

Patient Control and End-of-Life Care

Part I: The Advanced Practice Nurse Perspective

Deborah L. Volker, RN, PhD, AOCN®, David Kahn, RN, PhD,
and Joy H. Penticuff, RN, PhD, FAAN

Purpose/Objectives: To explore understanding of preferences of adult patients with cancer for control in the context of end-of-life care and to explore strategies that oncology advanced practice nurses (APNs) use to assist patients in achieving personal control at the end of life.

Research Approach: Descriptive, naturalistic using Denzin's model of interpretive interactionism.

Setting: A variety of settings throughout the state of Texas.

Participants: 9 oncology APNs.

Methodologic Approach: Participants were recruited via a mailed invitation to APN members of the Oncology Nursing Society who resided in Texas. Interviews were recorded on audiotape and analyzed via Denzin's interpretive process of data analysis.

Main Research Variables: Patient control.

Findings: APNs' descriptions of patient preferences for control at the end of life included engagement with living, turning the corner, comfort and dignity, and control over the dying process. APN roles included presenting bad news in a context of choices, managing physical care and emotional needs, and facilitating care services and systems.

Conclusions: Patient desire for control manifests in a wide variety of actions and desires to live fully and remain actively involved in personal decision making in the context of an advanced cancer diagnosis. APNs play a pivotal role in determining and facilitating patient preferences for control.

Interpretation: Academic programs to prepare oncology APNs must include attention to communication skills, clinical care needs, and care management strategies for the end-of-life continuum of care. APNs may need to increase efforts to dispel patient and family misperceptions about value and timing of palliative care and hospice services.

Key Points . . .

- In this study, oncology advanced practice nurses (APNs) used a variety of strategies to assist patients to achieve control at the end of life.
- APN education programs must include emphasis on both theoretical and practical aspects of communicating bad news and other sensitive information to patients and families.
- Unfortunately, many patients and families still equate hospice-type services with imminent death and do not understand the role of hospice in enhancing quality of living in the context of terminal disease.

stantial reform of healthcare policy to deliver and finance quality end-of-life care (Lynn & Adamson, 2003).

The value of autonomy and right to self-determination in Western society is evidenced by public interest in increased control over the end-of-life experience. The Oregon Death With Dignity Act (passed in 1997), which allows terminally ill patients to request lethal prescriptions for assisted dying, is an example of this search for control. Since 1998, Oregonians who have engaged in assisted suicide have been concerned about their loss of autonomy and are determined to control the way they die (Leman, 2004). Although maintaining a sense of control appears to be important to patients in end-of-life care, empirical evidence about what constitutes control over a good or dignified death as a patient-defined outcome is lacking (Steinhauser et al., 2000). Little is known about the types of control that patients prefer during the end of life and how nurses can support such preferences (Volker, 2001). Hence, the purposes of this study were to explore strategies that oncology advanced practice nurses (APNs) use to assist patients in achieving personal control at the end of life and to examine preferences of adult patients with cancer for control in the context of end-of-life care.

Deborah L. Volker, RN, PhD, AOCN®, is an assistant professor, David Kahn, RN, PhD, is an associate professor, and Joy H. Penticuff, RN, PhD, FAAN, is a professor, all in the Austin School of Nursing at the University of Texas. Funding for this study was provided by an ONS Foundation Genentech Outcomes Research Grant. (Submitted August 2003. Accepted for publication January 29, 2004.)

Digital Object Identifier: 10.1188/04.ONF.945-953

Since the early 1990s, numerous legislative, research, and clinical initiatives have addressed concerns about improving care at the end of life. In 1997, the Institute of Medicine issued a landmark study summarizing the current state of knowledge about care for patients with life-threatening illnesses and proposed how policymakers, healthcare providers, and others could correct deficiencies in care at the end of life (Field & Cassel, 1997). The Institute of Medicine subsequently issued a second report that defined barriers to delivery of expert palliative care and recommended initiatives to overcome such barriers (Foley & Gelband, 2001). Other private and public foundations have followed suit by funding activities designed to improve public understanding of care options for the dying, broaden professional caregiver knowledge and skill levels, and enhance the availability of palliative care services. For example, the RAND Corporation released a white paper synthesizing research on the challenge of living well with chronic illness in older age and recommended sub-

The participants in this study were people with advanced cancer diagnoses and oncology APNs who have the theoretical and research-based knowledge and skills to provide insight into individualized care requirements and needs of the dying. The APN perspective on strategies to facilitate patient control and comfort at the end of life adds an invaluable viewpoint to this challenging component of patient care. This two-part article reports the study results. Part I explores the APNs' experiences with patient control; Part II describes the patients' perspectives about desire for control at the end of life.

Conceptual Orientation

This study was grounded in the theoretical concept of personal control and Lewis' (1987) conceptual typology of control. The concept of personal control is central in Western culture. As a society, we spend considerable time and energy attempting to control the circumstances of our lives. The control of a person's life, which takes many forms, is connected closely with the concepts of choice and autonomy. The control of daily schedule, work setting and practices, and home environment is but one manifestation of control that many Americans value.

The concept of personal control also is a core concept in oncology nursing practice. Because many different types of personal control and relationships between control and health exist, Lewis (1987) developed a conceptual typology to clarify the multidimensional nature of the concept of control. This typology was derived from an analysis of both theoretical and empirical work. Lewis outlined five different types of control: processual control, contingency control, cognitive control, behavioral control, and existential control. She explained that these types of control constitute responses to aversive events, stimuli, or stressors. **Processual control** refers to an individual's participation in "discussions or decisions affecting the event, the response, the outcome, or the environmental context" (Lewis, 1987, p. 280). This type of control includes interactions between the individual (patient) and the person who has the power (nurse) to influence the aversive event. **Contingency control** is an individual's perception of a direct relationship between her or his response to the event and the individual's outcomes. Lewis linked the concepts of learned helplessness and self-efficacy to this perception that a person's actions or responses to events matter. **Cognitive control** refers to an individual's intellectual management of an event to reduce its perceived threat. Such cognitive control allows an individual to reframe an aversive situation as manageable. **Behavioral control** is the actual behavior that alters the qualities or outcomes of an event. **Existential control** includes an individual's attribution of meaning and purpose to an event such that potential threat is reduced. All five types of control described in Lewis' typology may be used by patients who seek to control the end-of-life experience to achieve a comfortable death.

