Seeking and Managing Hope: Patients' Experiences Using the Internet for Cancer Care

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Purpose/Objectives: To describe the experiences of patients with cancer using the Internet for information and support to manage the self-care aspects of illness and treatment, including symptom management.

Research Approach: Heideggerian hermeneutics branch of phenomenology.

Setting: The interviews took place in outpatient settings in the northeastern United States, including clinics, patients' homes, and the researchers' office.

Participants: 20 patients self-identified as users of the Internet for cancer care.

Methodologic Approach: Data were collected by informal interviews that provided the narrative stories for hermeneutic analysis.

Main Research Variables: Internet use for cancer care and patient-provider relationship.

Findings: Five related themes and one constitutive pattern described patients' experiences. The themes were retrieving and filtering Internet information according to personal situation by Internet-savvy people in patients' support networks, seeking hope from the newest treatment options while coping with fear in manageable "bytes," self-care for personal illness situations with meaningful information regarding symptom management, empowering patients as partners when Internet information served as a second opinion in decision making and validating treatment decisions, and Internet as providing peer support. The constitutive pattern was Internet use as assisting patients in discovering ways to live with cancer as a chronic illness instead of a death sentence.

Conclusions: Patients with cancer are incorporating Internet use into their cancer care. They perceive changing provider-patient relationships when they participate in treatment decisions.

Interpretation: Computer-savvy patients and their personal support networks will avail themselves of Internet information, creating the need for new interaction patterns and relationships with providers.

Key Points . . .

- ➤ Patients' support networks are important in processing information.
- ➤ Internet use encourages patients' desire for involvement in care decisions.
- ➤ The necessity for nurses' Internet use is patient driven.
- ➤ Nurses should be aware of the social influence of technology in affecting trust and confidence in healthcare providers, as well as encouraging or discouraging partner relationships.

Many cancer-related Web sites are available to provide information and contacts for patients. Although research has shown that patients with cancer have received information and support for cancer care by using these sites (Eysenbach, 2003; Eysenbach, Powell, Englesakis, Rizo, & Stern 2004; Fernsler & Manchester, 1997; Fogel, Albert, Schnabel, Ditkoff, & Neugut, 2002; Klemm, Reppert, & Visich, 1998; Sharf, 1997; Vandenberg et al., 1997; Weinberg, Schmale, Uken, & Wessel, 1996), little research has been conducted to examine the experience, perceptions, and impact of Internet use for patients with cancer. The purpose of this study was to describe the experiences of patients using the Internet for cancer care through phenomenologic interpretation of their narrative stories. Cancer care was defined as information and support to manage the self-care aspects of illness and treatment, including symptom management. The specific aims were to describe patients' experiences using the Internet for cancer care and to determine components of Internet use that are helpful to patients in facilitating cancer care.

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Because little is known about the everyday experiences of patients with cancer using the Internet, analysis of data from the current study provides information on how patients use the Internet for their cancer care. The term "cancer care" was used during recruitment and in the interview process specifically to enable the researcher to ask open-ended, unbiased questions that allowed patients to tell their personal stories of how the Internet was used and what it meant to them during their cancer journey; the term also focused the stories on Internet use for cancer care versus everyday Internet use. The issues and implications of Internet use will be discussed, thereby increasing the understanding of ways in which it is effective for cancer care. Insight will be gained into what works best, what is useful, and how patients maneuver through the vast amount of information on the Internet. The findings may suggest new dimensions in nursing practice on which future nursing continuing education and patient care interventions can be developed and tested.

Literature Review

Eighty percent of Internet users (about 93 million Americans or half of American adults) have searched the Internet for health information (Pew Internet and American Life Project, 2003). In a previous survey (Pew Internet and American Life Project, 2002), 91% of health seekers reported that health-related information found on the Internet was useful and 47% of health seekers reported that the information influenced their healthcare decisions and provider interactions. In another study of Internet use by providers and patients, 90% of physicians and nurses reported that patients brought them Internet information (Jadad et al., 2001). In another study, nurses reported increased frequency of patient encounters involving discussions of Internet information (Dickerson, Boehmke, Ogle, & Brown, 2005).

One review of the educational needs of patients with cancer indicated that patients often sought information when making treatment decisions and managing side effects and preferred obtaining information via discussions with healthcare providers (Chelf et al., 2001). Researchers reported that computer-assisted learning increased patients' knowledge of their disease and improved quality of life; however, Internet use and accessibility were not evaluated.

In some studies, patients with cancer used Internet support groups effectively (Klemm et al., 2003; Schultz, Stava, Beck, & Vassilopoulou-Sellin, 2003). Individuals sought and gave information and encouragement (Klemm et al., 1998), found online communication supportive (Weinberg et al., 1996), and learned skills in personal empowerment from a breast cancer online discussion group (Sharf, 1997). Some studies found that patients with cancer who had computer-based support experienced less depression, anxiety, and distress than the control group (Vandenberg et al, 1997). However, in another study, more depressed individuals used online versus face-to-face supports (Klemm & Hardie, 2002). In a literature review of online cancer support groups, Klemm et al. (2003) found that information seeking and giving were prevalent, barriers to using the groups were identified, and further outcome studies were indicated.

