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Patient Control and End-of-Life Care Part II: The Patient Perspective

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Purpose/Objectives: To explore the nature of what people with advanced cancer want regarding personal control and comfort at the end of life.

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

Setting: A variety of urban and rural communities throughout the state of Texas.

Participants: 7 people with advanced cancer diagnoses.

Methodologic Approach: Participants were recruited via oncology advanced practice nurses who also participated in the study. Interviews were recorded on audiotape and analyzed via Denzin's interpretive process of data analysis.

Main Research Variables: Patient control.

Findings: Thematic analysis revealed six themes: protection of dignity, control of pain and other symptoms associated with disease, management of treatment, management of how remaining time is spent, management of impact on family, and control over the dying process.

Conclusions: Participants expressed a wide variety of preferences for personal control and comfort. Their desires reflected personal values and beliefs about how they spend their time and how they want control over their care.

Interpretation: Nurses must be sensitive to the variety of preferences their patients with advanced cancer may have for engagement in decisions regarding treatment, care management, and activities of daily life.

Key Points . . .

- In this study, people with an advanced cancer diagnosis expressed a wide variety of preferences for personal control and comfort in the context of end-of-life care.
- For people with advanced cancer who are nearing the end of life, active engagement in the business of life and living while desiring treatment to modify disease may not be unusual.
- Organizations such as the Oncology Nursing Society can play a key role in national systems and policy changes that better support the needs of individuals with advanced cancer diagnoses.

Western bioethical tradition focuses on the importance of individual autonomy and choice over healthcare decisions. Indeed, healthcare practitioners expend considerable energy instructing, coaxing, and cajoling patients to take control of their own health. Messages to control weight, blood pressure, medication regimens, diabetes, and other conditions permeate society, ranging from individualized patient teaching episodes to mass media marketing strategies. Yet some practitioners voice surprise and dismay when people with life-limiting illness express a desire to control the timing and circumstances of the end-of-life experience.

As introduced in part I of this article (see pp. 945–953), the concept of control over end-of-life care has not been well explored. Steinhauser et al. (2000) studied factors considered important at the end of life by surveying 340 seriously ill patients under the care of the Veterans Administration system. The authors used a 44-item survey tool designed to capture attributes of experience at the end of life. Although none of the attributes explicitly included the word "control," items addressed issues such as freedom from distressing symptoms, being kept clean, and naming a decision maker. Because the study used a survey tool with forced-choice attributes, respondents did not have the opportunity to register other concerns that may have related to control over the dying process. Teno, Casey, Welch, and Edgman-Levitan (2001) sought to develop domains of care that define quality end-of-life care by reviewing published professional care guidelines and conducting focus groups with family members who recently had lost loved ones. Of the five domains identified by focus group members, one included the idea of control and was described as helping dying people to control decisions about treatment and daily routines. Although bereaved family members represent an important voice, validation studies of these care domains with patients are warranted.

Studies of older patients' preferences for end-of-life care also are emerging. Vig, Davenport, and Pearlman (2002) explored attitudes about and preferences for end-of-life care by interviewing moderately healthy older patients. Attributes associated with a good death included dying quickly in the person's sleep without suffering or prior knowledge of impending death. Had the participants been facing terminal diagnoses, study findings may have differed. Fried and Bradley

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(2003) also interviewed older patients but focused on end-of-life treatment preferences. Their sample consisted of individuals who had diagnoses of congestive heart failure, chronic obstructive pulmonary disease, or cancer and a life expectancy of less than one year. Patient preferences for treatment varied widely according to the perceived burden of treatment versus the likelihood of benefit and the shifting valuation of health status as their health declined. That is, once some patients experienced a health state that they previously had considered undesirable, they became more accepting of that decline in health. This study implicitly assumed that patients want to control treatment decisions throughout the continuum of disease. The researchers did not address the possibility that patients might have preferences for forms of control other than decisions about burdensome treatment.

