine for assistance when it came to choosing a treatment regimen or which type of hormone therapy to undergo. This suggests that the information-seeking behaviors of women in the study was based more on their own personal desire for information and assistance, rather than whether or not they had access to CHES. Furthermore, women in both conditions had access to the Internet, so even if an individual was not in the group that received CHES, she could still conduct her own research and try to answer her questions and concerns. This may have contributed to a lack of disparity between the information-processing and recall skills of the two groups.

### **Doctor-Patient Interaction**

A key factor that seemed to play a role in the moods, feelings, information-seeking techniques, and coping tendencies of women was the quality of doctor-patient interaction they possessed with their medical providers. Women from both groups experienced communication problems with their doctors or oncologists. At times, they felt their doctors did not care and only treated them like a number or statistic. Some patients expected to receive emotional support to assist in their coping process; when they did not, they became frustrated and negative about their own prognoses. Doctors who were not forthcoming about information or did not explain procedures, tests, and

their reasoning for conducting these processes often left the women feeling elevated levels of anxiety, fear, and frustration.

### **CHES Utilization**

One issue that regularly surfaced was whether or not participants granted access to CHES actually took advantage of these services. Particularly when it came to the discussion group, numerous women were hesitant to utilize them, or avoided them altogether. Some patients cited feeling burdened by the plight of others struggling with cancer. Other women expressed guilt at reading about other CHES participants' troubles; they felt their treatment and recovery processes were not as brutal or difficult as other women's experiences. Thus, these women did not want to post about their situation or ask questions because they did not want to make light of the struggles of others or appear to be bragging about their own success in dealing with breast cancer. Furthermore, reading about the plights of others made some women anxious about their own bout with cancer. Both Daphne and Isabelle voiced their distaste for posting on or reading through the discussion board topics because they felt depressed and upset about their own circumstances.

Another interesting phenomenon that emerged from the data was the avoidance of information by some participants. Lydia and Maura both commented on their wish to not have too much information prior to their surgery, and only after the operation would they be ready to start learning about breast cancer. This raises the interesting point of how much information is too much, and when it is best for patients to receive medical information about their illness or disease. The degree to which women wanted more

information could be linked to the extent they had cognitively processed and accepted their positive breast cancer diagnosis. If a woman was still struggling to cope with the traumatic news, or angry as to why she of all people had cancer, she might not be ready to start talking about the illness and seeking out information.

### **Support for Research Questions**

Regarding the research questions addressed in this study, there were adequate results to answer and support two of the four areas of focus. For *R1*, the themes addressed in the women's narratives were spirituality and religiosity, coping, support, depression, information-seeking behavior, cancer and death, and other factors (e.g., financial difficulties, family health concerns and preexisting illnesses). In terms of *R2*, there was substantial evidence that the CHES/Mentor combination provided both action-facilitating and nurturing support. Of the 105 participants in the CHES/Mentor group, 87 women explicitly discussed taking advantage of both online access and the ability to talk to Elaine to seek out information and social support during their treatment and recovery processes. This value was greater than the 59 women in the Mentor-Only group discussed these two forms of support. The difference between the two categories of women was statistically significant (chi-square value = 4.611, p-value = .032), indicating that it is unlikely such a difference in practicing both forms of support could have happened by chance. Esteem support was a common form of social support that all women sought from Elaine and/or their loved ones, regardless of whether the women belonged to the CHES/Mentor group or Mentor-Only condition.

When it came to *R3*, there were mixed results, which ended without firm support for whether differences existed in coping ability for women in the CHES/Mentor condition versus women in the Mentor-Only group. While 97 women in the CHES/Mentor group expressed how they coped with their positive cancer diagnosis at some point during their interaction with Elaine, this may just mean that the personalities of the women in this category meant they vocalized their rationale more than the 91 women in the Mentor-Only condition who vocalized their coping strategies. The difference between the two groups was not statistically significant (chi-square value = 1.020, p-value = .313). It is impossible to presume that Mentor-Only patients did not use some of the same coping behaviors and attitudes as the CHES/Mentor group based solely on the fact that these points were not discussed; the Mentor-Only women just may not have readily discussed these behaviors compared to their CHES counterparts. However, one could reasonably argue that the CHES/Mentor condition led women to vocalize their problems and coping methods more frequently because access to support groups bolstered their comfort level in discussing their rationale. Therefore, no evidence was gathered to substantially support *R3*.

