

What Patients with Cancer Want to Know About Pain: A Qualitative Study

Jacqueline L. Bender, BSc, MSc, Joanne Hohenadel, BHSc, Jennifer Wong, BSc, Joel Katz, PhD, Lorraine E. Ferris, PhD, LLM, Cindy Shobbrook, RN, MN, ACNP, David Warr, MD, and Alejandro R. Jadad, MD, DPhil, FRCPC

Departments of Public Health Sciences (J.L.B., L.E.F., A.R.J.), Medicine (D.W.), Health Policy, Management and Evaluation (A.R.J.), Anesthesia (A.R.J.), and Nursing (C.S.), University of Toronto; Centre for Global eHealth Innovation (J.L.B., J.H., J.W., A.R.J.), University Health Network, Toronto General Hospital; Department of Psychology (J.K.) and School of Kinesiology and Health Science (J.K.), York University; Clinical Epidemiology Unit (L.E.F.), Sunnybrook Health Sciences Centre; Institute for Clinical Evaluative Sciences (L.E.F.); and Princess Margaret Hospital (C.S., D.W.), University Health Network, Toronto, Ontario, Canada

Abstract

Research indicates that patients feel more satisfied and obtain better health outcomes when they are able to discuss their questions with their health professionals. A better understanding of cancer patients' questions may help guide interventions to address their information needs and improve pain management. This study sought to explore and describe the questions that women with breast cancer have about pain related to cancer. Semistructured interviews were conducted with women with pain related to breast cancer or its treatment, recruited from a large teaching hospital in Toronto, Canada. Interviews were audio recorded and fully transcribed. Data saturation was reached after 18 participants were interviewed. Analysis involved the identification of themes and the development of a taxonomy of questions about pain. In total, over 200 questions concerning seven main themes were identified: (1) understanding cancer pain, (2) knowing what to expect, (3) options for pain control, (4) coping with cancer pain, (5) talking with others with cancer pain, (6) finding help managing cancer pain, and (7) describing pain. The information collected suggests that formulating and articulating questions about pain is a context-dependent, time-intensive process that requires reflection, knowledge, and a good use of language. Patients have numerous and diverse questions about pain and its treatment, which may be difficult to address within the context of a typical

This research was funded in part by the Canada Research Chair in eHealth Innovation and the Rose Family Chair in Supportive Care (held by A.R.J.), the Ivey Foundation, the Rose Family Chair Fund and the Princess Margaret Hospital Foundation. J.K. is supported by a Canada Research Chair in Health Psychology at York University. J.L.B. is supported by the Canadian Institutes for Health Research, Strategic Training Program in Cell Signaling in Mucosal Inflammation and Pain. The work for this study was performed at The Centre for Global eHealth Innovation, Toronto General Hospital and Princess Margaret Hospital, University

Health Network, Toronto, Ontario, Canada, and the Department of Public Health Sciences, Faculty of Medicine, University of Toronto, Toronto, Ontario, Canada.

Address correspondence to: Alejandro R. Jadad, MD, Centre for Global eHealth Innovation Toronto General Hospital, R. Fraser Elliott Building, 4th Floor, 190 Elizabeth Street, Toronto, Ontario, M5 G 2C4 Canada. E-mail: ajadad@ehealthinnovation.org

consultation. To manage pain adequately, innovative efforts are needed to enable patients and health professionals to recognize, articulate, and answer such questions. *Internet-based tools could provide some of these solutions.* J Pain Symptom Manage 2008;35:177-187.
© 2008 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

Key Words

Pain, breast neoplasms, patient participation, patient education, patient-physician relations, questions

Introduction

Despite advances in the management of cancer pain, many people with cancer continue to obtain inadequate analgesia.¹⁻³ This has been attributed, to a large extent, to important barriers that hinder communication during the treatment of cancer pain at the levels of the health system, health professional, and patient.³⁻⁷ Effective communication between patients and health professionals is known to improve health outcomes, including pain control.⁸ One way to improve this communication is to enable patients to participate actively during the management of their pain. To facilitate patient participation, patients need to be provided with sufficient and appropriate information and enabled to ask questions.⁹

Research indicates that patients who are able to ask questions of importance to them and get answers, feel less anxious, more satisfied with the consultation, experience greater information recall and better health outcomes, including pain control.¹⁰⁻¹⁴ Unfortunately, many patients may not know what questions to ask or how to articulate their concerns. In an effort to improve communication between patients and health professionals, several researchers have developed question-prompting interventions to ensure patients' questions are addressed.¹¹⁻¹⁴ However, only a few investigators^{15,16} have examined the questions that cancer patients would like addressed.

