

This material is protected by U.S. copyright law. To purchase quantity reprints, e-mail reprints@ons.org. For permission to reproduce multiple copies, e-mail pubpermissions@ons.org.

Striving to Respond to Palliative Care Patients' Pain at Home: A Puzzle for Family Caregivers

Anita Mehta, RN, PhD, S. Robin Cohen, PhD, Helene Ezer, RN, PhD, Franco A. Carnevale, RN, PhD, and Francine Ducharme, PhD

Patients with cancer at the end of life often experience pain. Patients with advanced cancer report a higher frequency and intensity of pain than patients with cancer at an earlier stage, with 20%–34% of those with advanced disease experiencing severe pain (Davis & Walsh, 2004). Pain is one of the most frequently reported physical symptoms for patients with advanced cancer (Coyle, Adelhardt, Foley, & Portenoy, 1990; Dobratz, 2001; Vallerand, Collins-Bohler, Templin, & Hasenau, 2007) and, perhaps, the most distressing (Davis & Walsh, 2004; Mercadante, Villari, Ferrera, & Casuccio, 2006). To date, many patients are receiving end-of-life care in their own homes and the day-to-day responsibility of pain management ultimately falls on their family caregivers (Aranda & Hayman-White, 2001; Aubin et al., 2006; Lobchuk & Vorauer, 2003; Redinbaugh, Baum, DeMoss, Fello, & Arnold, 2002; Vallerand et al., 2007). Pain management often presents as one of the most challenging aspects of the caregiver role (Vallerand et al., 2007). Part of this challenge is intervening for pain control, an ongoing issue for family caregivers because of the variability, number, and types of pain they are managing.

Background

Patients with advanced cancer often have many separate types of pain, varying in intensity, frequency, and location (Davis & Walsh, 2004; Lema, 2001; Portenoy, 1989). In fact, Twycross & Fairfield (1982) revealed that most patients with advanced cancer reported that they experience more than one type of pain; of these, 34% reported three or more types. Patients continue to experience and describe a number of distinct pains ranging from mild to severe in intensity (Davis & Walsh, 2004), and may, at times, have features of two different types of pain (e.g., nociceptive, neuropathic pain) (Christo &

Purpose/Objectives: To describe the types of pain patients in palliative care at home experience and how family caregivers assess them and intervene.

Research Approach: Qualitative using grounded theory.

Setting: Family caregivers' homes.

Participants: 24 family caregivers of patients with advanced cancer receiving palliative care at home.

Methodologic Approach: Semistructured interviews and field notes. Data analysis used Strauss and Corbin's recommendations for open, axial, and selective coding.

Main Research Variables: Pain, pain management, family caregivers, palliative care, and home care.

Findings: Caregivers assessed different types of pain and, therefore, were experimenting with different types of interventions. Not all family caregivers were able to distinguish between the different pains afflicting patients, and, consequently, were not selecting the most appropriate interventions. This often led to poorly managed pain and frustrated family caregivers.

Conclusions: The accurate assessment of the types of pain the patient is experiencing, coupled with the most appropriate intervention for pain control, is critical for optimal pain relief as well as supporting the confidence and feelings of family caregivers who are undertaking the complex process of cancer pain management.

Interpretation: Nurses involved with patients receiving palliative care and their family caregivers should be aware of all types of pain experienced by the patient and how caregivers are managing the pain. Nurses should be knowledgeable about different pain relief interventions to help family caregivers obtain accurate information, understand their options, and administer these interventions safely and effectively.

Mazloomdoost, 2008). The pain they experience may or may not be a result of their cancer or their cancer treatment (Christo & Mazloomdoost, 2008; Davis & Srivastava, 2003; Portenoy, 1989; Turk, Monarch, & Williams, 2002; Twycross & Fairfield, 1982; Twycross, Harcourt,

& Bergl, 1996). Family caregivers may be dealing with several sources of pain with different times of onset and different durations. Family caregivers may not always be able to recognize when the pain they are treating changes or a new one occurs. In fact, many caregivers struggle with managing new or unusual pain that develops (Schumacher et al., 2002). However, studies on the types of pain they must manage and how they are treating them are lacking.

Many different treatments exist for cancer pain at the end of life. Radiation therapy, palliative surgery, palliative chemotherapy, and neural blockades are some examples of interventions that are being used in conjunction with a range of different medications by healthcare professionals (Chang, Janjan, Jain, & Chi Chau, 2006). Pharmacologic and nonpharmacologic interventions are used to relieve pain (Godfrey, 2005; Mobily, Herr, & Kelley, 1993; Snyder & Wieland, 2003), including alternative and complementary therapies (Yates et al., 2004). For healthcare professionals, the type of pain often dictates the type of treatment or appropriate intervention. For example, neuropathic pain often is difficult to treat, reacting differently or not at all to opioids (Mercadante, Casuccio, Pumo, & Fulfaro, 2000; Mishra et al., 2008; Seaman & Cleveland, 1999). Studies indicate that methadone (Gagnon, Almahrezi, & Schreier, 2003; Nicholson, 2004; Smith, 2004), gabapentin (Gilron et al., 2005; Smith, 2004), and pregabalin (Zareba, 2005) are useful for neuropathic pain. On the other hand, nociceptive pain can be targeted by combining treatments such as opioids, electrical modalities (Binhas, Krakowski, & Marty, 2007; Seaman & Cleveland, 1999), or other medications. This highlights the fact that the type of pain experienced by the patient is a prime consideration in the determination of the management of the pain by professionals.