Literature Review

Search for Personal Control in the Context of a Cancer Diagnosis

Numerous studies have investigated preferences of newly diagnosed patients with cancer for control over decisions about treatment options. Study findings reflected considerable disagreement regarding such preferences. Some studies indicated that most patients want control (with or without physi-

cian collaboration) over treatment decisions (Brandt, 1991; Degner et al., 1997; Degner & Russell, 1988; Hack, Degner, & Dyck, 1994), whereas other studies indicated that a majority wants to play a more passive role and allow their physicians to control treatment decisions (Beaver et al., 1996; Davison, Degner, & Morgan, 1995; Degner & Sloan, 1992). Desire for control may vary depending on a variety of factors, such as disease stage, the focus of control (e.g., treatment options versus other aspects of life), cultural orientation, age, and religious preference.

Lewis and her colleagues applied her typology of control in a series of studies of people with advanced cancer diagnoses (Lewis, 1982, 1989; Lewis, Haberman, & Wallhagen, 1986). In a quantitative, correlational study of the experience of personal control and quality of life in 57 patients with late-stage cancer, Lewis (1982) hypothesized that having a sense of greater experienced control would be associated with a better quality of life. Physicians identified patients as having late-stage cancer when their care focused on palliative, not curative, treatments. Based on findings from participants' scores on four standardized instruments (Rosenberg Self-Esteem Scale; Health Locus of Control Scale; Lewis, Firsich, and Parsell Anxiety Scale; and Crumbaugh Purpose-in-Life Scale), Lewis (1982) concluded that a sense of experienced control over life was associated with higher levels of self-esteem, low self-reported anxiety, and greater purpose in life. Lewis (1982) also found that as the length of time since diagnosis increased, the more that participants attributed control over their health to external sources.

Using data collected for Lewis' 1982 study, Lewis et al. (1986) conducted a content analysis of responses to four interview questions to explore how the patients described the noncontrollable aspects of their lives as well as the elements over which they maintained control despite a diagnosis of advanced cancer. The analysis revealed four conceptual categories: "monitoring progress," "waiting it out," "refocusing control," and "turning it over." The researchers observed that, although the participants were aware of the demands of illness, they sought to normalize their lives by actively attempting to control their day-to-day activities and attitudes.

In a follow-up, Lewis (1989) used regression analyses to examine attributions of control, experiential meaning, and psychosocial well-being. Consistent with the concept of health locus of control, individuals who have internal attributions of control may believe that their actions influence their health status. Conversely, those who make external attributions of control may believe that external events beyond their control influence health outcomes. Lewis (1989) concluded that participants' length of experience with a cancer diagnosis did not affect their attributions of personal control over their health nor influence their self-esteem or anxiety. Taken together, these early studies of control in people with advanced cancer represent an important step in investigating the issue of a search for control in an uncontrollable phase of disease. However, the participants were interviewed well before public interest in controlling the timing and circumstances of the end of life grew. Interest in control and manifestation of such interest may be different at this point in time.

Dignified Dying as a Patient Outcome

Measurable indicators that are specific to dignified dying and sensitive to individual patient preferences regarding control and

comfort have not been explored well. For example, the Iowa Nursing Outcomes Classification (NOC) (Johnson, Maas, & Moorhead, 2000) taxonomy was developed to identify nursing-sensitive patient outcomes. NOC defines the concept of Dignified Dying as maintaining personal control and comfort with the approaching end of life (Johnson et al.). A group of investigators from the Iowa NOC research team (Rankin et al., 1998) subsequently reviewed literature that was focused on dying with dignity and developed 23 indicators designed to measure achievement of dignified dying. The indicators were categorized as either relating to maintaining personal control or maintaining personal comfort; they are outlined in Figure 1. The literature used for this endeavor included journal articles and books that reflected personal opinions and experiences of healthcare providers and six research articles. The research included two studies that focused on Swedish and British patient experiences, one study that reflected an interview of one man, two studies of quality of life for patients with cancer in pain, and one instrument development study that had been based on the assumption that readiness for death is an indicator of healthy dying. The nonempirical literature reflecting healthcare providers' personal experiences and opinions adds a valuable but incomplete perspective to understanding potential components of dignified death. No studies that focused on testing the utility of the NOC indicators for dying with dignity could be located in the published literature.

Street and Kissane (2001) explored constructions of dignity in end-of-life care by conducting a discursive analysis of a wide variety of published texts (e.g., literary discourse, Internet sites, legislative and policy statements) and a selection of nar-

ratives and case studies from patient and family interviews. They concluded that dignity in end-of-life care is embedded in social relationships and embodiment. They observed, "For patients in our studies . . . key needs were a sense of control and a capacity for autonomy" (Street & Kissane, p. 95). Two patients' descriptions of control included desire to define their own limits of suffering and a need to control treatment decisions. Unfortunately, the study is difficult to evaluate because the report included little detail about study design, methods, and sample.

Chochinov et al. (2002) studied the extent to which dying patients with cancer perceive that they are able to maintain a sense of dignity. Only 7.5% of the 213 participants expressed that loss of dignity was of great concern. Of note, the concept of dignity was not overtly defined; a person's sense of dignity was measured by a seven-point scale that ranged from no sense of loss of dignity to an extreme sense of loss of dignity. The researchers observed that all of the participants were receiving expert palliative care and that their findings may have reflected the age (\bar{X} = 69 years) of their sample.

