Abstract and Introduction

Abstract

Background: Cancer patients experience many physical, psychosocial, and existential problems and worries during their illness. To support patients in managing their illness, we implemented an online patient-nurse communication (OPNC) service, where breast and prostate cancer patients could ask questions and receive advice from oncology nurses.

Objective: The aim of this study was to explore the use and content of patients’ e-mail messages sent to oncology nurses and thus gain a "snapshot" of patients’ experiences of living with cancer as expressed through these messages.

Methods: Using qualitative content analysis, 276 messages from 60 breast and prostate cancer patients were analyzed. Messages were coded into categories and major themes. Both manifest and latent content was coded.

Results: Four main themes emerged from patients' messages: (1) living with symptoms and side effects, (2) living with a fear of relapse, (3) concerns for everyday life, and (4) unmet information needs from health care providers.

Conclusions: Patients used the OPNC service actively to pose questions and raise concerns related to symptom experiences, fear of relapses, and uncertainty in everyday life. However, patients also expressed experiences of being "left in a void" after being discharged from hospital and living with serious unmet informational needs.

Implications for Practice: The study demonstrated that online communication can provide patients with a space for otherwise unmet questions and worries and that they will seek support from nurses online when given the opportunity. Therefore, OPNC can be an important means and supplement to traditional health care in the effort to support patients to better manage their illness.

Introduction

An increasing number of cancer patients survive their illness, and many live with cancer as a chronic disease.\(^1\) Worldwide, 24.6 million people live with cancer, and each year, 10.9 million are newly diagnosed.\(^2\)

For the individual patient, having cancer implies challenging life situations all the way from diagnosis through treatment and rehabilitation. A confirmed cancer diagnosis may result in considerable psychological distress, existential concerns, and a strong awareness of one’s own mortality.\(^3,4\) For many patients, treatment decisions cause uncertainty and anxiety, especially when several treatment options are available.\(^3,5-8\) Treatment most often involves distressing adverse effects and an impaired quality of life.\(^9,10\) After treatment, when medical monitoring and support from health care providers are terminated, patients can experience loneliness and uncertainty.\(^11-13\) Several studies have reported that cancer patients often live with a constant fear of a relapse or recurrence,\(^14-16\) depression,\(^17\) and doubts about their long-term future. These studies indicate that patients may have considerable need for support even years after they have completed treatment.\(^18\) The ordinary follow-up support and care after cancer treatment are delivered in many different ways. In general, it involves regular medical examinations to check for recurrence or
metastasis, addressing treatment-related problems, and checking for physical and psychosocial effects that may develop months or years after treatment ends.[18]

One way to support cancer patients in addition to regular medical follow-ups is to allow them to communicate online with health care providers. Studies have documented that approximately 16% to 69% of cancer patients use the Internet for health information[19] and that e-mail communication is the most common reason why patients use the Internet.[20] Studies have shown that patients are highly interested in the possibilities for the exchange of electronic messages with their health care providers[20,21] but that there has been some reluctance from physicians and concerns about workload and time demands, confidentiality, data security, and inappropriate use of e-mail, by patients.[22] So far, research on patient-provider electronic communication has focused primarily on patient-physician communication, where the perspectives of both physician and patient have been studied.[23] A recent review that explored, among other subjects, the content of e-mail messages from patients to physicians reported that most inquiries and topics in patients’ e-mails addressed nonacute issues, medical information, medical condition or updates, and subspecialty evaluation.[22] To date, there is little research reported in the literature on patients’ use of online communication with nurses.[23–26] This indicates that either nurses have so far only played a limited role in providing support through online communication or this area has not been much researched.

To provide patients with support in their homes aside from face-to-face visits, our research group developed and tested WebChoice, an Internet support system for breast and prostate cancer patients that allowed patients to communicate online with oncology nurses. Patients undergoing treatment or rehabilitation could ask questions to oncology nurses, discuss concerns, and ask advice where and when they needed it, and the nurses responded within 24 hours (weekdays). The electronic messages from the cancer patients provided our research group with rich material about how patients communicated online with nurses, the experiences of their illness that they wished to share with them, and the type of questions and concerns for which they sought support.

As far as we know, no earlier studies have explored in-depth online communications between patients and oncology nurses through an online patient-nurse communication (OPNC) service. Therefore, there is little previous knowledge about how cancer patients use this communication service and what they choose to express when given the opportunity for e-mail communication with oncology nurses. Because nurses have a primary focus on the consequences and management of illness and its impact on daily life, they therefore have a different role than physicians, who primarily have a medical orientation toward the disease and its treatment. Thus, cancer patients may raise different questions and concerns and communicate about their illness differently in personal communications with nurses than they would with physicians.