A basic understanding of the types of pain, pain mechanisms, and patterns of pain experienced by patients with cancer can help focus pain assessment and, in turn, lead to targeted pain management strategies that are more effective (Coyle, 2006). Given this fact, family caregivers

would benefit if they understood that different types of pain may need different treatment. Whether or not patients and family caregivers assess the type of pain and intervene differently for different types of pain is unknown. Although family caregivers need not be schooled on the pathophysiology of the pain being experienced by the patient, they should be able to distinguish the different types of pain the patient is feeling. If they are able to do so, they can treat each type of pain differently.

For healthcare professionals to provide assistance and offer the most appropriate support, more information is needed on how family caregivers are managing pain. Nurses are in a prime position to address the specific needs of these family caregivers (Dobratz, 2001; Firth, 2006; Mazanec & Bartel, 2002; Whitecar, Jonas, & Clasen, 2000) and have a fundamental responsibility to ensure pain relief (Cahana, Arigoni, & Robert, 2007).

This article presents some of the findings of a grounded theory study that generated a conceptual model of family caregiver pain management processes as they cared for patients with advanced cancer at home. This conceptual model is the Puzzle of Pain Management (Mehta, Cohen, Carnevale, Ezer, & Ducharme, 2010 (see Figure 1). The main research question was, "What is the process used by family caregivers at home to manage the pain of patients with cancer undergoing palliative care?" This article focuses on the secondary questions explored: the types of pain family caregivers were managing at home

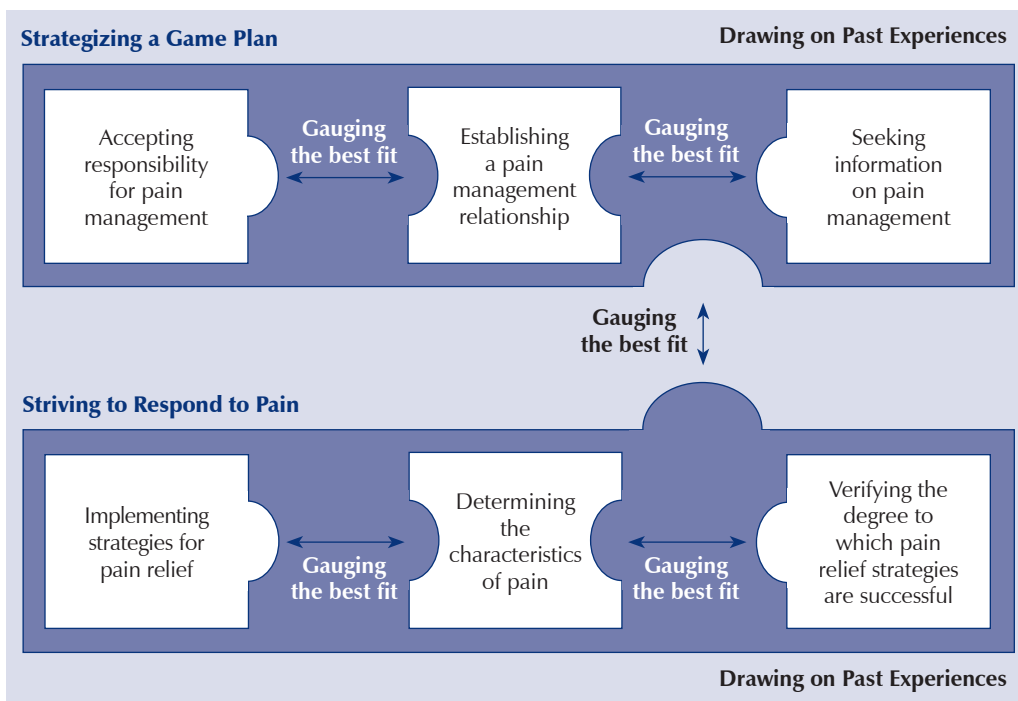


Figure 1. The Puzzle of Pain Management: The Pain Management Process at Home

Note. From "Family Caregivers of Palliative Cancer Patients at Home: The Puzzle of Pain Management," by A. Mehta, R. Cohen, F.A. Carnevale, H. Ezer, and F. Ducharme, 2010, *Journal of Palliative Care*, 26, p. 80. Copyright 2010 by Institut Universitaire de Gériatrie de Montreal. Reprinted with permission.

Table 1. Interview Guide: Family Caregiver Questions and Probes

Question	Probes
Tell me about a specific time you thought your family member was in pain. Tell me about that experience.	What did you feel and what did you think when you observed that your family member was in pain? How did you know he or she was in pain? How did you judge how bad the pain was? What made the pain worse? What made the pain better?
Tell me about the types of pain you have to manage. How do you differentiate between them?	How would you describe each one? Tell me about how you feel about each one. Are some more worrying than others? Are some more challenging to manage? How do you assess for each one? Are there particular cues you use to tell the pains apart?
Tell me about how you help to do something to help him or her when you feel they are in pain. How do you feel when you do an intervention (for each intervention)?	Tell me about how you decided how to help him or her. (Does it change depending on the kind of pain and where it is?) How was the intervention selected? Tell me about how you know if it has worked (for each type of pain). Tell me about any uncertainties you have when trying to help.

and the interventions they were performing. Although several important processes were discovered, this article focuses on the process of “striving to respond to pain,” and, in particular, the subprocess of “implementing a strategy of pain relief.” It describes the types of pain family caregivers said they were managing, the pharmacologic and nonpharmacologic interventions they used, and how these were selected.