In addition to dignified dying, other citations in the literature focused on similar concepts, including attributes of a good death, bad death, and healthy death. The Institute of Medicine's definition of a good death is "one that is free from avoidable distress and suffering for patients, families, and caregivers; in general accord with patients' and families' wishes; and reasonably consistent with clinical, cultural, and ethical standards" (Field & Cassel, 1997, p. 24). From an empirical perspective, the question of what constitutes a good death remains in question. For example, Steinhauer et al. (2000) collected descriptions of components of a good death from patients with advanced, chronic illness (including cancer, end-stage renal disease, congestive heart failure, and advanced chronic obstructive pulmonary disease); recently bereaved family members; and healthcare providers. Participants outlined six components of a good death: pain and symptom management, clear decision making, preparation for death, completion, contributing to others, and affirmation of the whole person. The authors observed that, although their study revealed areas of consensus about a good death, patients did differ from healthcare providers regarding certain priorities. For example, patients ranked the importance of maintaining mental awareness as a higher priority than did physicians. Contrary to a prevailing notion that dying at home is preferable, participants ranked dying at home as the least important attribute in quality of dying. However, patients and healthcare providers consistently rated comfort (pain and symptom management) as an important aspect of end-of-life care. Although the small sample size limited generalizability, Steinhauer et al.'s study findings suggested that the definition of what constitutes a good death is dynamic and that a variety of expressions and preferences is associated with what constitutes a good death.

Hopkinson and Hallett (2002) explored the concept of a good death by interviewing 28 British nurses working on acute care units. Of note, the participants were relatively inexperienced (two months to three years of experience). The researchers concluded that the nurses conceptualized an ideal death as peaceful, comfortable (including symptom control), and dignified. An important aspect was that death be anticipated, such that staff could spend time with the patient and arrange for someone to be present while the patient died. The

Indicators Related to Personal Control

- Shares feelings about dying
- Completes meaningful goals
- Maintains sense of control of remaining time
- Participates in decisions
- Controls treatment choices
- Chooses food and drink intake
- Puts affairs in order
- Resolves important issues and concerns
- Exchanges affection with others
- Disengages gradually from significant others
- Discusses spiritual experiences
- Discusses spiritual concerns
- Maintains physical independence

Indicators Related to Maintaining Comfort

- Expresses readiness for death
- Expresses hopefulness
- Recalls lifetime memories
- Reviews life's accomplishments
- Appears calm and tranquil
- Verbalizes comfort
- Expresses pain relief
- Expresses symptom control (e.g., nausea, anxiety, dyspnea)
- Maintains personal hygiene

Figure 1. Indicators for Dignified Dying

Note. From "Dignified Dying as a Nursing Outcome" by M.A. Rankin, M.P. Donahue, K. Davis, J.K. Katseres, J.A. Wedig, M. Johnson, et al., 1998, *Outcomes Management for Nursing Practice*, 2(3), p.109. Reprinted with permission.

researchers also observed similarities and differences in the participants' notions of an ideal death and suggested that an even greater variability could exist in conceptualizing a good death by more socially diverse groups.

Some of the published work on the nature of control over the end-of-life experience is not empirical in nature. Rather, it represents diverse values, opinions, and experiences of healthcare practitioners, ethicists, philosophers, and consumers. For example, Emanuel and Emanuel (1998) constructed a framework for understanding and evaluating a good death. They identified physical, psychological, and cognitive symptoms; impact of economic and caregiving demands; need for social relationships and support; spiritual and existential beliefs; and hopes and expectations as important dimensions to be addressed and studied in the context of a search for what a good death could be. Interestingly, nursing care needs are represented as a significant economic demand and caregiving burden on families. Although Emanuel and Emanuel advised clinicians how to ensure that dying patients experience a good death, they raised numerous research questions regarding the need for better understanding of what constitutes a good death.

Oncology Advanced Practice Nurses and End-of-Life Care

According to the Oncology Nursing Society (ONS), APNs are RNs who have acquired specialized knowledge and skills by completing a master's or doctorate degree in their specialty (ONS, 2003a). Oncology APNs are well positioned to provide leadership in outcomes research for end-of-life care issues. In the ONS (2003b) *Statement on the Scope and Standards of Advanced Practice in Oncology Nursing*, the oncology APN's role is used across the cancer care continuum in a variety of roles and settings, including palliative and hospice care.

Several studies have documented the effectiveness of oncology APN interventions in patients in a variety of healthcare settings. Some examples include the care of people undergoing radiation therapy (Weintraub & Hagopian, 1990), psychological distress in bereaved spouses (McCorkle, Robinson, Nuamah, Lev, & Benoliel, 1998), information needs of rural patients with cancer (White, Given, & Devoss, 1996), quality-of-life and cost outcomes of women newly diagnosed with breast cancer (Ritz et al., 2000), and home care of older, newly diagnosed postsurgical patients with cancer (McCorkle et al., 2000). McCorkle et al. (1998) described the interventions provided by APNs to 37 newly diagnosed older patients facing terminal illness. Examples of interventions included teaching, psychosocial support, care environment management, and care need determination. No studies were located that used oncology APNs to describe patient preferences for control in the context of end-of-life care.

In sum, the studies about the search for control in the context of terminal illness do not reveal specific information about what patients might wish to control to achieve a dignified death. Taken together, the patients were living with cancer in a range of stages, from newly diagnosed to advanced disease. Dignified dying may be a subjective, unique, dynamic process. Thus, the investigation of what constitutes a dignified death must be compatible theoretically with the experiential and individualized nature of the dying process. Additionally, oncology APNs have the theoretical and research-based

knowledge and skills to provide insight into individualized care requirements and needs of the dying. In the current study, the APN perspective on strategies to facilitate patient control at the end of life will add an invaluable viewpoint to this challenging component of care of patients with cancer.