In a study of dignity in the terminally ill, Chochinov, Hack, McClement, Kristjanson, and Harlos (2002) interviewed 50 hospitalized people with advanced terminal cancer from one setting to develop a model of dignity in the terminally ill. They queried participants regarding their understanding of the concept of dignity and their experiences with support for and undermining of personal dignity. The investigators developed a model that suggests interactions among illness-related concerns, dignity-conserving perspectives and practices, and social and relationship concerns that subsequently have impact on one's sense of dignity. Future research to test this model via interventions that promote dignity is anticipated.

In a phenomenologic study of the meaning of dignity, Enes (2003) interviewed eight patients with cancer, six relatives, and seven healthcare professionals in a British inpatient hospice unit. A sense of control was identified as an important theme. Control of bodily functions, body image, emotions, and personal space was indicative of dignity. Enes observed that attributes of a person's sense of dignity may vary depending on the individual's needs and experiences. Although the study revealed information about control as a feature of dignity, the setting (hospice) may have influenced the nature of the participants' responses. A sense of dignity and desire for control may take on other dimensions in people who are not close to death or for those who decide not to enroll in a hospice for care at the end of life.

The choice of where a person prefers to die is another possible manifestation of control in end-of-life care. Tang (2003) interviewed 180 terminally ill patients with cancer and found that almost 90% preferred to die at home. Of note, most of the patients lived with another person, which may have influenced their sense of the feasibility of a home death. As in the Fried and Bradley (2003) study, the assumption that terminally ill people want control over end-of-life decisions was foundational to the study.

Other nonresearch literature reflects a continuing dialogue about what constitutes a good death and how to best achieve this goal. For example, Ackerman (1997) provided a critical analysis of hospice ideology and posited an interesting argument as to why people may not choose to follow an end-of-life experience consistent with hospice philosophy. McNeil (1998) questioned the relevance of control over place of death and suggested that, in certain circumstances, dying in a hospital setting may be a far better alternative to dying at home. Indeed, she observed, "It matters less where we die than how we die" (p. 6). Dunn and Milch (2002) described challenges that surgeons face in identifying their role in provision of palliative care, ascertaining and communicating accurate prognoses in advanced disease, and providing nonsurgical comfort measures. Together, these articles represent professional and philosophical opinions, but not the patient's voice.

Although a social consensus seems to exist that people desire end-of-life care that is compatible with personal values and needs, the concept of desire for control in this context warrants further investigation. To avoid prompting or suggesting specific types of control, an open-ended interview technique was used in the current study. Rather than suggest to participants that control over a particular aspect of life or care is important, an open-ended interview technique was used to elicit preferences and ideas that did not inject interviewer preconceptions or biases.

Part I of this article contains a discussion of the study purpose, conceptual framework, and background literature. Data from oncology advanced practice nurse (APN) interviews are presented in part I. The focus of part II is to present results from interviews with people with advanced cancer. The results described here focus on the patient perspective regarding study aim 2, to explore understanding of preferences for control of adult patients with cancer in the context of end-of-life care.

Methods

As described in part I, the study method and data analysis were guided by Denzin's (1989) model of interpretive interactionism. The study was reviewed and approved by an institutional review board. APNs who participated in the study were asked to assist with patient participant recruitment by identifying one community-residing person with advanced cancer who might be interested in the project. Assistance with recruitment was voluntary; some of the APN participants recruited one or more potential patient participants, whereas others did not locate potential participants in the study time frame. The principal investigator (PI) instructed the APNs regarding patient recruitment at the time of the APN interview.

Patient inclusion criteria included being at least 21 years of age, being alert and oriented, being able to communicate in English, being willing to participate in a one-hour interview with the study investigator, and having a diagnosis of advanced cancer. A person with advanced cancer was defined as no longer receiving curative treatment but perhaps receiving other forms of noncurative treatment for control, comfort, or supportive care. Examples of noncurative treatment include pain medication, antiemetics, chemotherapy, radiation therapy, hormone therapy, biologic agents, and complementary therapies. No limit or boundary was placed on life expectancy to meet the definition of advanced cancer.