Methods

Methodologic Approach

Grounded theory (Strauss & Corbin, 1994) was the methodology used in this study. It has been described as a successful way to discover the main concerns of patients and their families and to identify the process whereby these are managed (McCallin, 2003). This also has become a methodology increasingly used in the study of nursing phenomena (Polit & Beck, 2004) and was deemed the most appropriate method to use in this study because available knowledge suggests that caregiver pain management in the home is a dynamic process.

Setting and Recruitment Procedure

The study was conducted from January 2006 to June 2006 in an urban setting in Quebec, Canada. Approval was obtained from the ethics review boards of the organizations from which participants were recruited. The nurses and physicians of the supportive care team of a university teaching hospital and nurses from a homecare agency providing palliative care identified eligible family caregivers willing to hear about the study. Once family caregivers expressed interest in the study, the principal investigator phoned potential participants, explained the study briefly and, if they agreed, made an

appointment to meet them at their home to explain the study in more detail and obtain written informed consent. Consistent with grounded theory, family caregivers were recruited using purposeful and then theoretical sampling.

Participants

Eligible family caregivers were those identified by the patient as the family member most involved with the management of their pain at home. Eligibility criteria included being age 18 and older, being able to speak and read English or French, and having given consent to participate in the study.

Data Collection

Data were collected using semistructured audiotaped interviews with family caregivers as well as written field notes. The interview guide was created by the authors, and the interviews included questions related to the types of pain the caregivers said they were managing, how they knew when it was time to intervene, the strategies they used to reduce each type of pain, how they chose a strategy, and how they evaluated the success of their interventions (see Table 1).

Most caregivers were interviewed at two separate times approximately one week apart to discuss the findings, give them time to reflect, and ask clarifying questions as needed. Interviews were conducted in the family caregivers' homes by the primary author and were usually 45–60 minutes in length.

Data Analysis

Strauss and Corbin's (1994) framework of open coding, axial coding, and selective coding was used. During open and axial coding, important processes and subprocesses were identified and relationships were established

between them. These processes were the ones that were selected for closer examination and were seen as most critical for the development of the theory. They were central to the phenomenon of study and occurred frequently in the data (Strauss & Corbin, 1994). The processes were then integrated and helped formulate the theory during selective coding. This was aided by memoing, in which the researcher recorded her analysis, thoughts, interpretations, questions, and directions for additional data collection, and constant comparison, through which the emerging ideas and processes were continuously compared and used to guide the ongoing research (Strauss & Corbin, 1994).

A more detailed description of the methodology, including the sample, the data collection, and analysis, has been published in Mehta et al. (2010).

Findings

Sample

Most family caregivers participated in the study. Their mean age was 69 years. Sixteen family caregivers were women. Sixteen were spouses of the patient. The mean length of the family caregiving experience was 2.2 years. They were caring for patients with differing cancer diagnoses and were from a variety of different ethnic backgrounds (see Tables 2 and 3).

Themes

Four main processes emerged to form the Puzzle of Pain Management: (a) a frame of “drawing on past experiences,” (b) “strategizing a game plan” that included the subprocesses of accepting responsibility, seeking information, and establishing a pain management relationship, (c) “striving to respond to pain” that included the subprocesses of determining the characteristics of pain, implementing a strategy for pain relief, and verifying whether pain relief strategies were successful, and (d) “gauging the best fit,” a decision-making process that joins the pieces of the puzzle.

This article focuses on the two subprocesses (determining the characteristics of pain and implementing a strategy for pain relief) of “striving to respond to pain” that together represent the processes family caregivers actively engage in with the patient as they work toward obtaining pain relief. The subprocess of verifying the success of pain relief strategies is explained in Mehta et al. (2010).

Determining the Characteristics of Pain

Critical to the subprocess of determining the characteristics of the patient’s pain was the family caregiver’s exploration of the type of pain the patient had. They assessed the quality (e.g., tolerable, excruciating, stab-

Table 2. Sample Characteristics of Family Caregivers

Characteristic	\bar{X}	Range
Age (years)	69	25–90
Caregiving experience ^a	2.2 years	2 weeks–20 years

Characteristic	n
Gender	
Female	16
Male	8
Relationship to patient	
Wife	10
Husband	6
Daughter	4
Brother	1
Niece	1
Son	1
Sister-in-law	1
Self-described ethnic background of caregiver	
Jewish	4
White, Anglo-Saxon, Protestant	4
Scottish	3
British	2
Egyptian	2
French-Canadian	2
Irish	2
Italian	2
European	1
French	1
Portuguese	1
Family caregivers who were healthcare professionals	3

N = 24

^a Median length of caregiving experience was one year.

bing), the duration (e.g., lasting for a few minutes, it lasts all day long), the frequency (e.g., it comes and goes), and the location of the pain. Some family caregivers reported pain that was localized in one area, others pain that moved around. This differed depending on the type of cancer and whether the pain was related to the cancer or attributed to another underlying cause. Instances also occurred where more than one location was noted for the pain, and instances where different areas were painful at the same time. For some family caregivers, these assessments had a great influence on the types of interventions that were selected for pain relief, because some caregivers based their pain management strategies on what they determined the characteristics of pain to be. Other caregivers, who were less refined in their abilities to thoroughly assess and differentiate types of pain, often treated them similarly. This, at times, resulted in less than optimal pain relief.