The Science Panel on Interactive Communication and Health voiced concerns that unevaluated forms of interactive health communications have a potential to cause harm (Robinson, Patrick, Eng, & Gustafson, 1998). Although the panel recognized the benefits of interactive health communications in providing specific and current information 24 hours per day, allowing users to remain anonymous, and facilitating interaction with experts or other patients, the panel also recognized the potential harm as a result of inaccurate or inappropriate health information. Inaccurate or inappropriate information may lead to delay in seeking medical treatment and may damage the trust placed in current providers or treatments. The current study gives insight into patients' perceptions of the value of Internet use for daily self-care, their methods for determining the quality of information, and the influence on provider-patient relationships.

In a similar hermeneutic study of patients with implantable defibrillators who used the Internet for their daily self-care, Dickerson (2005) found that information searches, online interactions, and storytelling with fellow patients promoted understanding of the illness. The online interactions facilitated gaining knowledge of everyday life experiences by reading patients' stories. Stories gave practical advice on how to manage and accommodate the imposition of illness on their lives. Patients became better informed, asked vital questions during provider interactions, and became partners in health care. In this example, the Internet influenced provider-patient interactions when it became a catalyst for changing the power in relationships (Dickerson & Brennan, 2002). This potential change in provider-patient relationships needs to be studied in the context of cancer care because of the multitude of available cancer-related Web sites for patients' use and because cancer is one of the top two diseases for which people seek information on the Internet (Satterlund, McCaul, & Sandgren, 2003).

In the current study, the unique approach of qualitatively studying Internet use of patients with cancer at all stages of diagnosis, treatment, and survivorship adds to this body of knowledge by discovering how the informants' Internet experiences affected their self-care practices. As patients increase their Internet usage, research on the most appropriate way to use Internet communications is critically important to nurses to improve care by providing opportunities and support for patients' participation in self-care. Hermeneutics provides a personal perspective to explore how patients with cancer use the Internet for their care. Patients' experiences reveal an awareness of issues and problems as they are understood in the context of using the Internet for obtaining cancer care.

Methods

In the interpretive phenomenologic approach underlying a Heideggerian hermeneutical study, researchers attempt to discover the common meanings of the "everydayness" of an individual's life. The purpose is not to predict but to understand the contextual meaning of a situation. Interpreting the narratives of patients who use the Internet for cancer care enables researchers to be involved in and understand the practical knowledge of the world of patients with cancer.

Sample, Settings, and Procedures

A purposive sample of 20 patients with a variety of cancer diagnoses and stages (diagnosis, treatment, and survivorship) was recruited for this study. A Social and Behavioral Science Institutional Review Board approved the research

proposal. Researchers attended local and national Oncology Nursing Society meetings, explained the study, and asked for volunteers to recruit patients who used the Internet for cancer care. Nurses' experiences using the Internet in their practice and having their patients use the Internet also were obtained but were reported elsewhere (Dickerson et al., 2005). Despite attempts to recruit male and female patients, only female patients volunteered. The nurses provided patient volunteers' contact information to the researchers, who then contacted the study participants (informants) by phone or e-mail to set up an interview that would last approximately one hour. At the beginning of the interview, the researchers explained the study and obtained written consent. The informants were interviewed at a time and location of their convenience. In the case of four informants, interviews were by telephone. This approach was used because the interviews were of similar quality as the face-to-face interviews. The researcher sent a consent packet to each informant that was read, signed, and returned before the interview. Questions about the consent were answered at the beginning of the interview. To open the interview, researchers asked informants to "share stories of how the Internet helped them with their cancer care." Researchers then asked additional prompts to gain more details of patients' Internet use and how it helped them. The interviews were tape recorded and transcribed using confidentiality measures. The researcher checked the typed transcripts for accuracy by listening to the tapes and editing the transcripts. The transcripts or narratives provided the data for hermeneutic analysis.

Analysis

Narratives (texts) used in this study were interpreted by a seven-stage hermeneutical process (Diekelmann, Allen, & Tanner, 1989; Diekelmann & Ironside, 1998). The analysis team included one master's-prepared and two doctorally prepared researchers, two of whom were oncology nurses.

- Stage one: Each text was examined as a whole to gain an overall understanding.
- Stage two: Possible common meanings were identified from the texts with excerpts to support the interpretation.
- Stage three: The researchers compared their interpretations for similarities and differences at weekly meetings, reaching further clarification and consensus by returning to the original text.
- Stage four: All texts were reread to uncover themes that linked them.
- Stage five: Constitutive patterns were described to show the interrelationship among themes across all texts.
- Stage six: Themes were validated by a group of informants from the study by sending preliminary findings by e-mail to all informants who provided e-mail addresses. Five informants responded by indicating that the results were similar to their experiences.
- Stage seven: The principal investigator produced a final summary, including quotes, that allowed for validation by the reader.