The PI asked each APN to ascertain a patient's eligibility per the inclusion criteria, briefly explain the purpose of the study to the patient, and ask the patient if he or she might be interested in learning more about the study. The PI cautioned the APNs to approach only patients who knew their prognoses, understood that they no longer were receiving treatment intended to cure their cancer, and might (in the APN's assessment) be interest in talking with the PI about preferences in end-of-life care. If so, the APN mailed (or gave) the patient an information packet provided by the PI. Patients who

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received a study packet then had the option to review the recruitment letter in the privacy of their own homes and decide whether to contact the PI for more information. Patients who decided to participate mailed a reply form to the PI, who then contacted the patient, explained the study, and arranged to interview the patient in his or her hometown at a location of his or her choice. Patient consent was obtained in person prior to beginning the interview. Interview questions and samples of probes are described in Figure 1. Each patient received $50 as a thank you for participating in the study. Recruitment of APNs and patients ended once data analysis revealed redundancy in interview content.

Results

Seven community-dwelling adults with advanced cancer diagnoses from throughout Texas were interviewed for the study. Their mean age was 59 years, with a range of 46–76 years. Six participants were Caucasian; one was Hispanic. Six participants were female. All participants reported that they had metastatic disease. Primary cancer diagnoses included breast (three), ovarian (one), prostate (one), vaginal (one), and colon (one). Three participants had a high school education or less, two had a college education, and two had advanced degrees. Each described their religious affiliation differently, including nonsecular, Methodist, Christian, Catholic, Baptist, nondenominational, and spiritual. None of the participants was working at the time of the interview; employment status included retired, disabled, or between jobs.

A thematic analysis of the interview data revealed six themes: protection of dignity, control of pain and other symptoms associated with disease, management of treatment, management of how remaining time is spent, management of impact on family, and control over the dying process. Figure 2 contains a summary of the themes and their descriptions.

Protection of Dignity

Participants spoke of the desire to have their personal dignity protected and respected. They expressed concern about losing control over bodily functions, the ability to care for themselves, and personal privacy. Manifestations of a sense of personal dignity often were couched as losses were incurred as disease progressed. One woman described a recent hospitalization to illustrate her concern about maintaining control over her dignity.

1. Tell me about how you came to meet (insert name of the referring advanced practice nurse), the nurse who referred you to this study.
2. How would you describe your health and your daily life right now?
3. Some people who have a cancer diagnosis think about the way they want the final months of their lives to go. Do you ever think about that? If you do, what would be most important for you during those months?
4. Potential probes
   a. Is there anything in particular that you would want to have control over during that time?
   b. What would be important to you in terms of your personal comfort during that time?
   c. What would not be important for you to have control over during that time?

Figure 1. Interview Guide

- **Protection of dignity:** the desire to have personal dignity protected and respected
- **Control of pain and other symptoms associated with disease:** concern about past and present experiences with physical discomfort. Some expressed worry or an assumption that pain and symptoms would not be well controlled as disease progressed.
- **Management of treatment:** desire to be involved actively in decisions regarding cancer treatments
- **Management of how remaining time is spent:** reflections regarding changing priorities on control over time
- **Management of impact on family:** actions to prepare family for both financial and emotional consequences
- **Control over the dying process:** concerns about the process of how death will occur

Figure 2. Thematic Descriptions

> When I'm in the hospital, I don't like to have tubes in me and I don't like people coming in and seeing those things in me. I want them hidden because it's very uncomfortable for everyone. The last time I was in the hospital, I had a visitor with me. And it wasn't a family member. The nurse came in to check my [urinary] catheter to see how much it drained and to empty it. It just caught me so off guard. I didn't appreciate that, because it's like sharing my urine with other people.

Another woman who had lower extremity weakness secondary to spinal metastasis shared that her loss of physical mobility and ability to care for herself was indicative of losing dignity. At the time of her interview, she had a number of large bruises and scrapes on her arms and face that she attributed to a fall on her front sidewalk the previous evening.

> As far as dignity's concerned, it's just like last night [after falling and requiring paramedic intervention]. My dignity was hurt more than the bruises I've got. My pride and everything was gone at that point. It's been hard having to stay with my son. That's a great break in the independent thing. When I moved down here, my son said, "I never ever expected to have a wheelchair in my front room." I just can't accept the fact that I cannot work anymore and have to live with him because I can't afford to live on my own because I can't afford the help.

