
CULTURAL DIFFERENCES IN THE USE OF ADVANCE DIRECTIVES: A REVIEW OF THE LITERATURE

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Introduction

The new millennium marks the tenth anniversary of the Patient Self-Determination Act (PSDA). This law allows individuals the autonomy to authorize advance directives specifying the type and extent of life support medical intervention desired during their final hours. Despite the rationale in favor of the executing advance directives, experiential realities may impede their use by many people of color. This article provides an overview of advance directives and a discussion of the barriers that contribute to cultural differences in the usage of this nationwide policy option.

Background and Rationale for Advance Directives

In years past, when an individual's heart stopped beating or they stopped breathing, they simply died. Today, advances in medical technology have made it possible to sustain life long after the human body has permanently lost its natural ability to perform basic, life maintenance tasks.

The use of high technology life sustaining medical treatment measures has resulted in the ability to prolong the lives of persons who are permanently unconscious and/or irreversibly terminally ill. Unsolicited use of this medical technology has resulted in years of litigation and struggle between the legal and medical professions as well as among various interest groups, regarding when, if, and how long life sustaining medical treatment should be used to prolong a dying person's life.

The Patient Self-Determination Act (PSDA) was passed as a part of the Omnibus Budget Reconciliation Act of 1990 (P. L. 101-508, 1990). The PSDA, implemented nationwide in December 1991, is a law requiring all health care facilities receiving reimbursement from Medicare and Medicaid to ask patients, on admission, if they have an advance directive, provide them with written information explaining advance directives, and inform them of their right to complete advance directive documents if they so choose (Gockel et al., 1998; Haynor, 1998). The goal of the statute is to make it possible for (but not require) mentally sound individuals, age 21 and older, to declare their preferences regarding the use of life sustaining medical treatment options in writing so that their choices are documented and available for reference in the event they are unable to express their desires at a later time.

The Living Will (LW) and the Durable Power of Attorney for Health Care (DPAHC) are the written documents commonly referred to as advance directives. The LW contains the individuals direct instructions regarding the use of life sustaining medical intervention. The DPAHC, sometimes called the “health care proxy,” allows individuals to legally authorize someone else to make health care decisions on their behalf should they become terminally ill or incapable of communicating whether or not they wish to be placed on a life support system (Gockel et al., 1998). In understanding the intent of advance directives, it is critical to recognize that advance directives only become effective once an individual has been medically declared permanently incapable of expressing his/her treatment preferences and when there is no hope for recovery.

The Advent of Advance Directives

The development, availability and use of highly sophisticated life sustaining medical treatment (LSMT) procedures in the 1970’s gave rise to many ethical dilemmas regarding the individual’s right to make the choice to forego life prolonging, invasive medical treatment in the face of otherwise certain impending death. In some cases, life sustaining treatment measures have been used to prolong the lives of incapacitated, terminally ill patients against the wishes of their families.

The use of LSMT was first challenged legally in the landmark case of 21-year-old Karen Quinlan, in 1976, when she was kept alive for years in a permanent vegetative state against her parents’ wishes (Quinlan v New Jersey Department of Health, 1976). Another similar and much publicized case was that of 25-year-old Nancy Cruzan, who in 1983 following an auto accident, was kept alive for years in a permanently irreversible coma, with the use of LSMT (Cruzan v Director, Missouri Department of Health, 1990). It was only after years of litigation that the families of these two young women won the favor of the courts and succeeded in having life support stopped. These and many other cases have burdened the courts in challenge of the dominance and authority of the medical profession and related technology over the individual’s right to die with dignity.

Given the legal dynamics and common concerns of the two above mentioned landmark cases (as well as numerous other not so well publicized cases), it is understandable that policymakers may have made the assumption that, if afforded the opportunity to make end-of-life medical treatment preferences, people on the brink of certain death would prefer not to have their lives artificially prolonged indefinitely with the use of life support systems. This assumption has proven true for some Americans, but not for others. Research suggests that end-of-life medical choices differ significantly along racial lines (Hassmiller, 1991).