The following example illustrates that some family caregivers managed more than one type of pain and pain in multiple locations.

She has different types of pain. She has the pain that starts in her stomach like sometimes when she can’t digest certain foods. So we just avoid them

altogether. If she does happen to have something gritty like a grainy piece of toast that falls into her stomach, she has an excruciating sense of a rock sitting in her stomach, which is not very good. She has these sharp little needle pains in her liver area and the pain that radiates from her stomach area down her left side into her back. And her back, her back pain is quite like a scratching type of pain and it's pretty much, it was pretty much just the lower back that was affected. Now it's pretty much spread throughout her back. . . . Because she had stopped taking her laxatives and her stool softeners and I guess it was just a question of her bowels not moving at all. . . . It's hard to distinguish between the bowel pain and the cancer pain. But the cancer pain is definitely the lesser of the two.

The bolded text highlights the fact that the types of pain may be in different areas and may be related to the cancer or the side effects of medications. In some cases it is unrelated to cancer or its treatment. Other sources of pain were accidents or injuries, wounds, and constipation. The data revealed that, although pain from a tumor often was the main source of distress and the focus of much of the pain management, family caregivers needed to manage different types of pain caused by a variety of factors.

Implementing Strategies for Pain Relief

All of the patients in this study were taking at least one or more medications for pain and many also were on several nonpain medications. The most frequent immediate response following the assessment that the patient was in pain was the pharmacologic treatment of the patient's pain, regardless of the type of pain.

Pharmacologic strategies: Some family caregivers felt that giving medication was the only strategy that would successfully relieve pain. These caregivers did

discuss the other options available to them and tried, at first, to implement a range of different interventions, but found that pain medication was the only thing that worked effectively and quickly. This, then, became the sole intervention that they were confident in using when they observed the patient in pain. In fact, some family caregivers considered medications to be a successful strategy for pain relief almost all of the time. In contrast, others felt that pain control was not attainable by their current pharmacologic regimens. For example, family caregivers caring for patients experiencing severe neuropathic pain felt no intervention could completely relieve the pain. They were able to assess that the pain was neuropathic and recognized that they were unable to implement any strategies for pain relief to help them. In these cases, they were seeking interventions beyond medications such as "cutting . . . or blocking the nerve."

Nonpharmacologic strategies: Overall, regardless of the type of pain, most family caregivers were using pain medications as their primary intervention. Still, nonpharmacologic interventions were used frequently as well for varying reasons. Some examples of nonpharmacologic strategies described by family caregivers were distraction, massage, being present, positioning, and applying heat or cold (see Table 4). Such interventions were either used in conjunction with medications or independently depending on the situation and the type of pain. All of the nonpharmacologic strategies were rarely used alone, but rather were coupled with other interventions or were one of many strategies that the family caregivers experimented with. Also of interest was that many family caregivers took the initiative to use nonpharmacologic strategies based on intuition. In fact, some family caregivers invented their own nonpharmacologic approaches to managing the patient's pain.

Alternative pain relief strategies: Examples of additional alternative interventions were mentioned by family caregivers in this study. Of note were the motivations discussed by the family caregivers who chose to use such interventions. In each of these cases, the family caregiver had reservations (either about side effects or related to their beliefs) about the medications that their family member was taking.

Overall, both pharmacologic and nonpharmacologic strategies were used for pain management. Some family caregivers preferred starting off with interventions that did not involve medications to avoid the side effects they noted because the medications were unsuccessful or because they felt the pain was not severe enough to warrant them.

In all cases, family caregivers linked the process of "determining the characteristics of pain" to "implementing a strategy of pain relief." Their assessments of the type of pain, frequency, quality, location, and duration helped them decide their course of action. For example,

Table 3. Sample Characteristics of Patients

Characteristic	\bar{X}	Range
Age (years)	69.8	52–89
Characteristic	n	
Type of cancer		
Breast	4	
Pancreatic	4	
Prostate	3	
Colon	2	
Lung	2	
Other	9	
Gender		
Male	12	
Female	12	
N = 24		