This participant also described dignity as having the opportunity for privacy.

> Everybody needs their space. Even though you need to be compassionate, still respect their space. When I'm really in pain, just totally a mess, let me have my space. I don't know about other people, but that's one thing about me. When I'm really, really bad, I just want to be left alone.

Control of Pain and Other Symptoms Associated With Disease

Participants described past and present experiences with physical discomfort. Some expressed worry or an assumption that pain and symptoms would not be well controlled as the disease progressed. One woman described her initial hospitalization for a mastectomy and the reluctance of some nurses to administer prescribed pain medication. She worried that this experience would recur as she approached the end of life.

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> If I need something for pain, I want somebody there and they don't argue and tell me I don't need it. I want to be comfortable. I mean, if I'm dying, I should have all the pain medication I want. Who cares if you get addicted? I can tolerate a lot of pain, but when it's hurting—I mean, why should I hurt?

Another participant also expressed concern about maintaining control over his physical comfort and mental clarity. "You've got to have that pain under control. Cause if you don't got that pain under control, man, you're not going to think well." Some participants described experiences with losing friends to cancer and the nature of their dying days.

> I'm not afraid of death; I'm afraid of dying. The pain and disorientation, struggling for breath or whatever the case may be. I've had friends die in different ways. One died of lung problems and couldn't breathe. The other one just had excruciating pain, and it was horrible pain.

She then juxtaposed these examples with a third friend who was "happy, just smiling and talking" during her final days. The nature of this patient's desire for control clearly was influenced by her previous experiences with terminally ill friends.

Management of Treatment

Participants described active engagement with treatment decisions and the desire to control the disease and its sequelae for as long as possible to be able to live as fully as possible. In this context, some of the participants used phrases such as "I'm not dead yet," "God's not done with me yet," and "I want to live as long as I can." Other participants described their decisions to stop or decline treatments as a way of exerting control over their lives. A person with metastatic colon cancer explained her decision to control her quality of life by surgically reversing her ileostomy.

> I lived with an ileostomy for over a year. And I was so determined that I was not going to live any longer with one that I wanted it reversed. [The surgeon] advised me what might happen, but I wanted it reversed anyway. Now I really regret the decision. At least when I had the ileostomy I could go out to eat or shop. Now it's really difficult to leave the house for any length of time.

She then described a recent discussion with her hospice nurse regarding her desire to have further surgery to reopen the ileostomy. She subsequently had the surgery prior to her death.

Another person described her metastatic ovarian cancer as controllable.

> I'm terminal. But my physical health is excellent. If someone were to say to me, "You've got to choose what kind of cancer you want," I would say, "Just give me what I've got." Because it's in the lungs and it's controllable.

She then explained her approach to maintaining control over her treatment and the importance of being vigilant about chemotherapy administration and her blood counts. She described an episode when a nurse mistakenly tried to administer a dose of pegfilgrastim (Neulasta®, Amgen Inc., Thousand Oaks, CA) to her.

> I said, "No, you can't give Neulasta on the same day as Gemzar® [gemcitabine hydrochloride, Lilly Oncology, Indianapolis, IN]; I'm going to have to come back tomorrow." And so the next morning, I called another nurse, and she said, "No, absolutely not; we don't give Neulasta with Gemzar." This can be quite scary. Because you take a healthy patient like me and kill 'em. It really makes me mad. I'm really considered what I think is a pretty difficult patient because I'm so on top of what has to be done to me.

Management of How Remaining Time Is Spent

Many participants reflected on changing how they controlled their time left to live. Priorities shifted once they were aware that they had developed metastatic disease. Many participants observed that they now spent more time with family.

> What I value now, of course, is my kids. When someone announces they're dying, when it becomes evident to family and friends, then the entire perception of these relationships changes. My kids and I always had a tremendous relationship, but we didn't necessarily block out time that we'd be together. So what I value, and I have to say thanks to the cancer for this, is that we set aside time [to be together].

Another participant was making travel plans to see family and friends.

> I'm actually going home to my mom's and stay for a week, which I've not done in six years. I'm looking at it as an end-of-life issue. I figure it could get really worse a month from now, or three months from now, so I want to go while I'm feeling good. I want to see people and friends.