Several papers have documented the information needs and preferences of individuals with cancer. However, most of the literature discusses patient information needs from the perspective of health professionals, the topics identified are broad, and there are limited data on the specific questions that cancer patients would like addressed. Although information about pain management has been identified as a priority for individuals with

cancer,¹⁷ to our knowledge no studies have examined the questions that cancer patients have about pain related to their illness. A better understanding of cancer patients' questions and concerns may help guide interventions to address their information needs and improve pain management. Guidelines for the development of patient information materials suggest that patients' questions should be used as the starting point.¹⁸

Using qualitative methodology, McJannet and colleagues¹⁵ examined the information needs of recently diagnosed cancer patients consulting a surgeon, and Clayton and colleagues¹⁶ examined the information needs of cancer patients referred to a palliative specialist. Although both studies had important findings, neither focused on, nor specifically explored, the topic of pain. Clayton et al. identified pain to be an important topic among palliative cancer patients; however, the topic was not explored in detail and the questions identified were limited to controlling pain, concerns about morphine, and the experience of pain near the end of life.

In this study, we explored the questions that women with breast cancer have about the experience and management of pain related to cancer. We focused on the experiences of women with breast cancer because pain continues to be a prevalent symptom associated with breast cancer and is diverse in nature and etiology.¹⁹ We chose a qualitative descriptive approach because we believed it was the most appropriate method to learn from the perspectives of those who experience pain related to cancer and build an understanding based on their expressed needs.²⁰

Methods

Study Design

This study used a qualitative research approach called *fundamental qualitative description*,

as described by Sandelowski.²¹ Qualitative descriptive studies have as their central goal a comprehensive summary of an event or phenomenon, organized in a way that best fits the data collected and will be most relevant to the audience for whom it was written. There is no mandate other than to produce an accurate descriptive summary of an event in the everyday terms of that event. Such an approach is especially suited for those seeking to explore and identify the "who, what, and where" of events or phenomena. Although no description is free of interpretation, fundamental qualitative description involves a "low-inference" form of interpretation.²¹ It allows the data to "speak for themselves"²² and does not require the researcher to describe the data in terms of a specific conceptual, philosophical, or other abstract framework.

Participants

We sought participants who: (1) had pain, of any kind and of any severity, associated with breast cancer or its treatment, (2) were 18 years of age or older, and (3) were able to understand spoken and written English. The sample size was not fixed or predetermined, but rather was determined by the saturation point of the data. Recruitment ceased when the information being collected became repetitive across individuals and new themes no longer emerged.²³ This occurred after 18 participants were interviewed.

Participants were recruited from the Breast Cancer and Pain Clinics at the Princess Margaret Hospital in Toronto, Canada from June to October 2003. Given the diversity of pain syndromes related to breast cancer,¹⁹ we explored the questions that the participants had regarding any type of pain related to breast cancer or its treatment. We were interested in obtaining a maximum variation sample of participants with diverse characteristics (disease status, treatment profile, years since diagnosis) to capture the core experiences and central themes that cut across a variety of patient perspectives.²⁴ The constraints imposed by a busy clinic setting necessitated convenience sampling. Fortunately, the final sample comprised breast cancer patients with a range of characteristics and pain experiences (Table 1).

Data Collection

Each participant took part in one semistructured interview. Interviews were conducted by the same investigator (J.L.B.) to ensure consistency and reliability of the information collected. Interviews were approximately 60 minutes in length, were audio recorded and took place following a scheduled clinic appointment ($n = 16$) or by telephone at a later date ($n = 2$), depending on the participant's preferences. Full informed consent procedures were followed. Study approval was granted by the University Health Network and the University of Toronto Research Ethics Boards.