Methods

Given the existential, contextual nature of the study purpose, the study design used an interactive, hermeneutical approach. Denzin's (1989) postpositivist research method of interpretive interactionism provides a means to study and understand problems or life-altering experiences that occur in the daily lives of people.

Sample and Setting

Sample selection, or "capture" per Denzin's (1989) terminology, involved obtaining multiple, naturalistic instances of the experiences under study. A purposive, statewide sample of APNs in Texas was recruited via a mailed letter to the Texas members of ONS who have a master's degree in nursing and a primary employment position of clinical nurse specialist or nurse practitioner.

Procedure

The study was reviewed and approved by an institutional review board. Potential participants were recruited by a randomized, sequential mailing of recruitment letters to ONS members who met the sample characteristics described earlier. Letters were mailed until data analysis revealed redundancy in interview content. The recruitment letter described the study and contained a reply form and self-addressed, stamped envelope. Participants were contacted by the study's principal investigator (PI) to further discuss study participation and arrange for a one-hour, personal, audiotaped interview with the PI at a location selected by the participant. Interview questions and samples of probes are described in Figure 2. The PI obtained informed consent before beginning the interview. Participants each received \$50 as a thank you at the conclusion of the interview, and they were asked to assist with identifying patients with advanced cancer who might be interested in learning about the patient interview component of the study.

1. Tell me about your practice as an advanced practice nurse (APN).
 - a. What is a typical day like?
 - b. What kinds of patients and patient needs do you typically encounter?
2. Describe strategies you use to assist your patient(s) in achieving personal control and comfort at the end of life. Based on responses from the APN, potential probes may include the following.
 - a. Describe an example of how a patient sought to control an aspect of end-of-life care.
 - b. In your experience, what do patients seek regarding comfort care at the end of life?
 - c. Do your patients express a preference for the site (e.g., home, hospital) where they receive terminal care?
 - d. Have your patients expressed a desire to control the timing of or when they die? If so, please describe an example.
 - e. Have any of your patients expressed concern or worry about losing control during the end-of-life experience? If so, please describe an example.

Figure 2. Interview Guide

Data Analysis

Interview audiotapes were transcribed verbatim using a word-processing program. The PI compared all tape-recorded interviews with the transcriptions to verify accuracy of transcription. The transcriptions were analyzed using Denzin's (1989) interpretive data analysis process. Each interview text was reviewed multiple times, line by line, for key elements, structures, or statements. These key phrases were underlined and labeled. The phrases and labels then were reviewed for emergent, tentative themes. Denzin's process of interpretive analysis then calls for construction of the themes back into a coherent whole. This process was accomplished by reviewing the labeled textual phrases, questioning how the phrases affect the other components of the interview, developing concise thematic descriptions, and formulating ideas as to how the themes represent a coherent answer to the study question. Themes and textual passages were compared across all interview texts.

To safeguard the trustworthiness of the analytic process, the study's two coinvestigators then reviewed the transcripts to ensure that participants' experiences and viewpoints were portrayed accurately via the thematic analysis. Throughout the study, an audit trail was maintained, including field notes, transcripts and data reduction, and analytic decisions.

Results

Nine female, Caucasian APNs from throughout Texas were interviewed for the study. All were master's prepared; one also had a doctorate degree in nursing. Participant age ranged from 39–55 years with a mean of 48. They practiced in a variety of roles in both ambulatory and inpatient settings. The mean years of experience in nursing practice was 22 years (range = 10–32) and in oncology practice was 15 years (range = 2–26). Five had AOCN® certification; two were OCN® certified.

The data analysis revealed two categories of information. The first category focused on the APNs' experiences with what their patients wanted regarding control and comfort at the end of life. The thematic analysis of this component revealed four themes. The second category focused on APNs' descriptions of their roles in assisting patients to achieve control and comfort at the end of life. Figure 3 contains a summary of the themes and their descriptions.

Advanced Practice Nurses' Experience With Patient Desires for Control and Comfort

Engagement with living: Engagement with living refers to patient preferences for maintaining professional and personal role functions in the context of treatment. APNs spoke of patients' desires to continue employment and fulfill parenting and other family roles while participating in clinical trials and palliative treatments. The focus of this theme is on life and living in the context of end-stage disease. One APN reflected that "most of these patients are willing to give up a lot to simply feel better, be better for a length of time." Many APNs spoke of patient reluctance to take adequate pain medication because of fear that side effects might interfere with role fulfillment.

He had been very resistant to [take pain medication] because his goal was to be able to continue operating. That was what he wanted. He was still working pretty much

Patient Preferences Regarding Control and Comfort at the End of Life

- Engagement with living: maintaining professional and personal role functions in the context of ongoing treatment
- Turning the corner: decisions, choices, circumstances, and struggles that influence the timing of or transition toward the dying process
- Comfort and dignity: desires for comfort in the end-of-life experience that are respectful of a person's sense of dignity and personal values
- Control over the dying process: patient and family concerns, desires, and manifestations of control over the place, process, and logistics of end-of-life care

Advanced Practice Nurse's Role in Assisting Patients in Achieving Control and Comfort at the End of Life

- Presenting bad news in a context of choices: broaching end-of-life discussions and suggesting possibilities for choices
- Managing physical care and emotional needs: descriptions of specific strategies to address care needs
- Facilitating care services and systems: choreographing the systems and logistic aspects of end-of-life care

Figure 3. Thematic Descriptions

full-time, seeing patients in the clinic, doing his [operating room] time. But he refused to take pain medication because he didn't want to be obtunded, where he couldn't do his work.

Another APN spoke of a patient's desire to control aspects of her clinical trial participation to continue to meet work obligations.

I had a patient that was going to go on a clinical trial. And she wanted to control what she was going to do in the clinical trial to when she was going to come for her visits. The important thing for her was going to work every day and putting in that time. The trial involved coming in for a CT [computed tomography] scan every six weeks, and she just couldn't do it because work was more important.