Literature Review

Research on racial differences regarding the use of advance directives shows an emerging interest in attempts to recognize and explore the role ethnicity plays in end-of-life decision-making choices. Although the literature in this area is sparse, the few empirical studies that have been conducted to date have been highly consistent in showing two very interesting facts: 1) African Americans complete advance directives less frequently than do Whites, and 2) unlike Whites, those African Americans and other people of color who have completed advance directives tend to indicate that they *do* indeed want life sustaining medical treatment administered and continued regardless of the state of their illness, and even when there is no medical hope for recovery.

For example, Caralis et al. (1993) interviewed 139 African American, Hispanic and White subjects, age 65 and older, and found that more African Americans and Hispanics expressed a desire to have life prolonging treatment administered even if they were in a vegetative state. By contrast, Whites in this study indicated that, if in a persistent vegetative state, they would want no life sustaining medical intervention. This research also revealed that African Americans were likely to feel that, if they had an advance directive, they might be cared for to a lesser degree by medical personnel (Caralis et al., 1993). Similarly, Eleazer et al. (1996) reviewed the medical charts of 1193 elderly patients of African American, Asian, Hispanic and White descent and found that African American patients were significantly more likely to request the use of life sustaining medical interventions than other groups, and that White patients were significantly more likely than other groups to have completed advance directives documents.

Research has repeatedly shown that regardless of the specific ethnicity, members of minority groups are generally less desirous of completing advance directives than are Whites (Hauser et al., 1997). For example, studies involving Asian Gujarati and White elderly persons (Lindesay et al., 1997) and research comparing Hispanic and non-Hispanic White elderly (Romero et al., 1997) had similar findings regarding the understanding of and usage of advance directives. Both studies found that Whites were far more likely to have an advance directive and that ethnicity remained significant even when socioeconomic variables, such as age, gender, education and income were adjusted for.

In addition to research on patient populations, a few researchers have examined ethnic differences among health care professionals regarding end-of-life medical preferences. Baker (1995), for example, found that although both African American and White social workers employed in health care settings had positive attitudes toward advance directives, African Americans were less likely than White social workers to have actually executed advance directives for themselves. More recent research

(Melbane et al., 1999) examining the influence of physicians' race on end-of-life choices showed that African American physicians chose aggressive medical interventions significantly more frequently than did White physicians.

These findings consistently suggest that choices involving end-of-life medical treatment decisions may be more related to race and culture than to age, education, socioeconomic status or other demographic variables.

Conclusion

The Patient Self Determination Act, by definition, was intended to promote the principles of autonomy and self-determination. Yet there are also many assumptions inherent in the policy that may serve as barriers to some Americans and result in their reluctance to take advantage of this policy option. For instance, despite the benefits perceived by many, the PSDA is based on written communication and therefore makes the assumption that all Americans can read and write. Secondly, the policy assumes a basic trust in the system. That is, it is assumed that people will trust that the medical profession will have made every possible effort to save their lives before 'the plug is pulled.' Thirdly, the policy's very foundation assumes an individualistic/autonomous manner of thinking as opposed to familial/communal thinking. A broadened view of autonomy that includes respect for cultural values (Blackhall et al., 1995), and diverse beliefs around life and death issues (Klessig, 1992) needs to be recognized by policymakers.

Some cultures may prefer to trust their family to make the right decision when the time comes and may be hesitant to affix their signature to documents they fear they may not fully understand. Some may fear that instead of guaranteeing their autonomy, an advance directive could be used as a license to limit treatment prematurely, in the interest of cost containment, before all efforts to save their lives have been exhausted (Klessig, 1992). Religious convictions, distrust of the medical community (Klessig, 1992), coupled with family-centered decision-making styles (Blackhall et al., 1995) and other cultural values and beliefs may contribute to the reluctance of many people of color to execute advance directives, or to express a desire for continued LSMT in instances when advance directives are completed.

Finally, it is important for policymakers and health care professionals to recognize that what is perceived and promoted as advantageous to one group may not hold the same beneficial value to another group with a different frame of reference, a different value system, and different life experiences.

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