Open-ended questions were used to guide the interview. Participants were asked about their experiences with pain, related questions and concerns, specific information they wished they knew more about or had known earlier, questions they asked their health professionals, and any unanswered questions. Clarification probes and follow-up questions were used to clarify and explore issues in greater depth and to verify our understanding of the information being collected.²⁵ The interview guide was pilot tested to ensure the clarity of the questions and follow-up probes. As appropriate in qualitative research, new questions were developed and included in successive interviews as new issues and themes emerged.²⁶ Data collection and analysis were thus simultaneous and iterative, lending further credibility to the data.^{27,28}

Following the interview, each participant answered a brief questionnaire to obtain descriptive information about their disease status, treatment profile, pain intensity, and demographics. Pain intensity was assessed using a four-point categorical verbal rating scale²⁹ (none, mild, moderate, and severe). Participants rated their pain intensity at the time of the interview, on average, and at its worst.

Data Analysis

Data from the transcribed interviews were analyzed using qualitative content analysis following procedures described by Graneheim and Lundman³⁰ and by Creswell.²⁶ Multistage data analysis was facilitated by QSR NVIVO 2.0 data management software.

Each transcript underwent several close readings. Codes derived from the data were

Table 1
Participant Characteristics (n = 18)

Characteristic	No. of Participants (%)
Age (years)	
>55	14 (77.8)
Education completed	
Greater than secondary or high school	8 (44.4)
Language (native)	
English	14 (77.8)
Country of origin	
Canada	11 (61.1)
Years since diagnosis	
0-5	8 (44.4)
6-10	5 (27.8)
11+	5 (27.8)
Metastatic breast cancer	
Yes	10 (55.6)
Treatments received	
Surgery	17 (94.4)
Radiation therapy	12 (66.7)
Chemotherapy	14 (77.8)
Number of pains	
Greater than one pain	9 (50.0)
Pain intensity (at its worst)	
Mild	2 (11.1)
Severe	16 (88.9)
Pain intensity (in the last 7 days)	
Mild	10 (55.6)
Moderate	6 (33.3)
Severe	2 (11.1)
Pain intensity (at the interview)	
No pain	1 (5.6)
Mild	13 (72.2)
Moderate	2 (11.1)
Severe	2 (11.1)
Current analgesic therapy	
None	2 (11.1)
NSAIDs or acetaminophen	3 (16.7)
Opioid	13 (72.2)
Attributed cause of pain	
Cancer	8 (44.4)
Treatment	7 (38.9)
Unknown	2 (11.1)
Unrelated	1 (5.6)

NSAIDs = nonsteroidal anti-inflammatory drugs.

systematically applied to words and passages in the text. Three of the authors (J.L.B., J.H., and J.W.) independently coded the first 10 transcripts. Independent coding results were compared and a coding scheme was developed that was applied to all transcripts. Interrater

reliability was high; there were only a few disagreements among the coders, which were easily resolved in conversation. Similarities and differences in the codes and related text were explored and sorted into categories; the underlying meaning of the categories was then formulated into a theme; and the participants' questions were extracted and organized into a taxonomic structure based on the emergent themes. Findings emerged through consensus among investigators. A detailed description of the analysis procedure is described elsewhere.³¹

Several steps were taken to ensure the credibility of the results, following recognized criteria for assessing validity in qualitative inquiry.^{27,28} These included providing a detailed description of the research procedures, participants, and results to enable readers to judge the applicability of the results in other settings; independent coding of the data by three researchers and regular debriefing of the research team to corroborate the research findings; and respondent validation involving the use of clarification probes and follow-up questions during interviews to ensure that the participants' viewpoints were accurately captured and faithfully interpreted.

Results

The sample comprised breast cancer patients with a range of sociodemographic backgrounds, treatment profiles, disease characteristics, and pain experiences (Table 1). The majority ($n = 10$) of participants had been living with the cancer for six or more years and had evidence of metastatic breast cancer. Ten participants were receiving treatment at the time of the interview, two were about to begin treatment, and six women had received treatment and were in remission. Each of the participants described varied and extensive experiences with pain. The majority of participants ($n = 16$) reported experiencing severe pain at some point since their diagnosis. At the time of the interview, all but two of the participants were using some form of analgesic therapy for pain control and the majority ($n = 13$) reported experiencing mild pain. Eight participants believed their pain was caused by the breast cancer and seven attributed their pain to the treatment.

Analysis of the interview transcripts resulted in the identification of 208 questions concerning seven main themes: (1) understanding cancer pain (cause, meaning, and nature of cancer pain), (2) knowing what to expect, (3) options for pain control, (4) coping with cancer pain, (5) talking with others with cancer pain, (6) finding help managing cancer pain, and (7) describing pain (Table 2).