The analysis process included multiple levels of interpretation to eliminate inconsistencies and unsubstantiated meanings. Although no single correct interpretation exists, constant reference to the text ensured that interpretations were grounded and focused (Diekelmann & Ironside, 1998). Scientific rigor in analysis was facilitated by careful attention to the text, use of team approach for analysis, and verification of the findings with several of the informants from the original interviews. In addition, findings were supported by use of verbatim quotes in the text.

Findings

All 20 informants who participated were female. The mean age was 52.3 years (SD = 8.7, range = 34–65 years), mean years of education was 15 years (SD = 2, range = 12–18 years), and average time per week using the Internet was 13.95 hours (SD = 12, range = 2–40 hours). The informants reported using the Internet for a mean of six years (SD = 2, range = 2–10 years). Informants' diagnoses included breast cancer (n = 11), gynecologic cancers (n = 3), gastrointestinal cancer (n = 1), lymphomas (n = 3), and hematologic cancers (n = 2). Time since diagnosis also varied: Seven were newly diagnosed (less than one year), seven were involved in treatment (one to four years), and six were survivors (five or more years). Survivors, who technically no longer may be considered patients, wished to tell their story of their cancer experience and were included.

Five related themes and one constitutive pattern emerged from the analysis. Figure 1 summarizes the findings. Although the themes artificially separate the findings for clarity of presentation, in actuality the themes are interwoven in their meanings and context of the experience of using the Internet for cancer care. Each story was unique in describing how each person used the Internet in his or her cancer care for various reasons over time. Table 1 lists the variety of specific Internet uses; each patient had a different pattern of use.

Theme One: Retrieving and Filtering Internet Information According to Personal Situation by the Internet-Savvy Person in the Patient's Support Network

Once a cancer diagnosis was suspected, many Internet-savvy patients used the Internet to gain an understanding of the disease and possibilities for cancer treatment. Broad information was sought first by using disease-specific key words such as "lymphoma." As patients learned more about their diagnoses, the searches became more specific. The informants would explore multiple related links, and some were unable to remember where they retrieved the information. At times they would filter the information to suit their needs. For example, some would overlook statistical information. One informant described,

> I try not to flip out when I read the really bad things because I'm sure some of these Internet sites don't give you much hope. [However,] there are other sites that say wonderful things. . . . You have to take everything with a grain of salt and go to more than one site to see if these sites are in agreement, and just get a better idea.

Often the informants would seek confirming information from more than one site or consult with their support networks that often included a person with medical knowledge (e.g., nurses, physicians, pharmacists) who would assist in interpreting (filtering) and evaluating the vast amount of information. Other patients who were not Internet savvy or at times did not want to know the full information would rely on their support network to obtain, filter, and evaluate the information by proxy. One informant described her network help: "My sister and friends have sent me information. . . . It goes in, and I let

Related themes

1. Retrieving and filtering internet information
   - Internet-savvy patients access information.
   - Patients' support network may be the primary retrievers, where information is found by proxy.
   - Desired information influenced by disease stage and coping style.
   - Information was filtered according to appropriateness to personal situation or specific diagnosis.
2. Seeking hope with newest treatment options
   - Current treatments, hospitals, and physicians
   - Coping with fear (managing hope) in manageable "bytes"
   - Positive and negative value of statistics
   - Complementary and alternative therapy
3. Self-care
   - Symptom management
     - Disease symptoms, what is normal, and what to expect
     - What to do about treatment side effects
   - Meaningful information
     - Daily ongoing coping
     - Preparation for tests
     - Understanding medical language
4. Empowering patients as partners
   - Internet information served as a second opinion in decision making.
   - Validating treatment decisions
   - Changing patient-provider relationships
     - Mutuality in treatment decisions
     - Trust, confidence, and vigilance
5. Internet as providing peer support
   - Peer coaching through Internet communications
   - E-mail someone who has been through the disease.
   - Bulletin boards and chat rooms
   - Cyber friends

Constitutive patterns

Internet use as assisting patients in discovering ways to live with cancer as a chronic illness versus as a death sentence.

- Living with cancer and knowing what to expect and what is appropriate for self
- Maintaining appropriate hope or managing fear
- Maintaining optimum health

Figure 1. Patients' Experiences Using the Internet for Cancer Care

it come out . . . because I don't need to know this." At times, the Internet-savvy person was a husband, daughter, son, sister, or friend who would do the online searches and provide hard copies of information to the patients. One woman said, "My husband is my computer guy." Another patient with a family history of breast cancer gave an account of her progression of information gathering on the Internet.

> [At first,] I got very little information off the Internet because it was too much to observe. There is so much stuff out there that I don't know how people read through it all. . . . I didn't process a lot of [technical] information in the early phase. . . . It's too much for me to process.

To improve processing and decision making, she suggested "listening to at least two doctors, take your notes from the Internet . . . and define your case." She was receiving information from a friend who worked for the National Institutes of Health. She believed it to be updated and reliable. "She was sending me articles daily, especially if questions would come up about my treatment and my side effects." The cyber conversations between this informant and her friend, which included providing pertinent articles "one or two at a time," were helping her make important treatment decisions.