Patients with access to CHES reported they felt that breast cancer “put things in perspective” and brought people together through support groups and assistance from loved ones. They used phrases such as ‘I’ve got cancer, but it doesn’t have me,’ and that surgery removed the breast cancer, so all that was left was completion of preventative treatments. One woman who was in the Mentor-Only group, Margo, saw cancer as just another obstacle to overcome in her busy life. Women in both conditions attempted to

keep busy, either through their jobs, pursuing hobbies, or traveling to spend time with family and friends.

The only research question not at all supported was *R4*; there was no evidence to suggest differences in information-recall for women using the CHES/Mentor function versus women in the Mentor-Only group. Breast cancer patients sought information and support from Elaine, regardless of whether or not they had access to CHES. Within the CHES/Mentor group, 98 of the 105 women exhibited information and support-seeking behaviors. In the mentor-only group, 97 of the 106 women also sought information and support from Elaine. Comparing the CHES/Mentor group to the Mentor-Only group, the results were not statistically significant (chi-square value = .474, p-value = .491). Participants discussed treatment options, asked Elaine questions, verified topics discussed in doctor appointments, described their frustrations about the effect cancer had on their bodies and lives, and shared their successes with her. As previously suggested, how patients interacted with Elaine was related more to their personal opinion about the value of having a mentor, as well as how they themselves were dealing with breast cancer. Thus, their level of successfully recalling information was also dependent more on the women's personalities, rather than access to CHES. Women who naturally wanted to learn more information and utilized a variety of information sources (such as CHES, other support groups, books, Internet articles, and breast cancer survivors) could generally recall information better than women who did not. There were women in both the Chess/Mentor and Mentor-Only groups who readily sought information and shared it with Elaine.

Unfortunately, the data was not presented in a way to support dual-coding analysis. The findings were insufficient to determine the extent to which women who received access to both a mentor and CHESS benefitted more from this dual approach, compared to women who were only assigned a mentor. Women in the mentor-only group also had access to outside sources (e.g., books and websites), so in reality, they also had multiple avenues to access information and support. Thus, the dual-coding hypothesis was not an accurate assessment of the data.

A similar exercise in which the dual-coding analysis would be applicable must include at least two groups that are truly different in terms of their setup, such as access to information and support. In terms of a setup similar to the one discussed in this study, the women in the mentor-only group would have to rely solely on information and support provided by Elaine. They could not join support groups through other interactive websites, or browse the Internet, books, and other sources of data for information. When testing the data to see if a dual-coding approach was successful, participants in both the Mentor/CHESS and mentor-only group would have to fill out a questionnaire forcing them to explicitly discuss the extent to which the mentor or mentor and CHESS access assisted them in coping with breast cancer and their information-recall abilities. Only then could one argue that a dual-coding approach is more beneficial in this situation with a solid foundation of research.

While the dual-coding hypothesis was not an accurate way to assess the data, the social-cognitive theory appeared to be a better fit in terms of representing the mentor's notes. Though it was hard to determine the extent to which women coped or recalled

information based on whether or not they had access to CHESS, it appeared that a host of outside factors played a role in how women coped and sought information during treatment and recovery. Just as the social-cognitive theory emphasizes, a person's reaction to a situation is not a unidirectional response. An individual's behavior, social structure, personality, past experiences and environment are intertwined to play a role in how he or she handles an obstacle. CHESS provided a socially mediated pathway—a chance to connect breast cancer patients and provide an online community where they could gain information and support in an attempt to alter or change negative feelings and thoughts they had following their diagnosis. Elaine served as the catalyst for the direct pathway, by promoting a sense of support and being a source of information for women as much as needed during the study. In terms of the social-cognitive theory, Elaine's presence gave women perhaps the quickest and most direct way to change their negativity or assist in maintaining a positive outlook. During the course of a phone conversation or email, she could assess the mental state of participants and what steps she had to take to encourage, motivate, support, or inform them. Women in both the CHESS/Mentor and Mentor-Only groups took advantage of access to Elaine and utilized her as needed while they navigated personal struggles with a positive cancer diagnosis.