These seven themes form the core findings of this study and will be described in brief. In the description of each theme, the term "some" refers to two to four participants, "many" to five to eight participants, and "most" refers to nine or more participants (i.e., greater than 50%). Table 3 includes representative quotes from each theme. Table 4 includes typical questions from the taxonomy. A complete version of the taxonomy can be accessed from <http://www.virtualclinic.ca/coach>.

Understanding Cancer Pain

All participants expressed a desire to know the cause of their pain. A predominant concern was whether their pain was caused by or related to their cancer. Participants wanted to understand why and how cancer causes pain, the meaning of pain and why the nature of pain changes (quotes 1–3). They feared that new or more intense pain meant that the cancer was getting worse or spreading, the cancer had returned, or a new form of cancer was developing.

Knowing What to Expect

Most participants wanted to be well informed about what was likely to happen, particularly in regard to pain. They wanted to know when they should expect to experience pain and what the pain would be like. Participants desired detailed information about the expected location, intensity, duration, and sensory qualities of the pain (quote 4). They seemed to be under the impression that pain follows a predictable course.

Table 2
Themes

-
1. Understanding cancer pain
 2. Knowing what to expect
 3. Options for pain control
 4. Coping with cancer pain
 5. Talking with others with cancer pain
 6. Finding help managing cancer pain
 7. Describing pain
-

Participants explained that knowing what to expect would make them feel less anxious (quote 5). New or unexpected pains evoked fear and anxiety. Knowing what to expect helped them prepare for the pain as well as determine whether their pain was "normal." Participants considered "normal" pain to be that which is typical or experienced by others in similar situations (quote 6).

Options for Pain Control

Participants raised numerous questions about a range of different options for pain control, including analgesic medication, medical or surgical treatments, and nonpharmacological approaches. They expressed a desire to know all options available, how the drugs or treatments work, expected side effects, and under what circumstances they are used to treat pain. Many described a period of time when they endured severe pain because they were not aware of the treatment options available (quote 7).

Participants raised several practical questions about the use and administration of analgesic medication, including when and how the medication should be taken, how often, for how long, when to expect pain relief, and the expected duration of the relief (quote 8). Concerns about addiction and tolerance were common, particularly with respect to the use of opioids. Fear of unpleasant or unmanageable side effects prompted many to avoid or discontinue pain medication.

Participants also expressed a desire to learn about nonpharmacological approaches to pain relief: "things to help that aren't medically based." Some did not feel adequately supported in their pursuit of alternative approaches to pain relief and would have appreciated guidance from their health professional (quote 9). Participants also spoke about wanting to know what they could do for themselves to relieve their pain. There was a clear distinction between activities that one could do for oneself, while at home, to relieve pain versus methods of pain relief that require (indirectly or directly) the help of a professional.

Coping with Cancer Pain

The participants described numerous ways in which the pain had a negative impact on their lives physically, psychologically, and socially.

Table 3
Representative Quotes

Understanding Cancer Pain

- 1 "The one that to me would be number one is, 'Why am I having the pain?' and 'what is going on now in my body that I am having all this pain?' [Participant 16]
- 2 "I've asked, 'I know there are nodes in these areas, does that mean that there is some invasion there or that there is some cancer spreading?' As soon as you have aches and pains, you always think that there is some new form of cancer developing." [Participant 11]
- 3 "It moves around, back and forth for a couple of hours. Then when it returns it might be in a different spot. I can't understand 'why it's always there and not always there and why it goes away for a few weeks.'" [Participant 4]

Knowing What to Expect

- 4 "The type of pain, 'How it will manifest itself, the intensity?' 'Is it supposed to be constant?' 'Is it supposed to come in great big stabs?' This kind of thing might be helpful." [Participant 11]
- 5 "If you don't know about it then you get more concerned, and you're thinking, 'Should I do something sooner?'" [Participant 4]
- 6 "I guess I just wanted to know 'if it was normal'... 'whether other people have this kind of pain after having this kind of surgery.'" [Participant 17]

Options for Pain Control

- 7 "I wish I knew then that there was a painkiller like this to alleviate my pain because it was so bad and if it would have been alleviated then, I wouldn't have suffered so much, right?" [Participant 5]
- 8 "How long before it starts working?' 'How long it's going to work for?'... if I'm taking my pill at 8:00 in the morning, 'when should I feel relief?' 'An hour later, twenty minutes later?' And if I'm taking them every twelve hours, 'Is it going to last the twelve hours?'" [Participant 18]
- 9 "I pretty much felt like I was on my own trying different things and not really knowing where to go or who to approach or you know, what would work... I spent a lot of time and money trying to find the answer. So, I would have definitely have liked some guidance in that." [Participant 17]