Individual coping styles also influenced informants' decisions to gain information. Some informants initially did not want to know more than what to expect tomorrow. They preferred day-by-day information. They trusted others to oversee the bigger picture of their treatment and prognosis by accepting the information that was given to them as the most relevant. As one said, "I only want to know what I need to know tomorrow."

The stage of disease also influenced information needs. Soon after a cancer diagnosis, informants focused their information needs on understanding the disease and treatment possibilities. During treatment, they often needed to know what to expect to validate symptoms and side effects associated with treatment. During remission or in the later stages of the disease, informants monitored for new treatment options or alternative approaches to optimize their health or prevent reoccurrences.

Theme Two: Seeking Hope With Newest Treatment Options While Coping With Fear in Manageable "Bytes"

Informants told stories of seeking information about the newest treatment options through Internet searches. They often found that the most current treatment protocols were described online. In contrast, books often were several years old, and for some diagnoses, the treatment outcomes were described as poor. One informant related, "If you read the books, they said there was no hope." Another informant was not responding to traditional treatment and was given no other options by her physician. Her daughter did an Internet search that provided information for new treatment in another town. The informant said,

> When they first told me that I had this disease, they said there was no cure. We went on the computer, and we found out that wasn't necessarily the case. Here was . . . something more that could be done . . . there was more hope for me. They were doing good things with bone

Table 1. Incidences of Specific Internet Uses

Internet Use	n
Seeking information	
Information from proxy support network	6
Disease information	11
Statistical information	4
Do not want statistical information	2
Treatment information	15
Symptom information	14
Complementary and alternative therapy	5
Patient stories	7
Communication: information and social support	
E-mail updates to friends.	4
E-mail peer supports.	5
E-mail physicians.	1
Electronic bulletin board	4
Live chats	3
Do not want live chats	3

N = 20

Note. Each patient had different constellations of patterns of use.

marrow transplant. . . . [My daughter] got . . . updated information . . . that made it really a lot better for us, even though it was risky.

Sometimes information from the Internet provided peace of mind and hope, as in one story where both husband and wife had metastatic cancer with no cure. The wife said, "We accept [that there is no cure; however,] I do believe that medical science has made a great deal of progress in slowing down the progress of the disease . . . making patients more comfortable and improving their quality of life." In this case, the husband and wife were seeking the best care.

Some informants described hopeful treatment options in the form of complementary and alternative medicine (CAM). These included homeopathic approaches using vitamins and minerals in addition to natural hormone treatments. In one instance, an informant with late-stage uterine cancer used a CAM approach in addition to traditional radiation therapy to offer her hope. Her story was rich with hope and empowerment as she lived day to day and viewed her cancer as "a chronic illness." Another CAM user stated, "I knew if I continued the chemotherapy [traditional treatment], I would not survive." She sought "optimum health" with good nutrition, vitamins, and healthy living.

New procedures such as prosthetic limbs offered hope for normal function to another informant with multiple myeloma and a tumor of the humerus. The patient learned about a "shoulder replacement. . . . They just started doing in 1998. . . . It will not regenerate bone . . . but it prevents bone from being destroyed." Referring to a new medication, the same informant's husband stated, "[the new medication] was six times better. It's perfect for her now. . . . It is only a 15- to 20-minute infusion."

Some informants preferred timed or sequential information to process and cope with their cancer in manageable "bytes." One informant, a nurse with leukemia who had had a bone marrow transplant, preferred healthcare professionals to tell her what she needed to know, one step at a time, so she could process information and restrict it to the procedure at hand. This informant said that she was "kind of scared away by so much statistical information. It seemed like it wasn't appropriate at the time. Down the road, maybe." Fear is another factor in processing and managing information, and informants were ambivalent regarding the amount of information they wanted.

> Sometimes I am afraid to get on the [Internet] . . . if it's going to happen to me. I don't know if I really want to know that, although I know that these are the things that are going to happen, and I suppose I should be prepared.

Another informant with breast cancer described how her physician was concerned that she would be overwhelmed with information about statistics. However, she said, "I don't mind knowing the statistics, but I don't necessarily think they pertain to me because . . . a 15% chance it could be cancer and an 85% chance it's not. If it is me, it is 100%." Another informant stated, "I know they're only numbers; they don't really mean anything."

Theme Three: Self-Care for Personal Illness Situation With Meaningful Information Regarding Symptom Management

Informants' narratives described how they gleaned meaningful information about symptom management from the Internet. At diagnosis and during early treatment consultations, the informants accrued a great deal of information from physicians and experienced intense emotion and feelings of vulnerability. Once at home, overwhelmed with the diagnosis, the informants generally retained little knowledge about symptoms and side effects and would use the Internet for additional information. One woman with breast cancer had received paclitaxel and reported numbness in her fingers to the point where she could not button her clothing. She went online and found out that the numbness was a neuropathic side effect of the drug. Another patient had been placed on prednisone and experienced muscle spasms. Unsure what the cause was and concerned that the disease was spreading, she went online and discovered that

> The spasms were a side effect of the prednisone. I just have to stretch for a few seconds. I found out from the Internet I could use a muscle relaxer. I typed in a few medications I had at home to find out if any were muscle relaxants, and one was and it helped so much. So that was probably the biggest thing that impressed me the most with having the Internet.