Against this backdrop, our study seeks to explore what cancer patients choose to express to oncology nurses about their illness situation when given the opportunity for e-mail communication. This study then sheds light upon a “snapshot” of the study participants’ experiences of living with cancer as they have expressed it through this technological context of writing. This further answers the questions of how the cancer patients in our study used this patient-nurse communication tool in health care and whether this service might be useful in the care and support of cancer patients in the future.

**Methods**

This study is part of a larger study in which an Internet-based support system, called WebChoice, was tested in a randomized clinical trial (RCT) with 325 breast and prostate cancer patients to evaluate its effects on symptom distress, self-efficacy, quality of life, social support, and depression. Patients in the intervention group of this trial could access WebChoice from their home computer with the Internet Explorer Web browser. WebChoice offered 4 services:
1. An assessment section where the patients could monitor cancer-related symptoms, problems, and priorities for care in physical, functional, and psychosocial dimensions, currently and over time.

2. A self-management intervention section, where the patients could obtain helpful advice about how to self-manage their self-reported symptoms.

3. An information section where the patients could access reliable Internet resources, such as information about specific tests, treatment and potential adverse effects, patients' legal rights, and others.

4. An unrestricted open forum for group discussion, allowing users to exchange messages anonymously with other patients, and an online messaging system for private e-mail communication with oncology nurses (reported in this paper).

The developmental process of the WebChoice program, preliminary usage analysis of the system, [27] and preliminary results on patients' questions to oncology nurses [28] have been published elsewhere. Publication of outcome results from the RCT is in progress.

In the current study, we conducted a qualitative examination of the content of the messages from breast and prostate cancer patients to the oncology nurses in the OPNC service. The service allowed patients to anonymously ask questions, share experiences with, and ask advice from oncology nurses in cancer care. The oncology nurses entered the communication area daily, answered the patient's questions and concerns, and provided information, support, and counseling. An interdisciplinary team of other health professionals such as physicians, social workers, a priest, dieticians, and physiotherapists were available to the nurses if additional counseling was found to be necessary.

Study Participants

Study participants were breast and prostate cancer patients who participated in the RCT and who were randomly assigned to the experimental group with access to WebChoice and thus could use the nurse-patient online communication service as much as they wished. Patients were recruited through advertisements in the newspaper, on the Norwegian Cancer Society's Web site, and its membership magazine, as well as through information pamphlets mailed to patients from the Norwegian National Cancer Registry. Inclusion criteria were that patients had to be older than 18 years, able to read/speak Norwegian, and to have Internet access at home. The patients had to be currently in active treatment of breast or prostate cancer when included in the study.

Our study included all patients who sent at least 1 message to the oncology nurses during the first 15 months of the RCT study period (half of the entire RCT study period) from March 2006 until May 2007. During this time, 38 women with breast cancer and 22 men with prostate cancer sent in a total of 276 electronic messages to the oncology nurses. The mean (SD) age was 52 (7.9) years for women and 65 (7.6) years for men (age range, 35–77) years. Table 1 shows further demographical statistics of the study participants.

Characteristics and Collection of the Data Material

The electronic messages sent from the cancer patients to the oncology nurses consisted, in general, of a highly medical and technical language. Patients' descriptions of their cancer journey were common, including specific explanations of their treatment and blood test results that drew a picture of their illness situation to the oncology nurses. The e-mail messages could vary considerably in both length and content. One message might contain a short and straightforward question with few words, whereas another might include a patient's longer narrative about his/her illness experience or situation at the moment. Some of these messages were up to 1 page long and could contain several different and complex aspects at different levels.
To collect the communication material for analysis, we copied and saved all the 276 e-mail texts exchanged in the WebChoice messaging system during the study period and stored them in separate word documents, one for each patient's communication back and forth with the oncology nurses.

The process of data collection also included copying and reading the answers from nurses to each electronic message from the patient. However, this article includes only analysis of the patients' messages. Five different study nurses answered the patients' questions and concerns.

Ethical Considerations

This study was approved by the regional committee for Research Ethics in Norway and the Data Inspectorate. All procedures complied with the Norwegian Personal Data Act. Strong security measures were implemented in the WebChoice system to ensure data security and confidentiality. Patients did not communicate with their real names but through pseudonyms to ensure anonymity.