Coping with Cancer Pain

- 10 "I don't want it to stop my life. I want to be able to live with it." [Participant 11]
- 11 "Meditation, visualization, spirituality? Easy things to help you cope so that you're not feeling so victimized... It's never going to go away. I'm never going to get better, exactly. And we don't want people to feel like there's no help, because there is. It's just a matter of getting that out there." [Participant 18]

Talking with Others with Cancer Pain

- 12 "The main thing I would ask them is you know 'what have they found that has worked or at least helped to alleviate the pain'... And I guess I would want to know, 'how it has affected their life as well.'" [Participant 17]
- 13 "Um. I guess, more of a desire to talk to them. Because maybe their doctors have suggested something that my doctor doesn't know about." [Participant 5]

Finding Help Managing Cancer Pain

- 14 "I saw the surgeon a few times afterwards and complained about the pain. [They said] 'Just keep taking 'X'.' But it didn't really seem to do that much. So, my comprehension of pain was that I couldn't control it. Until I met Dr. A and she said to me, 'You do not have to be in pain in this day and age,' and that is when the lights came on." [Participant 12]
- 15 "If it were to happen again, I would ask more questions of my doctor. I would ask, you know, 'whether it is better to go the hospital and tell them that I am in terrible pain.' I wouldn't have wasted my time with my family doctor. Sometimes maybe some people feel like 'Oh, I don't want to bother the doctor, it's just pain, we all get pain.' But no, I would never do that again." [Participant 9]
- 16 "All I can say is make sure people are aware of what I found out, that you don't have to have pain. If I'd never been introduced to Dr. A, I don't know how long it would have gone on. I didn't even know there were pain control doctors out there. I mean why would any average person know that there is a doctor who specializes in pain control?" [Participant 12]

Describing Pain

- 17 "I guess just maybe different ways of describing it and sort of what it would mean to a doctor. Because you know he might say, 'It's throbbing,' but the doctor might have a different idea of what that means than I do. So I don't really know whether I'm using those words the right way or not." [Participant 4]
-

Many expressed fear that their pain and related disability would worsen with time and interfere with their quality of life indefinitely. In general, participants were determined not to let the pain disrupt their lives or reduce their enjoyment of life (quote 10).

Participants actively sought ways to cope with their pain and maintain a good quality of life despite the pain. Some expressed a desire to learn about cognitive and behavioral strategies to cope with pain. Participant 18 explained that developing effective coping

Table 4
Typical Questions

Understanding Cancer Pain	
What causes it?	Is my pain caused by cancer?
What does it mean?	Does the pain mean the cancer is getting worse or spreading?
Why is it like this?	Why does the pain come and go?
Knowing What to Expect	
What is normal?	What type of pain is normal and to be expected given my particular situation?
What will it be like?	Where will I have pain? How bad will it be? How long will it last? What will it feel like?
Options for Pain Control	
What about medication?	What are the most common types of pain medication and how do they work?
What about treatments?	Do cancer treatments help to relieve pain?
	What about alternative or complementary therapies?
	What alternative therapies are used to treat cancer pain?
What about self care?	What can I do for myself to help relieve my pain?
Coping with Cancer Pain	
Impact on life	Will I ever be able to do the things I did before?
How to cope	What can I do to cope with the pain?
Talking with Others with Cancer Pain	
Talking to your health professional	Is it just me or are there others like me?
Talking to other breast cancer patients	How has the pain affected your life?
Finding Help Managing Cancer Pain	
Who can help?	Who should I talk to and where should I go to get help managing my pain?
When to get help?	When should I get medical attention for my pain?
How to get help?	How can I get in contact with a pain specialist or a pain clinic?
Describing Pain	
	What words should I use to describe my pain?

strategies would make her feel less victimized (quote 11).

Talking with Others with Cancer Pain

Many participants expressed a desire to talk to other breast cancer patients about their pain and learn from their experiences. Specifically, they expressed a desire to learn if there were others who had similar pain experiences,

what their pain was like, how it has affected their lives, what they are doing to cope, what their doctors suggested in terms of pain relief, and the method of pain relief they found to be most effective (quote 12).

