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Am J Hosp Palliat Care 2005; 22; 442

DOI: 10.1177/104990910502200610

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Control and end-of-life care: Does ethnicity matter?

Deborah L. Volker, RN, PhD

Abstract

Patient control and autonomy are core values in Western bioethics and important components of end-of-life (EOL) care. However, the centrality of the patient as decision maker may not be relevant to culturally diverse groups of people. The purpose of this article is to present results of a literature review of patient control and ethnicity within the context of EOL care. The review revealed that the interplay between control and ethnicity in EOL care is complex and unpredictable. Implications for clinical care and future research are presented.

Key words: control, ethnicity, autonomy, culture, end-of-life care

Introduction

Patient autonomy and choice over healthcare decisions are cornerstones of end-of-life (EOL) care. The Patient Self-Determination Act,¹ the SUPPORT study,² advance-directive initiatives,³⁻⁷ and many other strategies have been put forth as ways to promote patient control within the context of life-limiting illness. These strategies are based on the underlying premise that people do indeed want control, and that the right to self-determination is a shared value between

patients, family members, and healthcare providers. Respect for autonomy can be viewed as a universal principle that is, according to Craig Calhoun, “valid under most circumstances for most people most of the time” (p. 38).⁸

However, the concepts of autonomy and self-determination have been interpreted as justification for mandating a patient’s duty to engage in medical decision making.⁹ Critics of this approach question the relevance of such a mandate for patients and families who do not agree with the centrality of the patient as medical decision maker or the necessity of telling the patient information he may not want to hear.^{10,11} The concept of personal control is important in Western societies, in which independence and individualism are dominant core values. Yet, asserting control over one’s future may have questionable relevance to non-Western patient groups.¹² Ethnic and cultural differences among individuals may result in varying preferences for control over EOL care. Hence, the purpose of this review is to examine how the concepts of patient control and ethnicity may influence EOL care decisions.

Is pursuit of control desirable?

Control is a key component of psychological health. A wide variety of conceptual paradigms have been proposed

to explain the relationship between a sense of control and physical and mental well-being, including theories of locus of control,^{13,14} self-efficacy,¹⁵ learned helplessness,¹⁶ causal attributions,¹⁷ social learning,¹⁸ cognitive adaptation,¹⁹ coherence,²⁰ and numerous others. A perception of personal control over our lives has been linked to positive attributes including health, achievement, optimism, persistence, motivation, coping, self-esteem, emotional well-being, personal adjustment, and decreased stress and depression.²¹⁻²⁵ For example, Dracup and colleagues²⁶ studied the effect of perceived control in patients with heart failure. They concluded that perceived control reduced emotional distress in their study group of predominantly white men. Similarly, in a study of older women with osteoarthritis, a sense of personal control was positively associated with life satisfaction.²⁷ Of note, 85 percent of the 107 study participants were white.

However, other studies have found a strong sense of control to correlate with poor health outcomes.²⁵ A sense of control may be maladaptive for individuals who face a disease process whose outcome is beyond their control; that is, a sense of personal failure or helplessness may occur at the realization that one has a severe chronic condition or is dying. Taylor and colleagues²⁸ studied

Deborah L. Volker, RN, PhD, The University of Texas School of Nursing, Austin, Texas.

the adaptiveness of self-generated feeling of control in 127 adults with severe heart disease, AIDS, or cancer. They concluded that a sense of control was negatively correlated with depression and anxiety in people with good prognoses. However, people with poor prognoses or advanced disease did not benefit psychologically from perceptions that they or others could control aspects of the disease. Of note, the participants with cardiac disease and AIDS were predominantly white men; ethnicity of the cancer patients was not reported.

In another investigation of personal control and psychological outcomes, Andrykowski and Brady²⁹ studied the relationship between health locus of control and distress and adjustment in a group of 69 bone-marrow transplant patients with hematologic malignancies. Health locus of control referred to beliefs regarding the extent to which one or others can control health outcomes. The study sample consisted of young (mean age of 36 years), well-educated Caucasian men and women. Patients who had strong beliefs in their own ability to control health outcomes and experienced decline in physical health experienced more distress than similar patients who perceived only small declines in health. These findings suggest that a sense of control may be a negative adaptive force for some patients.

The concept of personal control has emerged in studies of the EOL experience. Singer, Martin, and Kelner³⁰ interviewed 126 patients regarding their perspectives on quality EOL care. The sample included 48 dialysis patients, 38 long-term care residents, and 40 people with HIV/AIDS. Participants identified five domains of quality EOL care:

1. receiving adequate pain control;
2. avoiding inappropriate prolongation of the dying process;
3. achieving a sense of control;
4. relieving burden on loved ones; and
5. strengthening relationships with loved ones.