Turning the corner: APNs shared stories of patients' decisions, choices, circumstances, and struggles that reflected a search for control over the timing of or transition toward the dying process. One APN shared that she felt that patients "chose to turn the corner." Many APNs described patients who seemed to delay death until a special goal or special event had occurred; others described patients' decisions to refuse further treatment followed by a rapid progression to death. One APN shared the story of an older man with acute leukemia who had experienced several remissions and relapses. During his final relapse, he called her into his room one night, simply stated, "I'm done," and died two days later.

How could he die when he wanted to die? He was ready; he was going to die and he did. His wife was clear on it, his daughter, and his other children were, too. There was no wavering. He said his good-byes and that was that. He was hanging onto that control [over coming in for repeated treatments] until he finally realized that he wanted no more. But he had control anyway; he controlled it to the last minute.

Some of the patient experiences were marked by a struggle to prepare family to take on new responsibilities after the patient's death and by worry about leaving loved ones behind.

One APN described a childless man with advanced mesothelioma who spent most of the time at the end of life teaching his wife how to access the bank and manage the family trust.

When he was dying, he had a terrible time. He would not give up. He struggled for a good 24 hours. And I came into the room to see him that day, and he was just all over the bed. He said he didn't hurt. And so I just sat down on the bed and I said, "Marvin, what is it? What is bothering you?" And he said, "I can't leave Momma; who will take care of Momma?" And I said, "I will look after Mabel for you." And he said thank you and he died about an hour later.

Comfort and dignity: This theme refers to patients' desires for comfort in the end-of-life experience that is respectful of their sense of dignity and personal values. Not surprisingly, every APN in the study described pain as an important aspect that their patients wanted to control. According to one APN, "There's a fear about having pain and losing dignity when they die. Patients say, 'When I die, I hear that I may wet myself, or mess myself.' And that's a big issue." Another APN observed that her patient's increasing weakness "was the thing that took a lot of her control away" and injured her pride in her ability to independently manage her complex physical care needs.

Control over the dying process: This theme encompasses patient and family concerns, desires, and manifestations of control over the place, process, and logistics of end-of-life care. APNs described patient and family concerns about dependency, tensions regarding setting and which professionals should provide end-of-life care, and varying personal preferences for control over how the final days should unfold. Many of the APNs shared examples of patient reluctance to accept hospice services and worry that hospice meant a loss of control over care delivery in the dying days. One APN described a patient's response to her suggestion about hospice services.

The patient said, "I don't want strangers in my house. I'm doing fine. My wife's taking care of me. I just don't want people there 24 hours a day telling me what to do." And so I have had people refuse hospice because their understanding is that hospice takes control of their personal lives. They are very afraid of people coming in and they don't want anybody to take over the role of their caretaker.

Other APNs described patient worries that accepting hospice care meant that they would lose contact with their primary care providers.

The APNs were quite sure that their patients had preferences for where they wanted to die and that most patients preferred to be at home surrounded by family if their loved ones could manage it.

I think that if people feel that their family can cope with it and handle it, [home] is where they want to be. Most family members have not had any experience with this until they finally have their own personal experience with death of a loved one. And I think people are very afraid to know that they are going to be taking on that responsibility.

Some patients were described as taking very active control over the details of their medical care during the end of life. An APN told a story of a patient who manifested her desire for

control by agreeing to a do-not-resuscitate (DNR) order and then rescinding that order when she felt her impending death was the result of a medical error.

A couple of days later, after she was discharged from the hospital, she started having problems breathing and shortness of breath. She worsened and finally told her husband that she needed to go to the hospital by ambulance. She was sure that her respiratory problems were due to a changed dose of methadone. While they were in the ambulance, she told him she wanted to rescind the DNR. By the time she got to the hospital, she wasn't coherent enough to state that for herself, but he told them that is what she wanted, so they did intubate her and put her on the ventilator. It turns out she was right. The concentration of the methadone was 10 times greater than she should have gotten.

Advanced Practice Nursing Role in Patient Control and Comfort

Presenting bad news in a context of choices: APNs described their role in broaching end-of-life discussions with patients and suggesting possibilities for choices regarding treatment, employment, and interactions with others.

I bring up topics that may be under the rug or hard to deal with. I acknowledge the reality that things aren't going well and put that on the table. Irregardless of how bad the news is, you can still present it in the sense that they still have choices. That's a big part of the control issue. A lot of people don't even know what questions or issues they have to be thinking about or make choices about.

Another APN gave an example of facilitating a DNR discussion that initially frustrated a physician colleague.

The physician says, "Well, the patient wants everything. He doesn't want a do-not-resuscitate order, and I just can't understand." And I say, "What did you ask him?" [The physician replies] "He wants everything." [I reply] "Well, your everything and his everything are two different everything's!"

She then described her dialogue with the patient, starting with his understanding of the terminal nature of his disease and gently asking about how he pictured his dying days and what his preferences were for his care. She continued with a discussion of what resuscitation means in a hospital setting and the issues associated with dying in an intensive care setting. The patient then understood the situation and made his wishes known for comfort care and no resuscitation. A key issue that emerged in this theme was the importance of the APN having an established relationship with the patient to effectively communicate when such sensitive situations arose.

Managing physical care and emotional needs: APNs described approaches to managing physical needs, including pain, constipation, ostomy and wound care, and pruritus.

I said [to the patient], "We're gonna get rid of this damn itch tonight!" And so what we did, we just started putting washcloths into the freezer. We'd just keep rotating them around. It was almost like therapeutic touch but not quite. And we got rid of that damn itch. And do you know, she never had it the next day. We just did [morphine sulfate] and [lorazepam], and she just coasted right on. It was a beautiful death.

Many also expressed concern about addressing emotional needs and explained strategies for addressing such needs.