Table 4. Intervention Strategies for Pain Relief

Intervention	Examples	Reasons
Alternative	Homeopathy, vodka, Chinese oil	Beliefs about medications: "It just made him drugged up or whatever. To me that's not good management of pain to be always in a stupor sort of thing. You like to have pain management until you have no pain but you can still function day to day."
Nonpharmacologic	<p>Distraction: "There were family pictures in there. We were looking and we were laughing. . . . I just try to take her mind off so she's not thinking about the pain so much."</p> <p>Massage: "Massaging her back, her coccyx, makes the pain better."</p> <p>Being present: "When she has her terrible, terrible pain that makes her cry, of course I stay next to her . . . from the moment she has pain, I'm beside her, I don't leave her. I talk to her, I touch her . . . I tell her 'in a moment, it will be better.'"</p> <p>Positioning: "For the stabbing and shooting pain, it's just usually lying still and keeping his legs elevated. We put him on an antispasmodic for the shooting pain to see if that could help . . . but mostly it's just positioning, not moving."</p> <p>Heat or cold: "I just used a [heated] bean bag in an attempt at pain control."</p>	<p>Medications not successful: "My body is immune to pain killers."</p> <p>Pain intensity: "More severe [pain]; then you knew that you couldn't do any of these [non-pharmacologic] things [distraction or massage]."</p> <p>Side effects: "They want to keep her stoned and stupid. Stoned and stupid is what they want?"</p> <p>Beliefs: "Medication is poison." "Morphine means . . . the end."</p> <p>Experience over time: "Sometimes you don't need to medicate. You know sometimes it could be another reason that's causing the pain . . . you can't act on it immediately. Sometimes you have to wait and see what's causing it."</p>
Pharmacologic	Various medications: Continuous-release morphine, hydromorphone, fentanyl	"It's the only thing that works." "Sometimes there's nothing you can do about [the pain] except give drugs."

the intensity of the pain (e.g., not severe) determined the use of a nonpharmacologic intervention such as distraction instead of medication.

How strategies are selected: The following two examples illustrate how some family caregivers selected from among a number of different pain relief strategies dependent on the type of pain, whereas others used the same strategy for all types of pain. One woman assessed for the type of pain her husband had, then intervened accordingly. If she assessed that he had hip pain (secondary to a fall), she used warm compresses or suggested a hot bath. In the cases where she felt his bone pain was causing the discomfort, she preferred the use of medications. She also mentioned how different positions helped her husband with his different types of pain (e.g., bedsore on his coccyx). He also had stabbing pain in his lower back and shooting nerve pain down his legs. She tried to relieve the pain of these latter two using position changes. Her ability to assess, distinguish, and treat the different types of pain was related to her past experiences as a healthcare professional and as a family caregiver to her mother with cancer.

At the other extreme was a family caregiver who used the same intervention regardless of the type of pain the patient reported. She correctly used heat to manage arthritis but also used it for all of the pains the patient had, including the cancer pain, secondary to breast cancer, that she described as pain that was "deeper in the chest . . . because it's breast cancer." She

said she "just used our [heated] bean bag in an attempt at pain control." She also used heat for headache pain, and offered this suggestion: "They should wear a small [heated] towel around their neck or a warm bean bag if they have a headache." She used the same strategy indiscriminately for all types of pain. Again, it was her own past experience, in this case using heat for her own pain, that prompted her to assume it would be successful as an intervention for the patient's different pains. In this case, it was not always an effective strategy for pain relief, except for the pain caused by the arthritis.

Overall the results showed that, although the knowledge of basic pathophysiology and the ability to distinguish the types of pain certainly helped some family caregivers with pain management, it was not necessary for pain control. However, it may have explained those family caregivers who felt they achieved optimal pain relief and felt more comfortable and confident with their abilities to engage in the pain management processes. These family caregivers had been managing pain for longer periods of time, had strong pain management relationships with their healthcare team, felt they had received adequate and accurate information, and had past experiences with pain (personal or professional). Past experiences can lead either to the use of the same thing all the time or different things for different pains.

Once the interventions were selected and then carried out, family caregivers verified the degree to which pain relief strategies were successful. In this way, over time,

many family caregivers were able to develop increased confidence and comfort levels with their selection of pain control interventions.

Discussion

This article focuses on that part of the conceptual model put forth as the Puzzle of Pain Management that describes the family caregivers' processes of developing and joining the process puzzle pieces of "determining the characteristics of pain" and "implementing a strategy for pain relief." Although little evidence in the literature has indicated that family caregivers make links between assessment and management of advanced cancer symptoms, including pain (McMillan & Small, 2007), the results of this study suggest that many family caregivers are making such links. Many (but not all) family caregivers used the information from pain assessment to create and implement pain management interventions and plans.

The finding that patients with cancer had many types of pain in differing sites is consistent with previous work (Lema, 2001; Portenoy, 1989; Twycross et al., 1996). It already has been noted that "central to the management process is recognition of different types of cancer pain, which have their own individual management emphasis" (Kenner, 1994, p. 1272). Overall, the type of pain experienced by the patient should be of prime consideration in the determination of the pain management. However, the results of the current study showed that this was not always the case because not all caregivers were distinguishing the different types of pain the patients had. In addition, the results of the current study showed that managing several different types of pain often was a complex process requiring separate assessments, interventions, and follow-up for each type of pain. These different pains, at times, occurred simultaneously, requiring some family caregivers to implement multiple strategies at a given time. Their ability to do that was an important finding because they reported that, at times, this made the difference between controlled and uncontrolled pain.

Some family caregivers spoke of the need to treat different pains and severities differently, without necessarily labeling it nociceptive or neuropathic. However, these findings did suggest that a possible link exists between an increased knowledge of the pain mechanisms and better pain management by confident and knowledgeable family caregivers. This highlights the fact that other pain management processes (e.g., seeking information, past experiences) that are part of the Puzzle of Pain Management are important to evaluate as well, because they influence a family caregiver's assessment and subsequent interventions for pain relief.