Although the authors suggested the five domains could be used by clinicians as a checklist to guide care, the study did not provide information on what might constitute achievement of a sense of control for individual patients, nor did it suggest how a clinician might facilitate a patient's sense of control within EOL care. The authors also observed that their predominantly white (81 percent) patient sample limited study generalizability.

To study determinants of good care at EOL, Teno et al.³¹ conducted focus groups with 42 bereaved family members. Quality EOL care was defined as a) providing desired physical comfort to the dying, b) helping dying persons control decisions about medical care and daily routines, c) easing the family's burden of advocacy for quality care, d) educating the family to increase their knowledge and confidence, and e) providing the family with emotional support before and after the patient's death. Twenty percent of the sample included African American and multiracial participants. This study focused on family member perspectives; patient perspectives were not included.

Perhaps the potential benefit or harm from having a sense of control varies depending on context or circumstance. Studies to date raise a question of whether desire for control is always helpful to individuals facing a life-threatening disease. Given the small sample sizes and predominance of Caucasian participants, further investigation in this area is warranted.

Ethnicity and end-of-life care

The value Western society places

on autonomy and right to self-determination is clearly reflected in the interest in control over the EOL experience. Yet the assumption that people should have control over life and death may be influenced by culture, education, and social class.³² In the following research review, the use of ethnic categories varies considerably. An ethnic group is a self-perceived cultural group that has a shared sense of collective identity, belonging, continuity, and meaning in life.³³ No consensus has emerged regarding uniform use of categories or labels for various ethnic groups. Hence, the following summaries reflect the ethnic categories used within each study.

The influence of ethnicity on patient autonomy has been examined in several EOL decision-making studies. Advance directives (ADs) are a mechanism to protect control over decision making when one can no longer express preferences for care. Although some studies suggest that African Americans and Hispanics are less likely to complete ADs than European Americans,³⁴⁻³⁷ others have found no ethnic differences.^{38,39} Dupree⁴⁰ interviewed 17 African Americans to ascertain their attitudes about advance directives. She concluded that the study participants did not want unlimited EOL interventions and were positive about the usefulness of advance-care planning. Of note, the importance of using family to voice a patient's wishes was seen as more relevant than using a written, legal directive in this cohort. Perkins⁴¹ interviewed a triethnic sample of European Americans, Mexican Americans, and African Americans and found that all groups agreed with the idea of advance care planning, but that Mexican Americans and African Americans were less receptive to the need for a written advance directive.

McKinley, et al.⁴² reported that ambulatory African American patients with cancer were more likely than

Caucasians (67 percent as opposed to 41 percent) to want the benefit of life-sustaining technology if they were dying. Similarly, Cicerelli⁴³ examined the views of 447 Indiana residents aged 60 to 100 years to determine their views about EOL decisions, and concluded that whites were more likely than blacks to find refusal of treatment, ending life, and letting others make decisions to be acceptable options at EOL. Caralis and colleagues³⁸ analyzed the influence of ethnicity and race on attitudes toward ADs, life-prolonging treatments, and euthanasia in a Miami-based sample of 139 ambulatory internal medicine patients self-described as in "excellent or good health." The sample included African Americans, Hispanics (primarily of Cuban origin), and non-Hispanic whites. More non-Hispanic whites (89 percent) were positive about ending life-prolonging treatment than African Americans (63 percent) and Hispanics (59 percent). The authors observed, however, that given the large percentage of Cubans in the study, this finding might not be generalizable to all Hispanics.

In a study of 800 older adults from European-American, Mexican-American, African-American, and Korean-American ethnic groups, Blackhall⁴⁴ found that, while ethnicity was strongly related to preferences for life-sustaining technology in terminal illness, the relationship between the two was complex and sometimes contradictory. European Americans were the least likely to want life support, whereas Mexican Americans were more likely to want such treatment. Korean Americans were more positive about the use of life-sustaining technology than European Americans but did not want such technology used personally. African Americans felt it was acceptable to withhold and withdraw life support but were most likely to want to be kept alive on life-support equipment. The generalizability of Blackhall's study is

limited, however, by its focus on adults over age 65 who resided in urban Southern California.