Analysis

Messages were analyzed using qualitative content analysis (QCA)\[29-31] Qualitative content analysis is defined as a research method for the subjective interpretation of the content of text data and other qualitative data, through the systematic process of coding and identifying themes and patterns.\[31] At first, all the e-mail messages were inductively and repeatedly read to get a sense of the whole. Thereby, an analytical scheme was developed to analyze and interpret each message within.\[30] The meanings of each message texts were condensed into a description close to the e-mail text, the manifest content. Where possible, we did an interpretation of the underlying meaning of the e-mail messages, the latent content\[30] (Table 2). Not all of the messages were found to have a latent meaning. Further on, we abstracted the manifest and the latent content into codes, categories, and finally, major themes. In the end, all the text from the e-mail messages across the material that could represent a thematic dimension was gathered, reread, and interpreted to gain an "essence" of each thematic dimension. Because we used QCA, we were not interested in counting the number of categories or codes to analyze the frequency of each code, category, and theme or how many patients expressed similar experiences. Rather, our aim was to elicit phenomena that stood out from the patient's e-mail messages as persistent or striking during the analysis of the material. We chose not to apply a software package in categorization of data.

The first author (G.H.G.) coded all the data and discussed the coding in conversation with one of the coauthors (A.F.). To establish external validity, 10% of the message material was double coded by another researcher. When opinions differed between the first author and the second coder, we returned to the original message texts and discussed them until an agreement was reached.

During the process of analysis, the interpretations of the material were discussed repeatedly with fellow researchers and coauthors throughout data analysis. These discussions added important reflections and interpretations of codes, categories, themes, and patterns within the message texts from the patients. The goal of this process was not to seek total agreement among codes, categories, and themes but to determine whether various researchers would agree with the way the data were labeled and coded and to grasp the complexity of the material in line with the nature of qualitative research.\[32]

Results

By applying QCA, we identified that the cancer patients in our study used the OPNC service to communicate with the oncology nurses about 4 major thematic dimensions: (1) living with physical symptoms and side effects, (2) living with a fear of relapse, (3) concerns for everyday life, and (4) unmet informational needs from health care providers. These thematic dimensions also represent a snapshot of the study participants' experiences of living with cancer as they expressed it through this specific technological context of writing.
Living with Physical Symptoms and Problems: "Is This a Side Effect of Treatment or is it 'Just Me'?"

A major theme expressed in the e-mail communication with the oncology nurses was questions, experiences, worries, and concerns related to physical symptoms and problems. For example, women with breast cancer wrote to the nurses about lymph edema; phlebitis; nausea; heat flushes; pain in muscles, arms, and legs; and red, sore, and itching skin. A very frequent theme in this material was women's different expressions of the experience of being "tired and exhausted" during and after treatment. They described the experience of being fatigued as having a "huge lack of energy," feeling "tired and slow," feeling more forgetful or absent minded, and experiencing a loss of concentration. Some of the women felt insecure about their body limits. Their legs were feeling heavy and the body did not seem to "keep up" anymore the way it used to:

I am extremely tormented by fatigue, even though I was operated on in 2003. Chemotherapy, and then radiotherapy [...]. It doesn't take much at all before I feel lethargic, would cry and sleep. I am good at listening to my body's signals and taking care [of myself], and I am trying to live "my" life [...]. I have always been healthy and strong, taking part in many activities, and I have had a large capacity for work. The difference was therefore great… I sleep quite a bit, and rest a lot, everything goes slowly. Reading and concentrating is a big problem, even literature I like.

Other women wrote about being healthy and nearly finished with treatment, but not having the bodily experience of being a healthy person because of the large lack of energy. They tried to "listen to the body" and to do everything right like "eating, sleeping, and exercising," but even so, the body did not seem to respond. To be fatigued seems to be a largely unexpected experience, and some women wrote about not being informed of this adverse effect in their contact with health care providers.

The men with prostate cancer struggled with symptoms and problems at home as well. Heat flushes, urine leakage, frequent and painful urination, urine retention, urine infection, and pain and lack of flexibility in the hips were some examples. However, the most common theme for men in this material, in addition to incontinence and urine retention problems, was problems and worries related to erection and impotence. Most of the male patients wrote to the oncology nurses about these problems and mentioned directly that their sex life was more or less on "death row" using expressions like "my sex life is dead" or "I have no sex drive." Some men used a more latent language, telling the nurses about being "chemically castrated."

