Western bioethical tradition focuses on the importance of individual autonomy and choice over healthcare decisions. Indeed, healthcare practitioners expend considerable energy instructing, coaching, 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

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.