Another informant being treated for breast cancer encountered taste changes while on paclitaxel and had difficulty eating. She went on the Internet and found that "when you can't taste anything, mint things or lemon drops or staying away from acidic stuff and that sort of stuff was really helpful." Another informant complained about a sore throat to her physician, who suggested that she was coming down with a cold. She indicated that this did not feel like a typical sore throat and "this wasn't like when you get a cold normally." She went online to investigate other possible causes for this complaint and found that she was experiencing symptoms of oral candidiasis (thrush), a side effect of her chemotherapy. Proactively, she called her physician and insisted on a throat culture that came back positive for thrush. Believing that her symptoms were not related to a common cold, the Internet validated her concerns and allowed her to advocate for and self-manage her care.

Other informants described the value of the Internet in filling information gaps, as one woman indicated. "The Internet is important because I find that doctors tell you things, but I guess they see so many patients that they don't think to tell you the little things." This was a very powerful statement regarding symptoms that are important or meaningful to patients. Symptoms often caused anxieties and disrupted patients' functioning (e.g., inability to sleep or difficulty with fine motor skills from neuropathies). The Internet provided easily accessible information about side effects and symptoms as well as suggestions for handling these symptoms and helped to allay unfounded fears (e.g., that their cancer may be progressing).

Theme Four: Empowering Patients as Partners When Internet Information Served as a Second Opinion in Decision Making and Validating Treatment Decisions

Although they received their diagnosis, prognosis, and treatment options primarily from their surgeon or oncologist, informants often accessed the Internet to seek information about their specific type of cancer and to validate the recommended treatment. In this way, informants felt capable of having productive interactions with their providers and becoming

decision-making partners. One informant with stage I breast cancer performed extensive Internet searches before her physician appointment and described the value of looking at statistics and percentages to help her weigh options associated with chemotherapy.

> I just wanted to know . . . the statistics . . . the side-effect statistics . . . with the [doxorubicin] and [cyclophosphamide]. . . . I was trying to weigh back and forth this 1% possibility of cardiac side effect versus . . . dosages . . . then I decided that I may as well just go for the whole thing.

Finding relevant disease-related information helped informants to participate in their own self-care. As a result, treatment options and decisions could be made more efficiently to meet their specific needs.

Patient empowerment was demonstrated by informants' stories of seeking information regarding terminology so they could ask meaningful questions and of accessing information regarding diagnostic procedures and drug therapy. One woman diagnosed with breast cancer said, "I could ask more intelligent questions. I wanted to know whether I was going to have chemotherapy. Was it slow growing? Was it fast growing? I knew the questions to ask."

Another informant recently diagnosed with breast cancer was told that she would need a lumpectomy and sentinel node biopsy that would be done by radiograph. Not understanding what "sentinel node" or "radiograph" was, she turned to the Internet for answers. "I looked up information trying to find some radiographs, so I can understand how they did the needle location. I also did a lot of research on treatment depending on what they found." Informants also searched for information regarding upcoming procedures (e.g., bone marrow biopsy, positron emission tomography scans) and treatments (e.g., bone marrow and stem cell transplants) so they could discuss them with their healthcare providers.

Another empowering self-management strategy was evidenced in decisions to seek care at a specific healthcare facility. One patient with non-Hodgkin lymphoma described her experiences when she was placed on a new drug treatment. "Every time we got a new drug or they suggested a new drug, we found out which doctors were doing it and which hospitals were the best." Her daughter helped her access information on cancer centers and their locations. Her decision on where to receive care was based on information gleaned from the Internet and on the hospital's national ranking and reputation.

Other informants monitored the Internet daily for new developments related to their disease. One patient whose husband also had cancer researched "a lot of the information about a new drug." She proactively took the information she obtained from the Internet to her husband's physician.

> I believed there must be something else we can do. . . . So I handed [the physician] an article on using thalidomide in conjunction with chemotherapy for the treatment of prostate cancer and [indicated] that these tests are in the third phase of clinical trials [showing] some degree of success. I said, "Could we give this a try? This sounds promising." So [the physician] set [my husband] up three weeks ago to go on the treatment. It is our own clinical trial.

Some patients wanted as much information as possible so they could participate as partners in their own care. Referring to her preparation for a physician consultation, one informant said,

> You get told some information; you are not going to remember all the things, especially because it's something that you don't particularly care to hear. So I wanted to get as much information before I went in to see the surgeon . . . [so that] when he was speaking . . . I knew what was going on.

Other patients wanted to know everything they could about their treatment to be actively involved in decision making. In general, the informants and their support networks wanted to make their own judgments about the treatments recommended by their physicians. Sometimes, Internet information verified treatment decisions, thereby instilling confidence. At other times, informants would become more vigilant monitoring for evidence and verification of the treatment decision. If disagreement was found regarding the treatment or the doctor advised the patient not to access the Internet, the patient would look for another physician. One informant summarized,

> Doctors need to remember patients need to know what is going on. We are human, and we don't generally put our trust just in your words. You can get as much information you want from the Internet. It really helps to find out about side effects instead of calling the doctor all the time; they are busy. I'd rather know what I am dealing with to better prepare myself.