I think we underestimate how the spiritual or emotional discomfort—if it's not handled—really influences every other kind of comfort problem the patient has. The main thing I try to do about emotional discomfort is to normalize it. The way I often explain it to people is that, "You think it's terribly abnormal because you're not used to crying at the drop of a hat or getting angry so easily. But this is a normal response to an abnormal situation."

Facilitating care services and systems: This theme refers to the APN role in choreographing systems and logistical aspects of end-of-life care. Examples of activities included facilitating the patient's preferred site for end-of-life care, facilitating patient and family control over who provides care in the home, holding family conferences, and advocating for patient wishes.

My role in clarifying things is to be the advocate for the patient and remind the family that "It's your *dad's* death. We have to think about what your dad wants." Sort of put them in their place at times when they're wanting to jump in and take over.

Another APN gave an example of meeting with a patient and her family to illustrate her role in brokering patient control over the site for end-of-life care. Her surgeon had offered her gastric suction for bowel obstruction and total parenteral nutrition at a rehabilitation center in a city several miles away from the patient's home.

I said [to the patient], "Well, what do you want to do?" And she said, "Well, what am I allowed to do?" And I said, "What you want to do." She said, "You mean I can decide what I want to do?" I said, "Yeah, what do you want to do?" She said, "I want to take all these tubes out and I want to go home and to go back to church and do clog dancing." I said, "Well, what if . . . not your spirit, not your soul . . . but your physical body isn't going to do that? What else is important?"

The patient replied that she wanted to be at home and have her friends and family close by for visiting. The APN arranged for that to happen under hospice support.

APNs also spoke of the reluctance of some patients and families to accept hospice because of concerns that they would lose contact with the oncology care team.

I think there's a tremendous amount of separation anxiety, especially toward the end of life. When you have to move from the office-based staff to hospice, you've got to develop new relationships with these people when you're already drained. They may be very good and very competent, but you want to hold on to these people that you know and have been there for you.

Discussion and Implications

The interview data in this study exemplify two components of Lewis' (1987) conceptual typology of control: processual control and behavioral control. Processual control, participation by the patient in discussion or decisions regarding end-of-life care, was illustrated by the themes that emerged in APN stories of patients' desire for control. As APNs portrayed

them, their patients with advanced cancer engaged in exploring their choices and making decisions regarding treatment, the setting for care, the preparations of their families, and the timing and circumstances of dying. Similar to the findings of Lewis et al. (1986), the patients in the current study engaged in, and controlled, their day-to-day activities despite the diagnosis of advanced cancer. The APN role in facilitating processual control by communicating prognostic information and facilitating exploration of patient choices was evident. Behavioral control refers to the actual behavior that alters the qualities or outcomes of an event. The APN roles of presenting bad news, managing care needs, and facilitating care services are behaviors that can alter the quality of end-of-life experiences.

The patient stories revealed consistency with some of the NOC indicators for dignified dying. APNs relayed patient desires for control over decisions and treatment, maintenance of independence by maintaining role functions, management of pain and symptoms, and putting affairs in order in the context of "turning the corner." These examples reflect the APNs' reflections and recollection; Part II of this article will examine whether the NOC indicators are consistent with the patients' perspectives (see pp. 954–960).

The APN perspective on patient control and the end-of-life experience reveals a number of opportunities for improving clinical care for people with advanced cancer. Clearly, the management of symptoms and emotional distress forms a core component of APN practice and a fundamental patient need. Yet patients continue to express reluctance to take prescribed pain medications because they fear that side effects may interfere with their desire to engage fully in life and living. Many of the patient examples cited by the APNs were rich with details about patient priorities of continuing with work and managing family responsibilities. Challenges remain regarding the need to dispel patient and public worries that adequate pain relief at the end of life precludes engagement in valued roles and responsibilities at home and in the community.

All of the APNs described interactions with patients regarding the issue of hospice care. Numerous patient misconceptions regarding hospice and control over care surfaced in these interactions. Unfortunately, many patients and families still equate hospice with imminent death and do not understand the role of hospice in enhancing the quality of living in the context of terminal illness. Similar to findings in a recent study of barriers and enablers to hospice referrals (Friedman, Harwood, & Shields, 2002), some of the patients in the current study feared that when they surrendered to hospice they would lose control over care in their own homes; others worried that they would lose contact with the oncologists and nurses who had been the mainstay of treatment and support for many years. Not only do APNs play a key role in educating patients about hospice and other home-based services for palliative care, they also are ideally situated to provide continuity of care and ongoing contact with patients and families by continuing in a collaborative role with palliative care providers. Larger policy changes may make palliative care services a more palatable choice for people with advanced cancer. Regulatory barriers that allow only for reimbursement of hospice care in the final six months of life are coming under increasing scrutiny and criticism. Expansion of and payment for palliative care services that promote comfort in any life-threatening illness are vital (Goldstein & Lynn, 2002;

Jennings, Ryndes, D'Onofrio, & Baily, 2003; Lynn & Adamson, 2003).

The current study also provides direction for education and certification of APNs. All of the study's APNs emphasized their role in presenting bad news in very challenging and sensitive situations. Not surprisingly, APNs often opened the door to dialogue regarding patient preferences for end-of-life care or went beyond physician attempts to elicit patient choice.

The ONS (2003b) *Statement on the Scope and Standards of Advanced Practice in Oncology Nursing* outlines the APN's responsibility to communicate evidence-based information and education that facilitates patient and family "informed decision making, including advance directives and participation in clinical trials and other research projects" (p.19). Although this guideline does not quite capture the skill regarding communication of devastating news and planning for an uncertain future, the mandate to initiate a dialogue is clear. The AOCN® certification test blueprint includes communication as a vital element of the administrator/coordinator role and consultant role. Although the direct caregiver role content includes an emphasis on end-of-life issues and ethical issues associated with advance directives, proxies, treatment decisions, physician-assisted suicide, and euthanasia, no mention is made of the APN role in breaking bad news (Oncology Nursing Certification Corporation, 2004).