Patients seemed generally frustrated when they experienced that their ability to gain an erection was significantly reduced, and they expressed an urgent wish for the situation to change. As one man wrote:

I would have paid a lot to get my sex drive back.

The men with prostate cancer used the e-mail communication service to seek advice from the nurses in WebChoice about what they perceived as a large problem: inability to feel sexual desire or to have sex as they used to with their wives:

The only thing that doesn't function is my sex life, it's completely dead. I have discussed this with my wife and we have temporarily come to terms with the thought that this may return in time. On the other hand we have gotten closer to each other, so maybe we just have to accept that our sex life doesn't work? Maybe it also has to do with our age? If you have any thoughts or advice about this, I would like to hear your response.

Only 1 woman in this sample talked about problems and worries related to sexuality. On the other hand, there was only 1 male patient talking to the nurse about fatigue.

A persistent thread in the e-mail messages, along with the patients' need for writing and telling about their distressing symptoms, was patients' continuous need to have their symptom experience confirmed,
explained, and understood as something "normal" and especially as a "side effect" of medication and not a sign of relapse or sensations unrelated to the disease:

Now I am going to start working again, and I believe it will be extremely hard. I have very little energy and I become physically and mentally weary from noise, and crowds of people. I was operated on in February and finished radiation May 19. Went on Tamoxifen. After such a long convalescence you would think your condition would be good, but it isn't. Don't know if this is a side effect of treatment or if it's "just me." Do you have some comments on this problem?

Uncertainty about symptom experiences and how these experiences should be interpreted and understood seemed to be a central aspect of the cancer patient's communication in the OPNC service.

**Living With the Fear of a Relapse: "I Walk Around With My Nerves on Edge, Terrified of the Slightest Sign of Pain, No Matter Where it Might Arise"**

Both men and women wrote explicitly and implicitly about their fear of relapse or spread of the disease. In the communication with the nurses, this anxiety was expressed through several questions related to experiencing bodily changes or unclear blood test results. For men, the anxiety was often connected to the experience of "unpredictable" pain in the pelvis or hips and their concerns about spread of the disease: "I can also feel that there is some pain/discomfort in my hip on my right hand side. Of course I am a little bit worried whether the cancer has already developed and spread to the skeleton." The anxiety about relapse or spread of the disease was also strongly related to the value of the prostate-specific antigen (PSA) blood test. Most men wrote to the nurse about their PSA level, to present a whole picture of their situation and also how the PSA level had changed during treatment. Many sought an explanation from the nurse about whether their PSA value was "good" or "bad." The PSA level seemed to be an important parameter for the men to measure cancer progression and their own health. However, variations in PSA levels also seemed responsible for an "emotional rollercoaster" experienced by the men, based on varying results from one blood test to another:

I just called the hospital to find out what the PSA test result was that was taken before the last day [of treatment]. I started in December and the hormone treatment had a good effect. In March it [the PSA result] was already 0.57. Midway through the treatment it dropped to 0.3 for the last test and went up to 4 for the last test. Is this usual? I had expected it to decrease further, and became worried.

Female patients also expressed fear and anxiety related to relapse or metastases. The fear was often related to physical changes in their bodies such as a new experience of pain in their breasts or armpits and tiredness. One woman wrote about having discovered a lump in her lip that she had never had before, and she continued: "I am so afraid of every little change in my body." The fear of a relapse or deterioration of their condition was also associated with topics they read about in the newspaper and in the forum in WebChoice (the peer-to-peer communication) related to treatment of cancer. They read about other patients in the same situation who received different kinds of treatment. This could cause uncertainty about their own situation and treatment: "Can I be sure that the treatment I receive is the best?"

**Concerns for Everyday Life: "I Don't Want to do Anything Wrong"**

Many of the patients expressed simple questions and reflections to the nurses about their everyday life and daily activities. They asked to what extent the things they were doing or wished to do were safe and acceptable for their situation at the moment, living with a serious illness. Typical questions found in the material were the following: May I "take a bath in the sea?" "sunbathe?" "ride a horse?" "drink red wine?" "work in the garden?" "play golf?" "apply lavender oil to my skin?"

These specific questions to the oncology nurses might reflect a strong wish from the patients to live as normally as possible, doing ordinary daily life activities. At the same time, the patients expressed considerable uncertainty about doing trivial and normal activities. In the patients' messages to the nurses,
there seemed to be an underlying fear of "doing anything wrong" in their daily life that might negatively affect their treatment or their situation:

I take a few of each vitamin, mineral, and dietary supplements to strengthen my immune defense, but is this a mistake? I will not do anything that could negatively affect the treatment.