Theme Five: Internet as Providing Peer Support

Reading online communications about personal experiences and stories of others provided an additional source of information and support for the informants in this study. Chat rooms, message boards, and e-mail provided patients with a means for comparing the course of treatment with others, validating symptoms, and getting advice from others who had experience with cancer. This input, which informants described as a "gauge on their illness," helped them complete the emotional work that enabled them to resume activity and redefine their lives.

Online interactions, in which they compared their illness experiences, reassured patients and provided examples of day-to-day coping and hope that life goes on. "I just read other people's case studies, saw what they did. . . . It is nice to know you are not alone . . . [that] somebody else [is] on the same boat . . . other people with cancer." This minimized their feelings of isolation. E-mail allowed one informant the opportunity to share her diagnosis and gain a different perception about the reality of her situation. "I am lucky I am not in that situation . . . so she helped me pull back to reality when I found out how bad she had been." Writing on an electronic bulletin board was likened to keeping a journal of their emotions, "a catharsis." Chat room discussions generated questions that the patients asked their physicians. One informant's story described how she found comfort when she would wake up during the night unable to sleep. She would read the discussions on the chat group, even though her computer system would not allow her to respond. "It was very good to read what other people were going through . . . to find out that other people were experiencing the anxieties and frustration. . . . I wasn't the only one."

Internet communications facilitated connections with other patients. One informant validated symptoms with others via e-mail and learned what to expect after a bone marrow transplant. "Were you itching at day such and such, or were

you fatigued, or what kind of problems were you having?" Another informant described the value of participation on a bulletin board. "I go on the breast cancer board, and I say my feet are numb, and someone would write back and say, it's happened to them, it's normal. . . . It makes you feel better knowing that it is not just you." Others compared their treatments. "You talk about different types of treatment they are going through." And "I was on steroids too . . . to combat the side effects of chemo. . . . I would say I was lucky because some of them were talking about how sick they had gotten [on steroids]." Other informants asked for advice and how to deal with symptoms, as one said, "The best part of it is that you go on there and ask for advice, and everyone is so helpful." Another said that "once they have been through something, [patients] try different things; that's how they help each other by saying this is what I do or did for this problem, and it helped; maybe you should try it. . . . Because doctors don't think to tell you the little things, like side effects, or that it's normal to feel tingly." Another patient described the information that was important to her in coping with the side effects of treatment.

> I didn't know about hair loss. I thought it was just going to come out in strands. I didn't know it was going to be in clumps like it was. . . . So I was kind of devastated. Somebody had recommended when the hair was really coming out in chunks just have my beautician shave the rest off. She told me to go to a place for wigs.

She then was able to plan to cope with her hair loss.

The women in this study described a bond that formed among Internet patient support group members. "There is a big bond, the women want to help each other, they just want to reach out and help." The online forum allowed patients to voice complaints to each other without risk or threat to healthcare treatment. "Women complained about their doctors . . . how they treated the women. It was interesting to see what everyone else was experiencing. It made you feel not so alone." Another described her developing friendships.

> There is a group of us (from oxygen.com) that . . . formed our own group within the group called Just Us . . . and we continue to stay in touch . . . and have get-togethers . . . from all over the country. . . . If we feel like whining . . . or complaining . . . we will just whine to each other.

When referring to the breast cancer message board, one informant explained,

> You get very personal with these people who start out as strangers, and even though I have not met any of them, I feel very close to them. You can tell what they're feeling by how they write . . . when they're happy.

The emotional connection and communication among the chat room, message board, and e-mail users were supportive. One informant related, "I wrote [on the breast cancer message board] and said, 'I am going to my last treatment' and the responses were, 'We will be in the room with you, you won't be alone.' It's all very positive." Another informant used e-mail to give updates to all her friends and family instead of repeating her status to each one on the telephone. She stated,

> I was communicating with people [by e-mail] any hour, day or night, and they would get back to me. That made me feel good that they are out there and they care. They are supportive. That is a good feeling, and yet I didn't have to see anybody [in person], didn't have to talk to anybody.

Another woman described her feelings after she heard about the death of a friend in her online support group. "I know people that are on the breast cancer board; some have passed, but [I] just feel that my life was enriched by knowing them."

Informants indicated that support was provided readily when they asked for assistance in making decisions about a treatment or reasonable time frames for diagnosis. One woman who had suspicious mammograms and a breast lump reported, "People on the breast cancer board who had gone through the same thing basically told me, 'If [the physicians] want to watch [the lump], tell them to put it in a jar and watch it!'" Another told of her experience of receiving help during her very dark days. "When I was depressed, when I felt like throwing the towel in, when I didn't want to fight anymore, they gave me basic support." In return, patients who had received support returned it to others, as one described: "After I finished treatment and everything, I sort of sat on the boards just helping people who were newly diagnosed and answering their questions about my experience." Other informants related how their family and friends used the Internet to seek advice on how to help their loved ones. One said, "This is not just a woman's experience [referring to a breast cancer diagnosis], but the entire family's experience."