The need for APN education regarding communication of sensitive information regarding prognosis and consequent care planning is clear. In a survey of end-of-life educational needs of APN students, the students indicated that they had received the least amount of formal teaching in giving bad news and were the least skillful in this content area (Lehna, 2002). APN programs should include an emphasis on both theoretical and practical aspects of communicating sensitive information. Excellent resources are available for more information and guidance regarding communication issues as the focus of care changes (Quill, 2000).

The American Nurses Credentialing Center (2003) recently added a certification examination for palliative care advanced practice RNs. The palliative care advanced practice role has been highlighted by the Robert Wood Johnson Foundation (Emnett, Byock, & Twohig, 2002) and can serve as a collaborative partner to oncology APNs. Alternatively, oncology APNs may choose to achieve this certification as an additional specialty in their practices. For more information on the advanced practice role in palliative care, see *End-of-Life Care: Clinical Practice Guidelines for Nurses* (Kuebler, Berry, & Heidrich, 2002) and the *Michigan Palliative Advanced Practice Nurse Training Manual* (Kuebler & Moore, 2002).

Although people might assume that oncology APNs add value to patient care, more studies of oncology APN services must document the advantages of services that enhance patient and family outcomes and manage care costs for people with

advanced cancer. In the context of end-of-life care, studies of patient outcomes could include indicators such as decreased hospitalizations for unmanaged symptoms. Unfortunately, some of the services that APNs provide in this context currently are not rewarded by third-party reimbursement. Indeed, state-specific practice acts determine the extent to which APNs can receive Medicaid reimbursement (Kuebler, 2003). Nonetheless, some palliative care APNs are demonstrating success with reimbursement for their services via third-party payors or as salaried employees of institutions that bill for APN-provided services (Emnett et al., 2002). Patient and family needs for services that enhance control and well-being during the final years of life are not always easily packaged into cost savings. Rather, a cultural revolution of consumer demand for valued support services may drive changes in service provision. Community outreach activities such as the Bill Moyers public service television series, "On Our Own Terms: Moyers on Dying in America" (www.pbs.org/wnet/onourown/terms), and associated community town hall meetings are examples of activities that are ripe for oncology nurse activism.

Limitations

The APNs who participated in this study were middle-aged, well-educated, Caucasian women who practice in Texas. Their perceptions of patient desire for control could be a reflection of their demographic profile. Furthermore, the study did not capture the demographic characteristics of the patients described by the APNs. The issue of desire for control in the context of end-of-life care may be a culturally laden phenomenon and warrants further study. The APN sample also was purposive in nature. APNs who declined to participate in the study may have represented different experiences and viewpoints. Although the APNs described their perceptions of patient experiences with desire for control, this proxy approach must, and will, be expanded by including patient interview data (see Part II).

Conclusion

This study represents a first step in documenting the vital role that oncology APNs play in assisting patients in achieving their preferences for end-of-life care. Although oncology APNs are well positioned to provide leadership in end-of-life care, further study of the impact of APN interventions on patient outcomes in this context is vital. The concept of patient control will remain a key issue in U.S. health care, given Americans' value of self-determination and healthcare providers' emphasis on empowering people to take control of their health care.

Author Contact: Deborah L. Volker, RN, PhD, AOCN®, can be reached at dvolker@mail.nur.utexas.edu, with copy to editor at rose_mary@earthlink.net.

References

- American Nurses Credentialing Center. (2003). Advanced practice palliative care nurse examination. Retrieved January 7, 2004, from <http://nursingworld.org/ancc/certification/cert/certs/advprac/palliative.html>
- Beaver, K., Luker, K.A., Owens, R.G., Leinster, S.J., Degner, L.F., & Sloan, J.A. (1996). Treatment decision making in women newly diagnosed with breast cancer. *Cancer Nursing*, 19, 8-19.
- Brandt, B. (1991). Informational needs and selected variables in patients receiving brachytherapy. *Oncology Nursing Forum*, 18, 1221-1227.
- Chochinov, H.M., Hack, T., Hassard, T., Kristjanson, L.J., McClement, S., & Harlos, M. (2002). Dignity in the terminally ill: A cross-sectional, cohort study. *Lancet*, 360, 2026-2030.
- Davison, B.J., Degner, L.F., & Morgan, T.R. (1995). Information and deci-