It seemed that participants were seeking in others, information and support, as well as reassurance, that theirs was a typical or normal presentation. Questions such as "Is it just me or are there others like me?" were common. Participants were hopeful that by talking to others they might learn of questions to ask their doctor, as well as methods of pain relief that their doctor, might have not considered (quote 13).

Finding Help Managing Cancer Pain

Many participants stated that they were under the assumption that pain is an inevitable part of cancer. They were not aware that cancer pain can be effectively controlled in most cases or that there are specialists in pain management who can assist them. Many participants described a period of time when their pain was not adequately assessed or treated and they were not referred to others with more expertise (quote 14).

The participants confided that they often did not know which health professional to consult about their pain. In particular, they asked whether they should consult their family doctor, an oncologist, or a pain specialist about a pain problem. Some participants were concerned they had "wasted time" consulting their family doctor and wished that they had consulted someone else sooner (quote 15).

Participants said that they would have liked to have known who to talk to and where to go to obtain help managing their pain, how to get in contact with a pain specialist or a pain clinic, and where to access information about pain management. They described a need for increased public awareness about pain control. They implored that other cancer patients should be informed that cancer pain can be controlled and about the existence of a team of specialists that can help (quote 16).

Describing Pain

All participants seemed to find it difficult to describe their pain adequately. Often, participants began their description by saying "It is hard to describe..." and resorted to analogy or

metaphor. Some of the participants explicitly expressed that they would like to learn how to describe their pain to health professionals. For example, Participant 4 requested examples of words that are typically used to describe pain, descriptions of the meaning of those words, and more specifically, what they would mean to a health professional (quote 17).

Discussion

To our knowledge, this is the first study to focus on, and extensively describe, the questions that a sample of cancer patients have regarding the experience and management of pain related to cancer. Although comprehensive, we acknowledge that the taxonomy of questions is not exhaustive. However, the similarities between our core themes and those found in other studies examining cancer patients' information needs^{15,16} permit confidence in the comprehensiveness and credibility of the findings. This observation also suggests that these themes may represent information that is important to cancer patients regardless of cancer type and may not be specific to the experience of breast cancer pain.

This study has certain limitations. The study design and method of data collection may have skewed the sample toward individuals who find it easier to talk about their illness or who felt well enough to participate, and the constraints imposed by a busy clinic setting necessitated convenience sampling. Fortunately, given that we were seeking a maximum variation sample, the final sample comprised breast cancer patients with a range of sociodemographic backgrounds, treatment profiles, disease characteristics, and pain experiences. Saturation of themes was achieved across this diversity. The study findings, therefore, reflect important shared patterns that cut across individual cases and that derive their significance from having emerged out of heterogeneity. Although qualitative research does not aim to generalize findings to a wider population, it is common practice to provide sufficient descriptive detail to enable the reader to judge whether or not the findings apply in other settings.²⁷ Given that saturation was reached across a diverse sample, it is

reasonable to conclude that the findings could apply to similar middle-class breast cancer patients being treated in a similar context. The pain services offered at this hospital may have influenced the nature of the questions that the participants raised. Patients being treated at institutions that do not offer such services may have different questions about pain.

This study revealed that formulating and articulating questions is not a simple task. The process of formulating and articulating questions takes time—more time than is allotted for a typical consultation. The participants did not simply list their most important questions. They talked in-depth and reflected on their experiences with pain over the course of their illness. In the process of doing so, they described questions and concerns they had in relation to certain experiences. In addition, some participants expressed topics of concern and questions they had not previously articulated. If pain is to be managed adequately, efficient mechanisms are needed to help patients identify and articulate their questions and get answers.

Other researchers have recognized that patients may benefit from interventions that help them to prepare and articulate questions to discuss with their health professional.^{11–14} A common feature of these interventions is a 20-minute session with a trained clinical assistant in which a patient receives support formulating questions and coaching to communicate effectively with their health professional. Collectively, these studies suggest that patients who are enabled to ask questions that are important to them and get answers feel more relaxed, are more satisfied with the consultation, and experience greater information recall and better health outcomes. However, such strategies are unlikely to be implemented and sustained in a busy clinical setting, unless the time involved and the need for a clinical assistant can be avoided.