Pain medication and nonpharmacologic strategies such as distraction were used quite often. This was an

important finding because other studies have shown that pharmacologic strategies were sometimes underused by family caregivers caring for patients in pain (Yates et al., 2004). A few studies examined family caregivers' knowledge and use of nonpharmacologic interventions for pain relief despite the fact that the combination of pharmacologic and nonpharmacologic pain interventions ensures optimal pain relief (Ardery, Herr, Titler, Sorofman, & Schmitt, 2003; McCaffery, 1990; Mobily, 1994; Mobily et al., 1993; World Health Organization, 2007). Such studies are needed because some family caregivers in this current study reported that they had not been informed of or taught about nonpharmacologic strategies, and often had to be creative in their choice of nonpharmacologic interventions. This supports earlier findings that family caregivers are still learning about such interventions through trial and error (Given, Given, & Kozachik, 2001; Mazanec & Bartel, 2002) and suggests that, perhaps, a greater emphasis is needed on educating family caregivers about strategies other than medication.

Limitations

Although valuable information was obtained from this study about the pain management experience for family caregivers of patients with cancer receiving palliative care in the home environment, the results only reflect the experience of a limited portion of this population. Family caregivers who did agree to participate may have had more concerns related to pain, poor pain management, and uncontrolled pain than those who did not participate. On the other hand, those family caregivers caring for patients with severe pain requiring more care may have been unable to participate in the study based on their lack of time and ability to participate. Therefore, the described processes may not accurately address the process experienced by all family caregivers who are trying to manage cancer pain at home.

Nursing Implications

As family caregivers strive to respond to pain, their assessment, intervention, and evaluation skills related to pain management differ. To respond to this, nurses must include an assessment of the caregivers' past experiences, the types of pain they are managing, their current pain control practices, and their need for information. With an established baseline, nurses can tailor the teaching of interventions to the specific needs identified by the family caregivers instead of proceeding with a predetermined standardized plan that may not be suitable for a particular family caregiving situation. The consequences of not doing this often includes poor pain control, feelings of helplessness and frustration by the family caregiver, and a strained relationship with

the healthcare team. These implications stem directly from the framework of the Puzzle of Pain Management.

Understanding and being able to teach or support interventions related to pain control is critical for nurses because they can then offer support to family caregivers. This can only be done if the nurse understands the process used by the family caregiver to select their interventions. This study showed that the process by which family caregivers select their interventions is related to the process of determining the characteristics of pain. Assessing for the types of pain is a vital part of this assessment. Nurses must assess whether the family caregivers are recognizing the different causes of pain, are treating all the pains experienced, and are treating them appropriately. The nurse's involvement in this must be at the onset of a family caregiver accepting responsibility for pain management and should be ongoing to keep abreast of any new pain that may present itself and to monitor the success of the family caregiver's pain relief strategies and any new strategies they may try or want to try. To achieve optimal pain control, ongoing provision of information, support, and monitoring of family caregivers is critical to ensuring that all types of pain are assessed and addressed.

Overall, what is required are individualized pain management care plans that incorporate the specific pain control needs of the patients and outline the most appropriate pain relief methods that take into account the family caregiver's knowledge of the types of pain the patient has and his or her current treatment plan in the context of the family caregiver's past experiences. Modifications to existing strategies or additions to them can be made accordingly. Additional studies would be beneficial so new data can be compared, incorporated, and even change the existing theory. The Puzzle of Pain Management can be adapted by additional studies and strengthened by new information.

Conclusion

Understanding the Puzzle of Pain Management allows healthcare professionals to gain insight into the processes involved as family caregivers manage pain at home for patients with advanced cancer. These caregivers are managing different types of pain and are experimenting with different types of interventions. Some are linking their interventions to the type of pain; others are not, despite the importance of doing so. Support, information and resources can and should be provided by nurses to enable these caregivers to successfully engage in the different processes involved in pain management and integrate them for the sake of their own health and that of the patients. The accurate assessment of the type of pain the patient is experiencing, coupled with the most appropriate intervention for pain control, is critical for optimal pain relief. It also is key to promote confidence and feelings of support in family caregivers who are undertaking the complex process of cancer pain management in their own homes.

Anita Mehta, RN, PhD, is a clinical nurse specialist in psychosocial oncology and the codirector of the Psychosocial Oncology Program at McGill University Health Centre at Montreal General Hospital; S. Robin Cohen, PhD, is a project director in palliative care research at the Lady Davis Institute at S.M.B.D. Jewish General Hospital; Helene Ezer, RN, PhD, and Franco A. Carnevale, RN, PhD, both are associate professors in the School of Nursing at McGill University; and Francine Ducharme, PhD, is a professor in Faculté des Sciences Infirmières at the Université de Montréal and a researcher in the Centre de Recherche at the Institut Universitaire de Gériatrie de Montréal, all in Quebec, Canada. Mehta received support from the Strategic Training Program in Palliative Care Research Canadian Institutes for Health Research–Canadian Cancer Society Research Institute (CIHR-CCSRI) and a studentship granted from CCSRI. Funding also was received from the CCSRI Sociobehavioural Cancer Research Network. Mehta can be reached at anita.mehta@muhc.mcgill.ca, with copy to editor at ONFEditor@ons.org. (Submitted July 2009. Accepted for publication November 18, 2009.)

