

Patient Control and End-of-Life Care

Part II: The Patient Perspective

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

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.

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

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.

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

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.) (Mention of specific products and opinions related to those products do not indicate or imply endorsement by the Oncology Nursing Forum or the Oncology Nursing Society.)

Digital Object Identifier: 10.1188/04.ONF.954-960