The patients seemed to seek confirmation, support, and assurance from the nurses for the activities or solutions that they wanted to be part of their daily life. The online communication with the oncology nurses functioned as a medium for the patients to connect with the health professional world to ask permission to "ride a horse," "drink red wine," or "work in the garden." Patients may see online communication with nurses as an extended "medical gaze" that offers the "true" answers about the "right" or "wrong" way of living with cancer. The online communication gives them space for an ongoing negotiation between the patients' lives "off the screen" and the health professional world. Reading the material leaves the reader with an impression that patients may wish for a normal life filled with activities that they used to do before the onset of the illness, but they do not dare to trust their bodies and their own judgment anymore. It seems that they have to be sure that they are not "doing anything wrong" that might "mess up" the treatment and medication—"the last chance"—and they seek support from the oncology nurses and health care professionals concerning these everyday questions and choices.

Unmet Information Needs From Health Care Providers: "I Have a Feeling of Hanging in the Air"

The online communication from the patients to the nurses sometimes contained patients' narratives after they had been in contact with the health care system and referred to their unmet informational needs.

Patients would write to the nurses about having completed different blood tests but being unable to reach the health care personnel for many weeks to receive the test results, or they would say that they had the test results but no one had explained to them what the test results actually meant for their situation. For example, one patient asked: "Does the blood test result mean that there are no cancer cells moving around in my body?" Patients living at home could be uncertain as to whether they were healthy or still have cancer. One man wrote to the nurses about this topic more explicitly:

I now have 5 radiotherapy treatments left and have managed pretty well the last 6 weeks. During this time I occasionally have a feeling of "hanging in the air." I had to ask for blood tests after 4 weeks… I think a lot about whether the treatment has worked…. How should I go forward? How can you find out if the cancer is gone…as I said, it is not easy when you get this hanging in the air feeling.'

The man expressed a feeling of "hanging in the air" during treatment that compelled him to take control of the situation and ask for his delayed blood test results. The hanging in the air feeling could be interpreted as a feeling of loneliness after treatment, where no one really takes the responsibility for him and his situation. One could also extrapolate that the feeling reflects the general uncertainty that cancer patients often experience about whether or not their treatment has been effective.

There were many other examples of unmet informational needs in the material for analysis. One woman wrote to the nurse about constant pain in her breast and armpit long after the operation and her recent consultation with her physician. After the examination, the physician told her that she (the physician) hoped that her pain was related to the treatment she received and not to a relapse. The woman left the physician's office with no answers, just an increased anxiety about a possible relapse, and no suggestions or referrals from the physician for further follow-ups. Another woman received several examinations at the hospital for pain and gynecological bleeding, only to be sent home with the explanation that the physicians did not know what caused the pain and the bleeding, and no suggestions for further examinations. She wrote to the nurses in WebChoice:
What do I do now? Wait and see whether there are abnormal cells? Do I myself, or my general practitioner contact the oncological outpatient clinic at the hospital…or?

By reading the e-mail messages within this thematic dimension, we got the impression that the cancer patients seem to struggle alone and in uncertainty, with many serious questions and concerns that are not being answered or addressed during their contact with their health care providers. We interpreted their situation as a situation of being "left in a void" where their informational needs were not even close to being fulfilled. However, the OPNC service created a space for their questions, experiences, and reflections to come through.

Patients with metastases also contributed their concrete experiences to this thematic dimension, but their questions seemed to be more strongly related to existential concerns, about the illness’ impact on their lives, and their future. One woman, who already by the time of diagnosis had a metastasis to the liver, expressed how she often thought about how her life was going to end, and she asked the oncology nurses what patients with breast cancer and metastases to the liver actually die of? She continued:

This is kind of taboo, because I am supposed to get well! It’s very hard to ask my doctor about this question during my follow ups.