A better set of research questions to address the social-cognitive theory would examine how women coped and the extent to which they garnered support from Elaine and CHESS. For example:

*R1: What factors motivated breast cancer patients in the Mentor-Only and CHESS/Mentor groups to utilize Elaine as a source of support?*

*R2: What factors motivated breast cancer patients to utilize CHESS during their treatment and recovery process?*

*R3: How did socially-mediated pathways benefit breast cancer patients who had access to CHESS and a mentor, compared to women in the Mentor-Only condition?*

Questions such as these could uncover various traits and characteristics of the women and possibly identify patterns of seeking support, information, and coping strategies for breast cancer patients. Such data could be utilized to implement better interactive cancer communication sites, since researchers would have a better idea of how and why people going through a traumatic situation are driven to seek out socially-mediated pathways. Elaine might have to directly question the participants' feelings of support, or have the women fill out a questionnaire asking them to explain the roles of CHESS and Elaine in their coping and support strategies.

### **Implications of Findings**

This study looked at differences in memory recall, information-processing, information comprehension, and coping measures for breast cancer patients either given a mentor or granted a mentor and access to CHES. The research ties into a growing topic of study—assessing the use of technology within the healthcare system. Electronic health communication modules and their utility are important to determine how to improve various facets of patient treatment and recovery, from information-seeking techniques to support to coping with the traumatic situation in the first place.

The most interesting result to come out of the research was the phenomenon of certain women practicing avoidance behavior when it came to support and information-seeking techniques. As previously mentioned, several women with access to CHES confided to Elaine that they were not comfortable utilizing the discussion boards because reading the plights of others increased their own anxiety and fear about breast cancer. Plus, some women did not want to talk about their cancer with Elaine or search for information about it prior to having a lumpectomy or mastectomy; only once they were to begin radiation or chemotherapy did they desire to address cancer treatments and side effects of those treatments.

These findings illustrate the need for healthcare providers to take into account that patients may desire to pace themselves when receiving information about a disease. An individual may encounter an overload of data upon finding out about an illness. Just like the women in this study, too much information in too short a span of time can cause an individual additional stress and prove to be more harmful than beneficial. If the person

has yet to fully come to grips with having the disease, he or she may not be ready to hear about numerous topics and in-depth data about that disease immediately. The majority of the participants joined the study within days or weeks of being told they had breast cancer. Given how recently they had received the traumatic news and the “newness” of the diagnosis, uncertainty was likely very high among the women. A lack of time to process such news could have exacerbated the stress from the diagnosis itself, delaying or inhibiting one’s desire to receive copious amounts of information about breast cancer and treatment options.

### **Uses and Gratification Theory**

While this study was grounded in research based on the dual-coding hypothesis and social support theory, the uses and gratification theory is relevant in terms of furthering these results and conducting future research. Uses and gratification theory examines how people utilize different media forms and the level of satisfaction attained from these techniques (Swanson, 1979). Rubin and Bantz (1982) developed five elements of this theory: the social and psychological environment, an individual’s communication needs or motives, functional alternatives to a particular medium selection, communication behaviors and the possible consequences and aftermath of one’s behaviors. Previous research involving uses and gratification theory has focused on individuals’ motives, factors that influence motives, and outcomes of media use (Chung & Kim, 2008).

The pervasiveness of technology within healthcare has lent itself to studies utilizing the uses and gratification theory to analyze how and why people choose media,

especially when faced with a serious illness. Particularly when it comes to online technology, this is due in part to elevated levels of interaction from users, compared to other media (Ruggiero, 2000). As previously discussed, online media often involves people rapidly communicating with one another via email, chat rooms, and video conferencing. Eighmey (1997) argued that the Internet was a far more goal-driven medium than other media forms because users were generally aware of the needs they wanted to satisfy and why they were utilizing the medium in the first place. Chung and Kim (2008) utilized a four-dimension coding process for uses and gratification theory (prevention and care, problem-solving, emotion management, and information-sharing) and studied cancer patients who blogged during their treatment and recovery. They noted that cancer patients and their spouses reported acquiring information through blogging. The authors argued that because blogs are a form of cyber interaction by their very nature, this allowed cancer patients to discuss their frustrations, stress, and acquire social support from others.

Applying the uses and gratification theory to the data in this study would allow one to examine how and why women utilized media during their cancer treatment and recovery processes. The methods and motives for media use of participants with access to a mentor and CHESS could be compared to media use for participants in the mentor-only group. From there, one could infer which medium the patients chose to get what they were looking for and achieve gratification. Did utilizing the services of CHESS or the mentor empower breast cancer patients? Furthermore, did CHESS or the mentor as a medium help to give these patients a sense of control over their breast cancer, i.e., that

they could fight back against the disease? Future research on these results could shed light on additional examples of utility for the uses and gratification theory. The level of quality information obtained from a mentor or an online communication program such as CHESS could be analyzed through this theory, and perhaps even further support for how multiple methods of information and support-seeking behavior relate to the quality of life for cancer patients.