Other participants spoke of shifting their focus to spending time helping other people. "I would like to think that the next 12 months that I could just be totally dedicated to helping other people that are going through this. Because whenever I'm doing that, I don't think about myself." This participant described how she had learned to use the Internet to find information about her disease and treatment and used those skills to help other patients.

> A lot of people now, when they want to know something or they need something researched, they come to me, and it makes me feel so good. Like this morning, someone asked me, "How do I know if my doctor is legitimate?" The medical association has a Web site where you can put in your doctor's name, and it comes up and tells you their degrees and where they went to school.

Management of Impact on Family

All participants voiced concern about the impact of their advanced disease and death on family. They described actions they were taking to prepare family for the emotional and financial consequences of death.

> I'm trying to get my children to be as familiar as possible with my property investments at this time. But this is a goal I've been working on right now, is to get a folio of data on each of my properties. So they can simply open the red book and go to the particular property in question and every little thing will be there.

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Many expressed concern about not wanting to be a burden on family.

> I'm trying to get my photographs catalogued. I haven't started with my papers, but I'm trying. I feel like if I don't survive this, my children are going to have to go through all this. And I don't want to leave that for them. I don't want to burden them.

Others described frank family discussions regarding advance directives, designation of medical power of attorney, and dissemination of personal property.

> Both my [adult] daughter and I have talked about my illness in detail. I've talked to her about me dying. We've both talked about how uncomfortable that is, but . . . I've talked about the things she wants, that I know are important to her.

Control Over the Dying Process

Concerns regarding control over the dying process included timing and place of death, yielding control over personal affairs to family members, and dealing with the uncertainty of how death would occur. One woman described an episode in which she came close to death and her daughter's response.

> My older daughter, in a loving way, wanted to take away things like paying bills for me. And she was doing it out of love and trying to help me, but it made me feel out of control. Like I didn't have any say in my life anymore. Don't take that away from me yet. I can still do that. I can't drive, I can't walk around the block, but I can do my bills.

One participant introduced the legal permissibility of assisted suicide in Oregon and was adamant that he never would consider controlling his time of death in that fashion.

> Like in Oregon, there's a law. You can go to the doctor and tell them you want this shot. And they'll give you a shot, and you just pass away. You just fall asleep. But as far as ending your life, any coward, anybody can do that. That ain't nothing. But what does it show of an individual? I'm not going out that way. Even if I would have to go [die] in pain, I would rather go in pain than do that.

Although the participant misunderstood the nature of legal assisted suicide in Oregon, he was clear about his opposition to deliberately ending his life.

Yet another participant worried about the uncertainty of how and when her death would occur.

> I wonder about the time of death, where am I going to be or am I going to be in a place where I feel comfortable with it? Or is it going to be scary? I think the scariest thing is that I've never actually been with anyone at the moment of death. I've never seen anyone die. It's a real unknown for me what it'll be like. I like to know—that's part of me. I like to do research, and I like to get answers, and I like to know what's going on. I like to know the facts. I do not like surprises.

Other participants described their thoughts about control over where they would spend their dying days. The woman who chose to have her ileostomy reversed described her decision to leave the hospital, refuse placement in a long-term care facility, and return to her home in a nearby town.

> I told the doctors that I didn't want to go to a long-term care facility because there I have no control over what happens. I'm laying there in bed and I can't do anything. I can't go anywhere. I can't see people I know very often. If I've got a couple of months to live, I don't want to live it that way. And so consequently, I came home.

Conversely, another woman who had lost a number of friends to cancer decided that she would prefer to die in the hospital.

> I pretty much decided I want to die in the hospital. I know that sounds crazy because a lot of people want to die at home. One of my friends died in the hospital; the other two died at their homes. It was so much easier on the family, I think, when my friend died in the hospital. When [people] die at home, the medical examiner has to come and say they're dead, and then the funeral home has to come. I just think that's a lot for a family to deal with. Especially when you've just died. I don't mind dying in the hospital. It's not the place so much. I would like to have the people who I love and who love me there.