Patients with metastasis express these sorts of existential concerns by writing about all the "diffuse," "vague," and "woolly" answers they got from their health care providers when they started to talk about treatment and questions about the future. By reading the material from this specific group of patients, we got the impression that those patients with incurable cancer sometimes "fall between chairs" in their relationships and communication with their health care providers. They found it difficult to express their existential worries and their uncertainty about the illness, the impact on their bodies, and the future. Sometimes, their health care providers had not responded to these worries and questions at all. As one woman with metastasis expressed in 1 of her e-mail messages:

I want to know, among other things, what I can and cannot do. What kind of holiday can I have, if I can do anything at all? How will further treatment be arranged, what decides next chemotherapy, what kind, when more radiation? How will the follow-ups be? I haven't had a proper and careful conversation since they found the metastasis. I notice that I am on the way to becoming a difficult patient[…] to find out how my life is going to be, I have to know how my disease is progressing.

Along with unmet informational needs from the cancer patients in general, a general mistrust of the "system" and the health care providers was expressed directly in the patients’ e-mail messages. Patients used strong metaphors, saying they were being "jolted about in the system" or "[walking] around in the dark" when they wrote about their experiences with the health care service. Sometimes, they did not feel confident about receiving the best treatment available, nor did they trust their physician or the hospital, or they would describe bad experiences of mistreatment or poor communication with health care staff. After this kind of experience with health care, the patients seemed to take a "role of responsibility" to take control over the situation with their illness: "Since I was treated in a small hospital, I feel that I have to be extra vigilant" or "it’s a lot to manage on my own, even though I regularly attend the treatment at the hospital."

Patients writing to the oncology nurses in WebChoice seemed to use the online communication as a way of conducting their own investigations to find solutions and opportunities when the health care system fails. A constant search for new studies to join, new vaccines, new treatment, and medication for cancer was a recurrent feature of the communication with the nurses:

I have information that [my hospital] is working on developing a vaccine that takes into account the tumor that the individual patient has, and that they are planning a vaccine study for patients with prostate cancer. I wonder if it is possible to be part of this study?

By reading the material, we got the impression that, from their homes, the cancer patients were constantly "hunting" for a cure, a sort of salvation that could improve their situation. They repeatedly used the OPNC
service as a way of "checking up on" their physicians or the information they had received from the hospital or their health care providers. We also got the impression that online communication with the oncology nurses could function as a "place for venting," giving the cancer patients an extended space for writing down their experiences or their frustrations with the health care system to oncology nurses who actually listened and responded directly to their personal stories.

**Discussion and Conclusion**

The present study on online communication from cancer patients to oncology nurses has shown that the cancer patients used the OPNC service to communicate about several already known challenges for cancer patients. Experiences of physical symptoms and adverse effects, fear of recurrence, and uncertainty about everyday life and its activities were expressed through the patients' e-mails. The OPNC service created a space for the cancer patients' serious unmet informational needs. However, more strongly than has been reported in earlier studies, patients expressed a feeling of being "left in a void" after follow-ups or discharge from hospital, living at home in uncertainty with unanswered questions. In addition, a general mistrust of the "system" and their health care providers was expressed through the OPNC service. The study participants seemed to take on a "role of responsibility" when the health care system failed, and they used the OPNC service as a way of searching for new possibilities to make their situation better and to check up on their physicians and the information they have received. The e-mail communication with the nurses also seemed to function as a "place to vent," giving the patients the chance to write about their frustrations, experiences, hopes, and loss regarding the challenges of living with cancer.

A strength of this study is that the data used for analysis are written utterances from the cancer patients as they communicate with oncology nurses in real time, which allows nurses, and our team of researchers, to hear cancer patients' own "voices" through their electronic keyboard. This adds an important new perspective to earlier research, which was most often based on questionnaires, surveys, or interview studies. This method provides better information and knowledge about the patients' illness experiences from the patient's perspective. Each text message represents a snapshot of the patient's situation at the time of writing and a personal narrative with a distinctive quality that sheds light upon the patient's questions, worries, and concerns based on their own personal needs, unshaped by rigorous questionnaires or structured interviews designed by researchers. However, the fact that their experiences were framed within a technological context has shaped the communication in some ways.

**Four Themes**

Worries and concerns related to living with symptoms and side effects were one of the major and persistent themes the cancer patients expressed in the OPNC service, confirming that living with symptoms is one of the major problems and concerns for cancer patients.