### **Future Research**

A future direction of study based on this research could be to examine whether patients asked their mentor to find more information for them addressing a concern, or whether the patients sought the information themselves and then critiqued and evaluated it with the mentor. What degree of coping and cognitive processing must be possible for this to occur? Furthermore, would the results vary depending on if participants had access to a comprehensive health site such as CHESS?

While this study conceptualized a unit of analysis as a conversation between a participant and the mentor, a branch of research could investigate the frequency of a theme, (e.g. seeking support or information) throughout the total number of interactions between a breast cancer patient and the mentor. For example, two people in the mentor-only condition may seek support, but research questions and hypotheses could be formulated if one patient sought emotional support only once during nine interactions, compared to the other individual who sought emotional support seven out of the nine times. Such a study would not merely identify repetitive ideas across all participants, but

rather compare and contrast the number of times a concept reoccurred within all conversations by one individual with the mentor.

Another potential focus for a study could be to examine whether patients enroll in programs or support groups themselves, or does a mentor need to suggest or coax them to do so first? This research would look at information-seeking behaviors, with a focus on availability of information and degree of coping or cognitively processing with traumatic information.

A fourth research problem might analyze the differences in information-processing and memory recall for cancer patients experiencing a primary positive diagnosis (i.e., the first time they ever have cancer) compared to a group of cancer patients dealing with cancer recurrence. Such a study might shed light on how patients with no prior experience cope with cancer, compared to individuals who have survived a past cancer diagnosis.

It is important to note that the patients analyzed in this study were all women facing breast cancer, and thus, does not examine men placed in the same situation. It would be interesting to devise a study with similar parameters (cancer patients assigned a mentor in one group, a second group attaining CHESS access and a mentor). However, the patients examined would be both women and men; this would open the door for comparisons between how males and females search for information, seek support, and attempt to cope with the situation. The results could provide insight into similarities and differences of how men and women experience traumatic situations and assist in developing better healthcare practices to assist these patients.

### **Study Limitations**

It is important to note the limitations of this study. While instances of coping ability and support could be identified and analyzed from the data, it is hard to make generalizations about breast cancer patients' coping strategies based on the interaction of their own personal styles and those of their partners with the type and degree of coping and social support sought from Elaine or other CHESS users. The ways in which a woman sought support and coped with her positive diagnosis might have been influenced more by her personality and whether or not she had a partner who provided support without posing a social constraint. Therefore, a woman received a high degree of support and assistance in coping from her partner, she may not have needed to rely on Elaine or other CHESS users to help her through the difficult recovery time.

Another limitation to this study is whether the CHESS/Mentor and Mentor-Only groups were truly dichotomous. Can one assume that Elaine would consciously withhold information that might prove beneficial for a patient in the Mentor-Only condition because she was not allowed access to CHESS? Elaine may have suggested sites that overlapped with CHESS in terms of information; not necessarily the actual CHESS program, but a site or book with information that was nearly congruent to the data found on the CHESS website. If this is the case, the CHESS/Mentor and Mentor-Only conditions may be more similar than they appear because patients got access to much of the same information or sites with similar formats to CHESS.

While providing a vast amount of knowledge and raw data for examination, the information available for research were the notes of Elaine (the mentor) during her

interactions with participants. The original recordings of the conversations no longer exist, thus making it impossible to analyze the communication style during interaction (tone, pitch, talking speed, etc.). Furthermore, the data did not include the ability to analyze how the women with access to CHESS utilized the site, i.e., being able to read through their posts on the discussion board or studying the questions they submitted using the “Ask an Expert” feature. Inferences must be made based solely on analysis of the mentor’s notes. However, the mentor took detailed notes, both on issues the patients talked about, as well as the advice she gave them. The email exchanges were copied word for word so one can see exactly what information was shared with participants. While certain areas of data were missing (access to CHESS to read through the discussion board, hearing the actual recordings of conversations), the information at hand provided an extensive look into the lives of over two hundred women in one of the most vulnerable times of their lives: undergoing treatments to become breast cancer survivors.

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