Ethnicity also influences attitudes about controlling the timing of death via physician-assisted suicide (PAS) or active euthanasia. In a survey of 299 Detroit residents, the majority of both blacks and whites favored legalized PAS; yet 52 percent of whites indicated they might request PAS for themselves compared with only 37 percent of blacks.⁴⁵ In the Miami-based study, ethnic differences also influenced preferences for PAS; non-Hispanic whites were most likely to agree that physicians should assist patients to die (61 percent), followed by Hispanics (53 percent) and African Americans (36 percent).³⁸

The idea of defining the attributes of a "good death" is familiar to both clinicians and researchers. Yet few studies have examined whether ethnicity influences one's preferences for how EOL should unfold. Tong and colleagues⁴⁶ used a series of small focus groups in Connecticut to identify the common domains characterizing a good death for community dwelling individuals. They also looked for possible differences between minority and nonminority views on these issues. Nonminority participants were defined as people from European or Judeo-Christian backgrounds; minority participants were defined either as "people of color" or from less common US religious groups (e.g., Buddhist or Muslim). The study revealed similarities and differences between the groups. Examples of common issues for both minority and nonminority people included physical comfort, burden on family, location and environment for dying, and presence of others. Differences were noted in the area of spiritual concerns, cultural concerns, and individualization. Minority group members were more vocal about religion and spiritual care needs. They also expressed concern that healthcare

providers would not understand or respect their cultural traditions; they desired to be treated as individuals and not stereotyped based on their ethnicity or culture. Conversely, the nonminority participants focused more on maintaining individual autonomy and control over decision making.

Discussion

The interplay between control and ethnicity in EOL care is complex and unpredictable. However, directions for clinical practice and further research are apparent. Koenig¹² observed that cultural analysis is a key component to understanding decision making at life's end, although she warned against using culture or ethnicity as simple predictors of behavior. Indeed, discussion of the influence of culture on control in EOL care must not be grounded on the assumption that all members of a particular ethnic group share the same values. Hence, using research findings to stereotype or predict values and beliefs of a certain ethnic group is inappropriate.

Regardless of ethnic background, not everyone wants to engage in advance care planning or to complete formal ADs. Respect for control and autonomy can take many forms and should include respect for a person's right *not* to complete an AD. People who place a greater value on familial relationships may prefer to designate a family member or other trusted person to make healthcare decisions. Signing a written document for advance planning may be offensive to some individuals. In Waters'⁴⁷ study of African American perspectives on EOL care planning, for example, one participant noted that "we don't write down a lot of stuff. That is the way African Americans communicate so much of their instructions and their history. We are an oral people" (p. 393). Conversely, other individuals may prefer

to retain sole control by drafting detailed living wills to direct future healthcare decisions.

Nonetheless, studies show that people from a variety of ethnic backgrounds value advance care planning. The challenge for healthcare providers is to assist people to identify their values and articulate their preferences for treatment in a way that is respectful of their unique cultural backgrounds.⁴¹ As Blacksher noted, "I don't see any way of getting around the hard job of asking what may be difficult and uncomfortable questions, each and every time, of each and every patient" (p. 15).⁴⁸ According to the American College of Physicians/American Society of Internal Medicine End-of-Life Consensus Panel, culturally effective EOL care includes the following elements¹¹:

- acknowledgment of and respect for cultural differences;
- willingness to negotiate and compromise when world views differ;
- awareness of one's own values and biases;
- communication skills that enhance empathy;
- knowledge of the cultural practices of patient groups regularly seen; and
- understanding that all patients are individuals and may not share the same views as others within their own ethnic group (pp. 676-677).

Although maintaining a sense of control is important in the EOL experience for some individuals, further study of the interplay between ethnicity, desire for control, and achieving a good death is needed. Given that the

effectiveness of ADs remains debatable,⁴⁹ other strategies to improve EOL care must be developed and tested. For example, research should focus on developing methods of advance care planning that are sensitive to individual needs. Waters⁵⁰ suggested that community-based, culturally competent educational interventions on EOL planning may be more appropriate for groups that distrust the healthcare system. Research on healthcare provider/patient communication also is needed. Communication techniques that are respectful of individual differences and that focus on the realities of the types of decisions patients and families confront should be tested. Drought⁵¹ observed that both patients and providers would benefit from a better understanding of the discrepancy between the technological imperative for extending life versus the reality of a patient's clinical condition.

In sum, showing respect for patient autonomy in EOL care is a multidimensional challenge. The cultural norms of healthcare providers trained in a Western medical paradigm may interfere with provision of appropriate care. Sensitivity to individual difference, self-awareness of personal biases, and understanding of patient preferences can enhance our ability to provide appropriate care to people of varying backgrounds.

Acknowledgments

This work was supported by Grant R15 NR07986 from the National Institute of Nursing Research, National Institutes of Health.

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