The study also revealed that cancer patients have a strong desire to seek reassurance and acknowledgement that their experienced symptoms can be considered as "normal" and commonly acknowledged "side effects" by the nurses and not as something abnormal such as a sign of recurrence, relapse, or deterioration of their condition. This specific need for their bodily symptoms to be seen, met, and understood was highly persistent throughout the material for analysis. One could therefore ask whether the ordinary health care system acknowledges and listens to the patient's worries and concerns related to symptoms and adverse effects. One could also reflect upon whether having their symptoms acknowledged and understood in a medical context would make it easier for patients to live with and accept their symptoms and their changed body during and after treatment. One could even suggest that the patients may experience their symptoms as more valid and trustworthy when they are acknowledged by professionals and can be understood and discussed in a medical context.
Living with the fear of a relapse was expressed through direct utterances of fear and concerns about a recurrence or deteriorating condition. However, feelings of insecurity about a recurrence were also expressed more latently, for example, in questions about the risk of a recurrence in the other breast or what types of tests can detect a recurrence. That cancer patient's fear of recurrence is nearly universal has been supported in other studies.\[^{33}\] It causes significant distress that compromises quality of life. A study of the transition from breast cancer "patient" to "survivor" showed that, very often, fear of recurrence is triggered by physical symptoms of unknown origin.\[^{16}\] These findings were also represented in our material. For the male patients in our study, the analysis showed that PSA levels were responsible for an uncertainty and anxiety experienced by the men and that anxiety about a relapse or worsening of their illness increased with a rising PSA level, as has also been documented in earlier studies.\[^{34}\] For health care providers, it is important to understand how much emotional pressure the PSA test result represents for these patients. It is not just a number; for the men receiving, it is an important measurement that indicates improvement or worsening of the cancer. The male patients who often asked the nurses in the OPNC service whether their PSA level was "good" or "bad" might indicate that there is not enough information given to explain what the PSA result means. We believe that a lot of worry and anxiety could be prevented if patients could bring forward their questions and concerns about their blood test results and their thoughts about the progression of the cancer when receiving their test result. It is also possible that prostate cancer patients ascribe too much importance to the PSA test, more than their physicians do.

There is room for further reflection and research on the subject of whether access to the information in the WebChoice application and to other cancer patients in the peer-to-peer communication was by itself able to create fear of recurrence or deterioration of condition. One woman wrote: "I use this [program] a lot and I am impressed by all the 'stuff' [information] I find here. [I] check the links, and think there's a lot of information in English. But I also get a little bit worried when reading, because there seems to be so many relapses and new incidences of cancer in people who already have had cancer. Now I am starting to think that's the way it's going to be for me too..." To be exposed to potentially worrisome information is something that these patients risk more than others. In a study from Sandaunet,\[^{35}\] the need to avoid painful details about breast cancer was one of the reasons why patients did not participate or withdrew from an online self-help group.

The thematic dimension, concerns for everyday life, contained several questions related to what to do or not to do and how to behave in relation to normal everyday life activities. Communications involving this topic indicated a general insecurity of the patients, afraid of doing anything wrong that may affect the illness and cancer treatment. Uncertainty in cancer is well documented in earlier literature. A recent review reported uncertainty in breast, prostate, and colorectal cancer patients because of lack of information about the course and treatment choices and uncertainty related to everyday life and coping with the disease.\[^{14}\] However, the everyday uncertainty in our study differs in some respects from the uncertainty reported in the review of Shaha et al.\[^{14}\] The thematic dimension "concerns for everyday life" in our study unveils an uncertainty in the patients that they express in questions about whether they should partake in various normal everyday activities. However, questions about these apparently easy choices suggest that the patients are suffering from an underlying fear that permeates their lives, preventing them from engaging in the simplest daily activities for fear that it will somehow negatively affect their illness or their recovery process. A study by Jonsson et al\[^{15}\] on men's experience of their life situation when diagnosed with advanced prostate cancer found that the most prominent wish the men in the study expressed was their desire to return to a normal life as soon as possible and have their cancer under control, thereby gaining control of their own life. That patients in our study frequently requested approval of everyday activities they would like to engage in can be understood in a similar way. The patients have a strong desire to live as closely as possible to the way they used to before the illness, but they feel insecure and do not dare to trust themselves, their judgment, or their bodies anymore. Their body is changed by their treatment's many adverse effects, and they need support from health care experts concerning these everyday and apparently trivial choices. One could even speculate that 24-hour access to oncology nurses from the privacy of their own homes may have created an artificial need to ask questions and double check their actions with the
experts, leading to increased dependence on health care services that actually interferes with their coping abilities and self-efficacy. There is, however, no evidence of such adverse effects of e-mail services.