As is evident in the quotes, humor was laced throughout the stories. One informant used humor in her e-mail correspondence that she referred to as a "lifeline." Thinking of how to humorously relate her experiences to others helped her cope with the difficulties of chemotherapy. The humor employed in her extensive e-mail network was like "a therapy . . . recreation, a light at the end of a tunnel in your darkest moments." Humor helped others realize that they would get through the experience, like a team effort. "You helped me realize that I can get through this if I just take it one day at a time."

Some informants in the study never used e-mail and bulletin board support services. Some informants had limited access to the Internet and gained information only from their local support network. Others related that they did not trust online information from other patients, and some thought it would be hard to verify the information. Another reason informants avoided online support was that they believed that stories of those with advanced disease would be too emotionally draining. One woman said, "I guess I am still in a bit of denial." Others found no need to access Internet support because they had local support of friends or family with similar experiences. Other informants were discouraged by family or providers from using chat rooms or bulletin boards because they were believed to be poor sources for facts, interpreted as "information that you really don't need to know." Only one informant, a nurse who had an open relationship with her physician, e-mailed her physician; she queried laboratory test results and discuss her view about one of the medical residents providing her care.

The Constitutive Pattern: Internet Use as Assisting Patients in Discovering Ways to Live With Cancer as a Chronic Illness Versus a Death Sentence

The constitutive pattern links the related themes across texts. Overall, patients in the current study described Internet use in obtaining information to understand their disease and treatments, to learn what to expect and what to do, and to live their lives as if cancer were a chronic illness. They verified treatment decisions as they came to understand how the disease and treatments would affect their lives, and they sought information to manage their symptoms. They learned to live with the cancer, understanding what was normal, what to expect, and what was appropriate and specific to their own case. This knowledge, in addition to hearing others' stories of survival, helped them manage their fears and maintain hope. Only a few longer-term survivors spoke of facing the death of a support group member, realizing that the friendship had value despite the sadness of the loss. Other patients with later-stage disease were using CAM therapies, seeking optimum healthy lifestyles through diet and herbal remedies. Informants were sensitive to potential environmental factors that affected their health. Not all patients on the Internet were open to discussions about CAM. One person was "flamed off a site" when she asked about alternative therapies but eventually found another site where people were interested.

Discussion and Implications

The Heideggerian hermeneutical approach provided a rich understanding of the everyday issues the informants experienced regarding use of the Internet for their cancer care and the practical knowledge it contributes. The primary limitation of the current study is that researchers do not know what others who did not participate would say; therefore, the study is not generalizable to others. Another issue is that only women responded to this recruitment effort. Through hermeneutic interpretation of informants' narratives of Internet use for cancer care, several themes for patient self-care emerged. Researchers gained an understanding of the informants' perceptions of the value and meaning of Internet use for cancer care that included information to support decision making, symptom management, and emotional support during their illness. Components of Internet use that were helpful for patients also were delineated to facilitate developing useful online resources.

A vital element for Internet use, as newly described in the study, was the support network surrounding patients. Each informant had a unique constellation of support that assisted in information retrieval and filtering. Filtering involved examining the information and deciding which was relevant to a specific cancer diagnosis. Whether patients themselves accessed the information or support people did by information proxy, the need for this information filtering was described. Eysenbach (2003) also explained the idea of Internet access for information by proxy. However, most studies focused generally on patient Internet use and not on the importance of patients' support networks. Nurses should be cognizant of this when considering how patients interpret the information. Key family members and friends should be recognized as contributors to patient decision making. Nurses also should consider patients who do not have access to knowledgeable people or intermediaries to assist in the information filtering. Nurses could develop the role of information consultants to assist patients during this process. Informants in the current study also recognized the need to assess the quality of the information they obtained on the Internet and, similar to other studies, often compared information from several sites before believing (Rozmovits & Ziebland, 2004).

The Internet provided access to the most current information for the informants that they could access in manageable bytes—meaning that specific information is available for patients when they need it, even in the middle of a sleepless night as some informants described. The Internet was a vehicle to provide information and support 24 hours per day, seven days per week. Similarly, in a longitudinal study of women with breast cancer, the women continued to use the Internet for information and preferred the Internet over other sources for as long as 16 months (Satterlund et al., 2003). The findings of the current study gave insight into the personal meanings of Internet use and the importance of having the ability to look at the information when patients want to and what they need at that time. Patients will tailor the information to meet their needs. A similar concept that has been described in the literature is computer-generated targeted and tailored interventions that have been found to be modestly effective for improving patient behavior (Revere & Dunbar, 2001). The informants in the current study valued obtaining personalized information to meet their own needs at their own pace. This differs from most studies of tailored interventions that were designed and implemented by healthcare providers.