Internet-based strategies may provide a solution.³² The Internet promises unprecedented opportunities to facilitate patient involvement in health care, enhance communication between patients and health professionals, and make more efficient use of health-related resources.³³ A meta-analysis conducted in 2003 revealed that 55–60% of cancer patients in high-income countries were using the Internet

either directly or indirectly (through family and friends) to find health information, connect with other patients, and communicate with their health professionals.³⁴ As information has become more accessible, patients are becoming better informed and their expectations of the health system are increasing.³³ Building on the literature and these study findings, several members of our team (J.L.B., J.H., J.W., and A.R.J.) are developing an online system to help cancer patients prepare questions to ask their health care team about their pain (<http://www.virtualclinic.ca/coach>). The program consists of an inventory of questions and answers about the experience and management of pain related to breast cancer and support developing a question list. Users are coached to select questions that are important to them, organize their questions into lists for different health professionals, prioritize their questions based on their level of importance, and print or email their questions in preparation for their next medical appointment.

We did not investigate whether patients in this study treat issues related to pain differently than questions related to diagnosis or treatment of the disease. However, the study did reveal that patients may be reluctant to ask questions about pain. There are many reasons why patients may choose not to ask questions or seek further information, such as being fearful of the answer, being thought of as stupid, or concerned the physician does not have enough time.^{35,36} Barriers to asking questions that were discovered during the course of this research include being fearful of the answer, concerned that the physician does not have enough time, the belief that pain is inevitable, feeling overwhelmed, long waiting times, and reports of pain that are ignored. While efforts to encourage cancer patients to ask questions can be realized, more research is required to identify why cancer patients may choose not to raise questions about pain. Important factors to consider are the barriers known to discourage patients from reporting pain to health professionals, identified by Ward and colleagues,⁶ as well as certain physician behaviors and communication styles that are conducive to an open dialogue about pain.

Our study findings revealed that breast cancer patients have numerous and diverse questions about pain and its treatment, which

may be difficult to address within the context of a typical consultation. If pain is to be managed adequately, innovative efforts are needed to enable patients and health professionals to recognize, articulate, and answer such questions. Many of the questions and concerns raised can be effectively addressed using patient education resources outside the clinical encounter. For those questions that require an individual response, Internet-based tools that help patients prepare questions in advance may enable a better exchange of information during consultations, improve the ability of patients and clinicians to target and address important issues, lead to more efficient use of consultation time, and ultimately to better health outcomes.

The themes identified reveal a lack of knowledge regarding the nature of cancer pain and options for pain control. They also reveal a lack of awareness regarding what to expect in terms of pain relief, the health services available, and how to access these services. There is clearly a need to develop better mechanisms to meet patients' information needs regarding pain and its treatment. It is our hope that these findings will spur further efforts to develop and evaluate strategies to adequately address patients' questions about pain, enhance communication between patients and health professionals, and support cancer patients in their pursuit of adequate pain relief.

Acknowledgments

The authors graciously thank the study participants for their time and contribution and the physicians and nurses from the Breast Cancer and Pain Clinics at Princess Margaret Hospital for their help recruiting participants.

References

1. Cleeland CS, Gonin R, Hartfield AK, et al. Pain and its treatment in outpatients with metastatic cancer. *N Engl J Med* 1994;330:592-596.
2. Cleeland CS, Gonin R, Baez L, Loehrer P, Pandya KJ. Pain and treatment of pain in minority patients with cancer: the Eastern Cooperative Oncology Group Minority Outpatient Pain Study. *Ann Intern Med* 1997;127:813-816.
3. Yates MP, Edwards HD, Nash RE, et al. Barriers to effective cancer pain management: a survey of

