

# Patient Control and End-of-Life Care

## Part I: The Advanced Practice Nurse Perspective

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**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.

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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-