Discussion and Implications

The participants in this study expressed a wide variety of preferences for control in their daily lives and in the context of end-of-life considerations. A desire for control over dignity manifested as a concern about control over bodily functions, the ability to care for self, and respect for personal privacy. The APN study data parallel this finding (see pp. 945–953). APNs described their patients as desiring comfort in the end-of-life experience that is respectful of a sense of dignity. This observation is similar to other studies of end-of-life care. In Enes's (2003) study, participants indicated that a sense of dignity included control of bodily functions, body image, emotions, and personal space. In Chochinov et al.'s (2002) proposed model of dignity in the terminally ill, functional independence and maintenance of privacy boundaries are core aspects of dignity. In the practice setting, interventions that promote a sense of personal dignity vary depending on a patient's functional status, values and cultural norms, and environment of care. Certainly, simple strategies such as protecting physical privacy during caregiving (e.g., when emptying a catheter drainage device) should be the norm in any circumstance. But care providers may be challenged to protect patient dignity when a patient's personal circumstances no longer are compatible with a sense of dignity. For example, the study participant who found moving in with her son difficult may benefit from exploring other ways to promote her privacy and independence in her son's home. Future studies of the nature of personal dignity and interventions to enhance dignity in end-of-life care are warranted.

Not surprisingly, all of the study participants expressed a desire to maintain control over physical comfort. Similar to Steinhauser et al.'s (2000) study findings, participants in the current study wanted to have pain and other distressing symptoms controlled. Of note, some of the participants referenced previous experience as the context for worries about unrelieved symptoms. Nurses who care for people with advanced cancer should be sensitive to the potential impact of previous experience on patients' concerns about the quality of the end-of-life experience. Poorly managed symptoms in previous

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episodes of illness may influence patients' sense of how the dying process will unfold. Also, people with advanced cancer may have lived with the disease for many years and formed extensive support networks with other people in similar circumstances. As patients experience their friends' deaths, they encounter positive and negative occurrences that may influence their own wishes for end-of-life care. To understand this influence, nurses should ask their patients about previous experiences with losing friends or family members and what concerns those experiences may raise for their own end-of-life experiences.

Study participants were engaged actively in treatment decisions related to entering clinical trials, continuing or discontinuing chemotherapy, opting for palliative surgery, and the like. However, unlike the Fried and Bradley (2003) study findings, only one participant (the woman who had her ileostomy reversed) described a decision-making process that included consideration of perceived burden and potential outcome. This likely reflected the open-ended nature of the current study's interview questions. That is, participants were not asked to focus on explaining treatment decisions. Instead, most described ways in which they maintained control over treatment-related decisions.

The APN viewpoint of patient involvement in treatment decisions presented in part I was somewhat similar. They described patients who were engaged actively in their professional and personal role functions while managing their ongoing treatment decisions. Nurses must be sensitive to the fact that some patients desire to continue treatment for cancer despite the reality that life soon may be ending. Some patients prefer to actively fight the disease as part of their control in their end-of-life experiences. As one participant observed, "I'm going to try to be here as long as I possibly can. That's why I'm doing the chemo. They told me it would not cure me, but we're hoping it will shrink it enough to get it to release the pain that I'm in."

For people with advanced cancer who are nearing the end of life, active engagement in the business of life and living while desiring treatment to modify disease may not be unusual. Yet the current healthcare system in the United States does not provide optimal support for this paradigm. Lynn (2001) observed that

> Institutions such as hospice, developed for those who are dying, assume that the dying persons take to their beds, reflect on life's meaning, and proceed to die "on time." A dying person is not expected to run a business, make long-term investments, or do something frivolous, even when these activities are otherwise quite appropriate and satisfying (p. 928).

Lynn's (2001) observation does not preclude the necessity of hospice-type services nor the important contributions of hospice professionals. Rather, she highlighted the gap in U.S. healthcare policy that does not adequately address the clinical needs and values of individuals who desire active treatment for disease, support for family caregivers, and expert palliative care. Lynn and Adamson (2003) have proposed a revised care system for people with cancer that provides for advance care planning into early treatment, palliation and rehabilitation throughout the course of illness, certain more aggressive treatments late in illness, transitional care services across settings, and family support throughout the disease trajectory. Organizations such as the Oncology Nursing Society can play a key role in supporting such national systems and policy changes that will better support the needs of individuals who live with advanced cancer diagnoses.