Digital Object Identifier: 10.1188/11.ONFE37-E45

References

- Aranda, S.K., & Hayman-White, K. (2001). Home caregivers of the person with advanced cancer: An Australian perspective. *Cancer Nursing, 24*, 300–307. doi: 10.1097/00002820-200108000-00011
- Ardery, G., Herr, K.A., Titler, M.G., Sorofman, B.A., & Schmitt, M.B. (2003). Assessing and managing acute pain in older adults. A research base to guide practice. *Medsurg Nursing, 12*, 7–18.
- Aubin, M., Vézina, L., Fillion, L., Allard, P., Parent, R., Bergeron, R., . . . Giguere, A. (2006). Impact of an educational program on pain management in patients with cancer living at home. *Oncology Nursing Forum, 33*, 1183–1188. doi: 10.1188/06.ONF.1183-1188
- Binhas, M., Krakowski, I., & Marty, J. (2007). Nociceptive cancer pain in adult patients: Statement about guidelines related to the use of antinociceptive medicine. *Annales Françaises D'anesthésie et de Réanimation, 26*, 502–515. doi: 10.1016/j.annfar.2007.03.029
- Cahana, A., Arigoni, F., & Robert, L. (2007). Attitudes and beliefs regarding the role of interventional pain management at the end of life among caregivers. A four-year perspective. *Pain Practice, 7*, 103–109. doi: 10.1111/j.1533-2500.2007.00117.x
- Chang, V.T., Janjan, N., Jain, S., & Chi Chau, C. (2006). Update in cancer pain syndromes. *Journal of Palliative Medicine, 9*, 1414–1434. doi: 10.1089/jpm.2006.9.1414
- Christo, P.J., & Mazloomdoost, D. (2008). Cancer pain and analgesia. *Annals of the New York Academy of Sciences, 1138*, 278–298. doi: 10.1196/annals.1414.033
- Coyle, N. (2006). Assessing cancer pain in the adult patient. *Oncology, 20*(10, Suppl.), 41–49.
- Coyle, N., Adelhardt, J., Foley, K.M., & Portenoy, R.K. (1990). Character of terminal illness in the advanced cancer patient, pain and other symptoms during the last four weeks of life. *Journal of Pain and Symptom Management, 5*, 83–93. doi: 10.1016/S0885-3924(05)80021-1
- Davis, M.P., & Srivastava, M. (2003). Demographics, assessment, and management of pain in the elderly. *Drugs and Aging, 20*, 23–57. doi: 10.2165/00002512-200320010-00003
- Davis, M.P., & Walsh, D. (2004). Palliative oncology update. Epidemiology of cancer pain and factors influencing poor pain control. *American Journal of Hospice and Palliative Care, 21*, 137–142. doi: 10.1177/104990910402100213
- Dobratz, M.C. (2001). Patterns of advanced cancer pain in home