The fourth major theme concerned the patients' experiences with health care providers, in particular in relation to information needs. Earlier studies on cancer patients' satisfaction with health care have documented that patients are generally satisfied with health care services, the treatment they receive, and their communication with providers. However, despite a high degree of satisfaction, several studies show how patients report unmet information needs, in particular about the long-term implications of treatment and disease and their impact on daily life. These findings were confirmed and exemplified in the present study, and the areas of unmet informational needs described in the studies mentioned correspond well with the main themes reported by our informants. Similar information needs have been reported by partners and family members of cancer patients.

Some of the e-mail messages in our study refer to an absence of information more explicitly than has been shown in former studies, sometimes by the use of powerful metaphors such as "being left in the dark" or "hanging in the air." In the literature on communication in cancer care, there has been an emphasis on information about diagnosis. Our data and those of other studies indicate a need to give more emphasis to information about prognosis and the long-term consequences of the disease, as well as more continuity and better access to health care personnel throughout the course of the disease. The study revealed that it can be difficult for patients with incurable cancer to communicate their existential concerns in a medical context, where saving lives seem to be the first priority. The study suggests that it would be helpful to cancer patients to include existential issues in communication about the disease and its effects.

It may be that the nature of the Internet, which allows anonymity and the ability to "write and hide behind a screen," was a possible medium in which the OPNC service could create such a safe space for patients to discuss their bad experiences and unmet informational needs in their contact with their health care providers. The privacy of the Internet made it easier and less risky for the patients to communicate about their bad experiences. One could also reflect upon whether writing about his/her own experiences in itself might have had a positive health outcome.

**Limitations**

This study has several limitations. First, inclusion in the study required Internet access.

Second, patients were participating in an RCT to test an Internet application that, in addition to the messaging service, contained several other information resources that patients could access. Patients may have found answers to their questions there. This may have affected the type and amount of questions that patients asked. Third, the messaging service was administered by oncology nurses and patients from all over Norway. Nurses did not have access to patients' records and their individual medical history, which limited the types of questions and the specificity of information they could give. The system provided a welcome message to the patients the first time they logged on, giving them suggestions for the types of topics that they might ask the nurses about. This is likely to have influenced the type of questions patients asked and, equally as important, did not ask (eg, about their specific medical history or treatment for which they had to consult their physician). Because nurses had no access to the record system, there were obviously no messages asking about appointment times, medication refills, or other questions that are common in e-mail systems that allow communication between the patient and the hospital. A messaging service that would allow patients to communicate with "their" nurses who they knew and were also involved in their care may have yielded different results.

**Conclusion and Implications**

This study reveals that cancer patients live at home with many serious concerns, questions, and unmet information needs that create considerable uncertainty and anxiety. Cancer patients in our study actively
used the OPNC service to address these challenges. The traditional health care system does not seem to meet patients' information and support needs sufficiently, especially when it comes to acknowledgement of the long-term effects of treatment, fear of relapse or recurrence, support regarding everyday life, and concerns about the future. This study suggests that there is a lack of support, information, and follow-up of cancer patients in the health care system to such an extent that some patients feel that they are left in a "vacuum" after discharge from hospital. Better continuity in cancer care and better information about prognosis and long-term impact of the disease should promote more effective coping. We must not forget that patients living with incurable cancer might have different information needs than do patients with first-time diagnosis. Patients could be encouraged to communicate their existential questions and the impact of the illness on their life and the future.

Second, the study suggests that a nurse-delivered, e-mail-based messaging service can, to an extent, meet patients' need for advice and information and thus be an important health care supplement. As nurses in their professional role have a special focus on illness management and self-care, nurses might be particularly qualified to help patients with problems related to the impact of their illness on their daily life. Because questions and worries are often the reason why patients schedule a physician's appointment that may take weeks to arrive, a nurse-delivered messaging service, as in this study, may reduce patients' needs for office visits and the time needed for rehabilitation and recovery. As cost concerns and shortages of health professionals continue, this could become a viable health care supplement and means to improve care quality for many patients while reducing health care costs at the same time. Nurses should become actively engaged in the opportunity to provide online support to patients that can effectively help them in managing their illness. However, online support should remain a supplement and not a substitute for face-to-face interaction with nurses, physicians, and other providers. More research is needed on how interactive e-mail interventions may satisfy information needs and promote coping with the disease. There is a need for further examinations on whether e-mail communication might be an effective way for nurses to understand and respond to cancer patients' cues and concerns expressed in their e-mail texts. Studies on the nurse's role in providing online care are suggested, in line with a development of guidelines for nurses on how to communicate with patients online.