Informants in the current study used Web sites and bulletin boards for seeking self-care information and validating their experiences with others. The bulletin board provided a method to post questions to fellow patients at any time of day and was anonymous except for the screen name. Sensitive questions were posted and answered without embarrassment. Informants related the need for information about the "the little things," that their doctors did not have time to explain, which is a very powerful statement because symptoms that are important or meaningful to patients, if missed or omitted as important by the healthcare provider, can result in serious symptom distress for the patient. Conflicting beliefs on what is necessary for patients to know, combined with distrust for quality of information, reflect the concerns of the academic and healthcare provider community (Berland et al., 2001; Eysenbach, Powell, Kuss, & Sa, 2002; Jadad & Gagliardi, 1998). The informants in the current study did not always believe everything that they read on the Internet and often sought input evaluating the information from their support network and physicians. Informants in this study also gave examples of self-diagnosing side effects of their treatments for which they consulted their healthcare providers. The informants felt empowered to contribute to their self-care and interact effectively with their healthcare providers.

Informants sought information from the Internet and brought relevant questions to their providers. They also attempted to validate and verify treatment decisions. This affected the trust and confidence between patients and providers and, for some of the informants, lead them to seek alternative providers who were more open to discussion. A similar study of patients' quest for information described the importance of the patients being experts (Ziebland, 2004). Patients accessed online information and support to make sense of the

Table 2. Internet Use Components That Are Helpful for Cancer Self-Care

Useful Component	Meaning Value	Outcome
Information retrieval: current disease and treatment information and options	Flexible and accessible at all hours Newest treatment information available Facilitate decision making. Validate treatment decisions.	Hope for best outcome and best available treatment. Optimism Manage fear. Individualized care Pace of information retrieval suits patient needs and coping style. Gain or lose trust and confidence in providers.
Symptom information	Know what to expect and plan for.	Symptom management
Communications: e-mail, online bulletin boards, and chat rooms	Peer support and/or coaching and advocacy Coping with humor Update friends without repeating information. Cyber friendship Family support E-mail healthcare providers.	Emotional and spiritual support Reading stories to learn what to expect, gain everyday context, and plan for needs Camaraderie Keeping connected
Patient support network: family and friends, also may include friends and family who are nurses, physicians, or other healthcare workers; Internet-savvy people	Able to access information and evaluate for applicability and quality Discuss and challenge different options.	Quality information Care specifically individualized Friendship Emotional support
Partnership with providers	Open discussion of options	Empowerment Trust and confidence Appropriate individualized outcome and confidence in care

experience and display "competence and social fitness" that relates to the belief that they need to be experts. Optimally, nurses and other providers should be open to patients' questions and include patients in the decision making. Then the provider-patient relationship can be mutual, not paternalistic where the provider makes all decisions nor the other extreme where the patient feels autonomous and obligated to make all his or her own decisions (Henson, 1997). In mutuality, patients and providers have respect for each other's view and set agreeable goals.

The value of peer support is well known for patients with cancer (Klemm et al., 2003). A cancer diagnosis affects daily living as patients strive to maintain hope and cope with uncertainty while they learn new ways to gauge their illness. Informants described a supportive online community of caring that was created by the some of the patients sharing daily struggles with each other. Some chat room participants developed a survivor identity. One group called themselves "Amazons," which represented the strength and tenacity they claimed for themselves as stage IV breast cancer survivors. E-mail and chat rooms provided peer support where no local support was available, especially in finding someone with a similar or rare cancer. Some of the patients were reticent to access this feature because the advice of providers and family. Outcome studies have reported that, for women with breast cancer, online support groups have reduced depression (Lieberman et al., 2003) as well as perceived stress (Winzelberg, et al., 2003). When recommending an online support site to a patient, a nurse could suggest that the patient "lurk" for a while without entering into the discussion to see if the group would fit his or her needs. Internet participants naturally develop informal labeling systems for postings that will facilitate filtering of undesired messages (Sharf, 1997).

Components important for meaningful use of the Internet emerged from further analysis. The components had value for the patients and were related to desired and actual stated outcomes. Table 2 summarizes the components. Nurses can use them to guide development of Web sites that are helpful to patients.

Conclusion

As patients with cancer in the study became partners in their health care, making meaningful decisions regarding treatment options became a high priority. Although the type and stage of cancer often dictated treatment protocols, the advent of each new day brought forth the potential for new discoveries and new treatment options. Patients described being barraged with incredible amounts of information from diagnosis through treatment. Sorting through all of this information was overwhelming for some, with questions coming to mind only after they have left the physician's office. Once at home, as they began to digest all the information, they often accessed the Internet to gain a better understanding of their illness and their treatment options as well as to seek corroborating information. Nurses can facilitate patient partnerships by encouraging patients to bring information found on the Internet to their attention and by being open to discussion about what patients find on the Internet.

Patients will continue to access the Internet for information and support, and nurses should be open to discussion of the information that patients bring to the interactions. Nurses also should be knowledgeable about useful Web sites and online support groups to recommend to patients. The approach of mutual exchange (mutuality) would help nurses and patients become accountable for managing health outcomes (Henson, 1997). Future research should focus on male experiences and gender differences. Internet-based nursing interventions that encourage Internet solutions should be tested for self-care outcomes. In addition, further exploration of patients' decisions for CAM therapy would be informative.

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