- hospice patients. *Cancer Nursing*, 24, 294–299. doi: 10.1097/00002820-200108000-00009
- Firth, P. (2006). Patients and their families. *Recent Results in Cancer Research*, 168, 61–71. doi: 10.1007/3-540-30758-3_6
- Gagnon, B., Almahrezi, A., & Schreier, G. (2003). Methadone in the treatment of neuropathic pain. *Pain Research and Management*, 8, 149–154.
- Gilron, I., Bailey, J.M., Tu, D., Holden, R.R., Weaver, D.F., & Houlden, R.L. (2005). Morphine, gabapentin, or their combination for neuropathic pain. *New England Journal of Medicine*, 352, 1324–1334. doi: 10.1056/NEJMoa042580
- Given, B.A., Given, C.W., & Kozachik, S. (2001). Family support in advanced cancer. *CA: A Cancer Journal for Clinicians*, 51, 213–231. doi: 10.3322/canjclin.51.4.213
- Godfrey, H. (2005). Understanding pain: Part 2. Pain management. *British Journal of Nursing*, 14, 904–909.
- Kenner, D.J. (1994). Pain forum: Part 1. Nociceptive cancer pain. *Australian Family Physician*, 23, 1272–1277.
- Lema, M.J. (2001). Invasive analgesia techniques for advanced cancer pain. *Surgical Oncology Clinics of North America*, 10, 127–136.
- Lobchuk, M.M., & Vorauer, J.D. (2003). Family caregiver perspective-taking and accuracy in estimating cancer patient experiences. *Social Science and Medicine*, 57, 2370–2384. doi: 10.1016/S0277-9536(03)00132-1
- Mazanec, P., & Bartel, J. (2002). Family perspectives. Family caregiver perspectives of pain management. *Cancer Practice: A Multidisciplinary Journal of Cancer Care*, 10(Suppl. 1), S66–S69.
- McCaffery, M. (1990). Nursing approaches to nonpharmacological pain control. *International Journal of Nursing Studies*, 27(1), 1–5. doi: 10.1016/0020-7489(90)90018-E
- McCallin, A. (2003). Designing a grounded theory study: Some practicalities. *Nursing in Critical Care*, 8, 203–208. doi: 10.1046/j.1362-1017.2003.00033.x
- McMillan, S.C., & Small, B.J. (2007). Using the COPE intervention for family caregivers to improve symptoms of hospice homecare patients: A clinical trial. *Oncology Nursing Forum*, 34, 313–321. doi: 10.1188/07.ONF.313-321
- Mehta, A., Cohen, R., Carnevale, F.A., Ezer, H., & Ducharme, F. (2010). Family caregivers of palliative cancer patients at home: The Puzzle of Pain Management. *Journal of Palliative Care*, 26, 78–87.
- Mercadante, S., Casuccio, A., Pumo, S., & Fulfaro, F. (2000). Opioid responsiveness—Primary diagnosis relationship in advanced cancer patients followed at home. *Journal of Pain and Symptom Management*, 20, 27–34. doi: 10.1016/S0885-3924(00)00145-7
- Mercadante, S., Villari, P., Ferrera, P., & Casuccio, A. (2006). Opioid-induced or pain relief-reduced symptoms in advanced cancer patients? *European Journal of Pain*, 10, 153–159. doi: 10.1016/j.ejpain.2005.02.006
- Mishra, S., Bhatnagar, S., Gupta, D., Nirwani Goyal, G., Jain, R., & Chauhan, H. (2008). Management of neuropathic cancer pain following WHO analgesic ladder: A prospective study. *American Journal of Hospice and Palliative Medicine*, 25, 447–451. doi: 10.1177/1049909108322288
- Mobily, P. (1994). Nonpharmacologic interventions for the management of chronic pain in older women. *Journal of Women and Aging*, 6(4), 89–109.
- Mobily, P.R., Herr, K.A., & Kelley, L.S. (1993). Cognitive-behavioural techniques to reduce pain. A validation study. *International Journal of Nursing Studies*, 30, 537–548. doi: 10.1300/J074v06n04_07
- Nicholson, A.B. (2004). Methadone for cancer pain. *Cochrane Database of Systematic Reviews*, 2, CD003971. doi: 10.1002/14651858.CD003971.pub2
- Polit, D.F., & Beck, C.T. (2004). *Nursing research, principles and methods* (7th ed.). Philadelphia, PA: Lippincott Williams and Wilkins.
- Portenoy, R.K. (1989). Cancer pain, epidemiology and syndromes. *Cancer*, 63, 2298–2307. doi: 10.1002/1097-0142(19890601)63:11<2298::AID-CNCR2820631140>3.0.CO;2-A
- Redinbaugh, E.M., Baum, A., DeMoss, C., Fello, M., & Arnold, R. (2002). Factors associated with the accuracy of family caregiver estimates of patient pain. *Journal of Pain and Symptom Management*, 23, 31–38. doi: 10.1016/S0885-3924(01)00372-4
- Schumacher, K.L., Koresawa, S., West, C., Hawkins, C., Johnson, C., Wais, E., . . . Miaskowski, C. (2002). Putting cancer pain management regimens into practice at home. *Journal of Pain and Symptom Management*, 23, 369–382. doi: 10.1016/S0885-3924(02)00385-8
- Seaman, D.R., & Cleveland, C. (1999). Spinal pain syndromes, nociceptive, neuropathic, and psychological mechanisms. *Journal of Manipulative and Physiological Therapeutics*, 22, 458–472. doi: 10.1016/S0161-4754(99)70035-7
- Smith, P.A. (2004). Neuropathic pain, drug targets for current and future interventions. *Drug News Perspective*, 17, 5–17. doi: 10.1358/dnp.2004.17.1.829021
- Snyder, M., & Wieland, J. (2003). Complementary and alternative therapies: What is their place in the management of chronic pain? *Nursing Clinics of North America*, 38, 495–508. doi: 10.1016/S0029-6465(02)00098-1
- Strauss, A., & Corbin, J. (1994). Grounded theory methodology: An overview. In N.K. Denzin & Y.S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 273–285). Thousand Oaks, CA: Sage.
- Turk, D.C., Monarch, E.S., & Williams, A.D. (2002). Cancer patients in pain, considerations for assessing the whole person. *Hematology Oncology Clinics of North America*, 16, 511–525. doi: 10.1016/S0889-8588(02)00015-1
- Twycross, R.G., & Fairfield, S. (1982). Pain in far advanced cancer. *Pain*, 14, 303–310. doi: 10.1016/S0885-3924(96)00149-2
- Twycross, R.G., Harcourt, J., & Bergl, S. (1996). A survey of pain in patients with advanced cancer. *Journal of Pain and Symptom Management*, 12, 273–282.
- Vallerand, A.H., Collins-Bohler, D., Templin, T., & Hasenau, S.M. (2007). Knowledge of and barriers to pain management in caregivers of cancer patients receiving home care. *Cancer Nursing*, 30, 31–37. doi: 10.1097/00002820-200701000-00006
- Whitecar, P.S., Jonas, A.P., & Clasen, M.E. (2000). Managing pain in the dying patient. *American Family Physician*, 61, 755–764.
- World Health Organization. (2007). WHO definition of palliative care. Retrieved from <http://www.who.int/cancer/palliative/definition/en>
- Yates, P., Aranda, S., Edwards, H., Nash, R., Skerman, H., & McCarthy, A. (2004). Family caregivers' experiences and involvement with cancer pain management. *Journal of Palliative Care*, 20, 287–296.
- Zareba, G. (2005). Pregabalin: A new agent for the treatment of neuropathic pain. *Drugs of Today*, 41, 509–516. doi: 10.1358/dot.2005.41.8.910482