- sion-making preferences of men with prostate cancer. *Oncology Nursing Forum*, 22, 1401–1408.
- Degner, L.F., Kristjanson, L.J., Bowman, D., Sloan, J.A., Carriere, K.C., O'Neil, J., et al. (1997). Information needs and decisional preferences in women with breast cancer. *JAMA*, 277, 1485–1492.
- Degner, L.F., & Russell, C.A. (1988). Preferences for treatment control among adults with cancer. *Research in Nursing and Health*, 11, 367–374.
- Degner, L.F., & Sloan, J.A. (1992). Decision making during serious illness: What role do patients really want to play? *Journal of Clinical Epidemiology*, 45, 941–950.
- Denzin, N. (1989). *Interpretive interactionism*. Newbury Park, CA: Sage.
- Emanuel, E.J., & Emanuel, L.L. (1998). The promise of a good death. *Lancet*, 351(Suppl. 2), S1121–S1129.
- Emmett, J., Byock, I., & Twohig, J. (2002). *Advanced practice nursing: Pioneering practices in palliative care*. Missoula, MT: Promoting Excellence in End-of-Life Care.
- Field, M.J., & Cassel, C.K. (Eds.). (1997). *Approaching death: Improving care at the end of life*. Washington, DC: National Academy Press.
- Foley, K.M., & Gelband, H. (Eds.). (2001). *Improving palliative care for cancer*. Washington, DC: National Academy Press.
- Friedman, B.T., Harwood, M.K., & Shields, M. (2002). Barriers and enablers to hospice referrals: An expert overview. *Journal of Palliative Medicine*, 5, 73–84.
- Goldstein, N.E., & Lynn, J. (2002). The 107th Congress' legislative proposals concerning end-of-life care. *Journal of Palliative Medicine*, 5, 819–827.
- Hack, T.F., Degner, L.F., & Dyck, D.G. (1994). Relationship between preferences for decisional control and illness information among women with breast cancer: A quantitative and qualitative analysis. *Social Science and Medicine*, 39, 279–289.
- Hopkinson, J., & Hallett, C. (2002). Good death? An exploration of newly qualified nurses' understanding of good death. *International Journal of Palliative Nursing*, 8, 532–539.
- Jennings, B., Ryndes, T., D'Onofrio, C., & Baily, M. (2003). Access to hospice care. Expanding boundaries, overcoming barriers. *Hastings Center Report*, 33(Suppl.), S3–S7, S9–S13, S15–S21.
- Johnson, M., Maas, M., & Moorhead, S. (2000). *Nursing outcomes classification (NOC)* (2nd ed.). St. Louis, MO: Mosby.
- Kuebler, K. (2003). Article about palliative care omitted important information [Letter to the editor]. *Oncology Nursing Forum*, 30, 551.
- Kuebler, K., & Moore, C. (Eds.). (2002). The Michigan palliative advanced practice nurse training manual. Retrieved January 7, 2004, from http://www.minurses.org/apn/Palliative%20Care%201_03/PC_Intro.pdf
- Kuebler, K.K., Berry, P.H., & Heidrich, D.E. (Eds.). (2002). *End-of-life care: Clinical practice guidelines for nurses*. Philadelphia: W.B. Saunders.
- Lehna, C. (2002). A needs assessment for an end-of-life care curriculum for advanced practice nursing students. *Internet Journal of Advanced Nursing Practice*, 5(2). Retrieved January 7, 2004, from <http://search.epnet.com/direct.asp?an=9861432&db=aph&tg=AN>
- Leman, R. (2004, March 10). Sixth annual report on Oregon's Death With Dignity Act. Retrieved July 23, 2004, from <http://www.ohd.hr.state.or.us/chs/pas/ar-index.cfm>
- Lewis, F.M. (1982). Experienced personal control and quality of life in late-stage cancer patients. *Nursing Research*, 31, 113–119.
- Lewis, F.M. (1987). The concept of control: A typology and health-related variables. *Advances in Health Education and Promotion*, 2, 277–309.
- Lewis, F.M. (1989). Attributions of control, experienced meaning, and psychosocial well-being in patients with advanced cancer. *Journal of Psychosocial Oncology*, 7, 105–119.
- Lewis, F.M., Haberman, M.R., & Wallhagen, M.I. (1986). How adults with late-stage cancer experience personal control. *Journal of Psychosocial Oncology*, 4, 27–41.
- Lynn, J., & Adamson, D.M. (2003). Living well at the end of life: Adapting health care to serious chronic illness in old age. Retrieved January 7, 2004, from <http://www.rand.org/publications/WP/WP137/WP137.pdf>
- McCorkle, R., Robinson, L., Nuamah, I., Lev, E., & Benoliel, J.Q. (1998). The effects of home nursing care for patients during terminal illness on the bereaved's psychological distress. *Nursing Research*, 47, 2–10.
- McCorkle, R., Strumpf, N.E., Nuamah, I.F., Adler, D.C., Cooley, M.E., Jepson, C., et al. (2000). A specialized home care intervention improves survival among older post-surgical cancer patients. *Journal of the American Geriatrics Society*, 48, 1707–1713.
- Oncology Nursing Certification Corporation. (2004). *2004 ONCC certification bulletin*. Retrieved July 23, 2004, from http://www.oncc.org/?v2_group=0&g=1340&p=34592
- Oncology Nursing Society. (2003a). The role of the advanced practice nurse in oncology care. *Oncology Nursing Forum*, 30, 549–550.
- Oncology Nursing Society. (2003b). *Statement on the scope and standards of advanced practice in oncology nursing* (3rd ed.). Pittsburgh, PA: Author.
- Quill, T.E. (2000). Perspectives on care at the close of life. Initiating end-of-life discussions with seriously ill patients: Addressing the “elephant in the room.” *JAMA*, 284, 2502–2507.
- Rankin, M.A., Donahue, M.P., Davis, K., Katseres, J.K., Wedig, J.A., Johnson, M., et al. (1998). Dignified dying as a nursing outcome. *Outcomes Management for Nursing Practice*, 2, 105–110.
- Ritz, L.J., Nissen, M.J., Swenson, K.K., Farrell, J.B., Sperduto, P.W., Sladek, M.L., et al. (2000). Effects of advanced nursing care on quality of life and cost outcomes of women diagnosed with breast cancer. *Oncology Nursing Forum*, 27, 923–932.
- Steinhauser, K.E., Clipp, E.C., McNeilly, M., Christakis, N.A., McIntyre, L.M., & Tulsky, J.A. (2000). In search of a good death: Observations of patients, families, and providers. *Annals of Internal Medicine*, 132, 825–832.
- Street, A.F., & Kissane, D.W. (2001). Constructions of dignity in end-of-life care. *Journal of Palliative Care*, 17(2), 93–101.
- Volker, D.L. (2001). Oncology nurses' experiences with requests for assisted dying from terminally ill patients with cancer. *Oncology Nursing Forum*, 28, 39–49.
- Weintraub, F.N., & Hagopian, G.A. (1990). The effect of nursing consultation on anxiety, side effects, and self-care of patients receiving radiation therapy. *Oncology Nursing Forum*, 17(Suppl. 3), 31–36.
- White, N.J., Given, B.A., & Devoss, D.N. (1996). The advanced practice nurse: Meeting the information needs of the rural cancer patient. *Journal of Cancer Education*, 11, 203–209.