All of the study participants described their concerns about the impact of their advanced disease and death on their family members. Many described specific actions they were taking to prepare family members. This process of preparing family is consistent with the APN theme of turning the corner in part I. As patients struggle to prepare their loved ones for taking on new responsibilities after their death, nurses can serve as mediators and facilitators of this process. Nurses should ask which family members or loved ones patients want to know about their prognosis, offer assistance in sharing that information if patients desire this support, and suggest ways that patients can help their loved ones adapt to new duties in this context. Readers are referred to information on assisting patients with confronting the reality of approaching death and conducting family meetings as outlined in the *Michigan Palliative Advanced Practice Nurse Training Manual* (Moore, 2002).

The theme of control over the dying process reflected concerns that people had about how the dying days would unfold. Many voiced concern about the uncertainty associated with the how and when of death. Although none of the participants expressed a desire to take control of the timing of death, many expressed the hope for a quick and relatively comfortable end. Concerns about lingering and suffering were common. Acknowledgement of the uncertainty associated with the end of life is critical. Patients and their families may benefit from support groups, literature on the end of life and hospice care, and other strategies that can begin to normalize a very foreign experience.

Although not prompted to discuss desire for where they would choose to die, many of the participants shared that they preferred to die at home if possible. This desire is consistent with Tang's (2003) finding that most terminally ill people with cancer desire to die at home. However, the participant in the current study who expressed a preference to die at the hospital raised an important issue for nurses to consider. This participant's preference was influenced by her experience with other friends' deaths and her concern for her family. Although many people prefer to die at home, nurses must be careful not to impose this value on patients or families who are more comfortable in the healthcare setting (McNeil, 1998). Careful assessment of personal preferences and the complexity of care needs should drive the discussion about possible settings for end-of-life care. As presented in part I, nurses must be prepared to facilitate last-minute changes in care settings because patient condition or preferences may change in the final days.

An underlying assumption of this study was that people with advanced cancer may desire to control aspects of their end-of-life experiences. However, this raises the question of whether desire for control in this context is beneficial or detrimental, a question that should be investigated. Control is a core element of psychological functioning. Some investigators suggest that the drive for control is adaptive and serves as the motivation for human behavior (Geary, 1998; Heckhausen & Schulz, 1995; Thompson, 2002). Individual differences in perceived control are linked to numerous positive outcomes, including health and physiologic outcomes,

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personal achievement, optimism, persistence, motivation, coping, self-esteem, well-being, and personal adjustment (Skinner, 1996; Thompson & Spacapan, 1991). Conversely, under some circumstances, a strong sense of control can be associated with negative impacts on pain, distress, and adjustment to illness (Paterson, 2001). Because control perceptions also may be influenced by culture and ethnicity, future studies of desire for control should include ethnically diverse groups. If promotion of a sense of control is indeed a helpful strategy for some people who face terminal illness, interventions that promote a sense of control in those who seek it must be developed and tested.

Limitations

The participants in this study were referred by APNs. As such, selection of patients could reflect APN bias regarding personal values associated with the concept of control at the end of life. No information was collected on potential participants who may have declined the APNs' invitation to participate in the study. The demographic makeup of the participants is another study limitation. This predominantly female, Caucasian group of participants from Texas may have reflected unique opinions reflective of gender, culture, and geographic location. Future studies should include a larger number of more ethnically diverse individuals. Additionally, the focus of this study was on people with advanced cancer. The desire for control may manifest differently in other patient populations.

Conclusion

Caregivers must be sensitive to the many ways that people with advanced cancer seek to gain control in the context of the end of life. Insights shared by both the APN and patient participants in this two-part study revealed a variety of concerns that can inform future educational, clinical, and research endeavors. This study represents another step in understanding the nature of an essential outcome for patients—that of achieving dignified end-of-life experiences that are compatible with personal values, preferences, and beliefs.

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