- hospitalized cancer patients in Australia. *J Pain Symptom Manage* 2002;23:393-405.
4. Jadad AR, Browman GP. The WHO analgesic ladder for cancer pain management. *JAMA* 1995; 274:1870-1873.
 5. Cleeland CS, Janjan NA, Scott CB, Seiferheld WF, Curran WJ. Cancer pain management by radiotherapists: a survey of radiation therapy oncology group physicians. *Int J Radiat Oncol Biol Phys* 2000;47:203-208.
 6. Ward SE, Goldberg N, Miller-McCauley V, et al. Patient-related barriers to the management of cancer pain. *Pain* 1993;52:319-324.
 7. Davis PM, Walsh D. Epidemiology of cancer pain and factors influencing poor pain control. *Am J Hosp Palliat Care* 2004;21:137-142.
 8. Stewart MA. Effective physician-patient communication and health outcomes: a review. *CMAJ* 1995;152:1423-1433.
 9. Jefford M, Tattersall MHN. Informing and involving cancer patients in their own care. *Lancet Oncol* 2002;3:629-637.
 10. Jadad AR, Rizo C, Enkin MA. I am a good patient, believe it or not. *BMJ* 2003;326:1293-1295.
 11. Brown RF, Butow PN, Dunn SM, Tattersall MHN. Promoting patient participation and shortening cancer consultation: A randomized trial. *Br J Cancer* 2001;85:1273-1279.
 12. Oliver JW, Kravitz RL, Kaplan SH, Meyers FJ. Individualized patient education and coaching to improve pain control among cancer outpatients. *J Clin Oncol* 2001;9:2206-2212.
 13. Roter DL. Patient participation in the patient-provider interaction: the effects of patient question asking on the quality of interaction, satisfaction and compliance. *Health Educ Monogr* 1977;5:281-315.
 14. Sepucha KR, Belkora JK, Mutchnick S, Esserman LJ. Consultation planning to help breast cancer patients prepare for medical consultations: effect on communication and satisfaction for patients and physicians. *J Clin Oncol* 2002;20: 2695-2700.
 15. McJannett M, Butow P, Tattersall MHN, Thompson JF. Asking questions can help: development of a question prompt list for cancer patients seeing a surgeon. *Eur J Cancer* 2003;12:397-405.
 16. Clayton J, Butow P, Tattersall M, et al. Asking questions can help: development and preliminary evaluation of a question prompt list for palliative care patients. *BMJ* 2003;89:2069-2077.
 17. Wong RKS, Franssen E, Szumacjer E, et al. What do patients living with advanced cancer and their carers want to know? A needs assessment. *Support Care Cancer* 2002;10:408-415.
 18. Coulter A, Entwistle V, Gilbert D. Sharing decisions with patients: is the information good enough? *BMJ* 1999;318:318-322.
 19. Emery C, Romyne G, Hugi M, et al. and the Steering Committee on the Clinical Practice Guidelines for the Care and Treatment of Breast Cancer. Clinical practice guidelines for the care and treatment of breast cancer: 10. The management of chronic pain in patients with breast cancer. *CMAJ* 2001;158:S71-S81.
 20. Morse J, Field PA. *Qualitative research methods for health professionals*. Thousand Oaks, CA: Sage Publications, 1995.
 21. Sandelowski M. Focus on research methods: whatever happened to qualitative description? *Res Nurs Health* 2000;23:334-340.
 22. Wolcott H. *Transforming qualitative data: Description, analysis and interpretation*. Thousand Oaks, CA: Sage Publications, 1994.
 23. Lincoln Y, Guba EG. *Naturalistic inquiry*. Thousand Oaks, CA: Sage Publications, 1985.
 24. Patton MQ. *Qualitative research and evaluation methods*. Thousand Oaks, CA: Sage Publications, 2002.
 25. Kvale S. *InterViews: An introduction to qualitative research interviewing*. Thousand Oaks, CA: Sage Publications, 1996.
 26. Creswell JW. *Research design: Qualitative, quantitative and mixed methods approaches*. Thousand Oaks, CA: Sage Publications, 2003.
 27. Mays N, Pope C. Quality in qualitative health research. In: Pope C, Mays N, eds. *Qualitative research in health care*. London: Br Med J Publishing Group, 2000.
 28. Giancomini M, Cook JD, for the Evidence-Based Medicine Working Group. User's guide to the medical literature XXIII. Qualitative research in health care A. Are the results of the study valid? *JAMA* 2000;284:357-362.
 29. Caraceni A, Cherny N, Fainsinger R, et al. and the Steering Committee of the EAPC Research Network. Pain measurement tools and methods in clinical research in palliative care: recommendations of the Expert Working Group of the European Association of Palliative Care. *J Pain Symptom Manage* 2001;23:239-255.
 30. Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today* 2004;24:105-112.
 31. Bender JL. Questions that women with breast cancer have about pain related to cancer. M.Sc. Thesis. Public Health Sciences, University of Toronto, Toronto, 2005.
 32. Deshpande A, Jadad AR. Web 2.0: could it help move the health system into the 21st century? *J Mens Health Gend* 2006;3:332-336.
 33. Jadad AR, Bender JL. Using the Internet to improve the study and management of pain: could the