
Addressing Cultural Incongruities of Advance Directives

by Dula Pacquiao

Shared meanings and socially constituted realities have great significance to individuals and families facing critical illness, pain, suffering, or death. Actions are often based on the context of the professional and dominant societal culture. The concept of Advance Directives is consistent with the dominant value orientation in the American culture of self-reliance and individualism, which places a high premium on self-determination and control of one's own destiny. However, this value is not always consistent with the dominant cultural views of particular sick or dying individuals. Thus, at a time when individuals and their families need the most support, institutionalized care often creates incongruities and meaninglessness.

Ruth Benedict (1934) has postulated the concept of characteristic purposes within a culture that provide members with consistent patterns of thought and action not shared by other societies. These cognitive patterns or values are theorized as the central organizing force that gives direction to people's lives as well as meanings to their actions (Foster 1965). Culture is a learned system of meanings, communicated by means of language and other symbol systems, having representational, directive, and affective functions, and capable of creating cultural entities and particular senses of reality (D'Andrade 1997).

Shared meanings and socially constituted realities have great significance for individuals and families facing critical illness, pain, suffering, or death. Decisions relevant to these situations evoke realities that may expand the gap between the professional caregivers' world views and those of their patients. Actions are often based on the context of the professional and dominant societal culture. Thus, at a time when individuals and their families need the most support,

institutionalized care often creates incongruities and meaninglessness to their lives.

Cultural Context of PSDA and Advance Directives

The Patient Self-determination Act (PSDA) of 1991 requires that all healthcare facilities receiving federal reimbursement for services establish mechanisms for disseminating information about Advance Directives. Institutions must also designate personnel responsible for discussing Advance Directives with patients (Blackhall et al. 1995). Advance Directives are designed to promote patient autonomy and assist each patient with end-of-life decisions. The concept of Advance Directives is consistent with the dominant value orientation in North American culture, which places a high premium on self-reliance, individualism, self-determination, and control of one's own destiny. (Hsu 1963; Parsons 1965). This assumption is based on the premise that every person will have a positive regard for this legally assured inalienable right, even when one is unable to make decisions for oneself (Dunlap 1997).

Cultural Variability in Advance Directives

As the United States becomes increasingly multicultural, greater diversity is also apparent in healthcare populations, for example, among caregivers, patients, and communities. Such diversity results in inconsistent PSDA implementation and variability in the way caregivers and patients appreciate its intent. The intent of the law is honorable, yet it often creates less protection than fears associated with disrespecting cultural traditions and transgressing cultural taboos.

During interviews, elderly Filipinos who had recently been hospitalized revealed aversion to discussing the concept of Advance Directives. One woman said that discussing the conditions surrounding her death could bring on bad luck or death. If, then, she can avoid the issue; she will not hasten her demise. This belief is rooted in the cultural value of *Bahala Na*, the acceptance of suffering, endurance, and trust in a supreme being for one's fate (Pacquiao 1993). That older Chinese patients are also reluctant to talk about death has been documented by Eleazar et al. (1996).

Racism — and the experience of having been denied many rights and privileges — has conditioned black Americans to intuitively deny opportunities such as medical treatments in end-of-life decisions. Family is central to the support of patients in cultures that entrust decisions about end-of-life care to the family rather than to individuals or professionals. In fact, family members feel that physicians who exclude them from participating in decisions affecting their ill relatives are being disrespectful (Dupree 2000). Such decisions are made with trusted family members whose actions are guided by loving and caring relationships for each other. Similarly, Korean and Mexican-American families prefer a family-centered model of decision making rather than one supportive of individual patient autonomy (Blackhall et al 1995; McLaughlin and Braun 1998).

Many black Americans hold strong spiritual beliefs that view mortality as more than science

and biomedicine — it is the will of God. Aversion to prognostication and planning is embedded in the value that human beings are subject to a greater power. Members of many cultural and religious groups (e.g., Muslims, Orthodox Jews, many Hispanic groups, and others) that do not subscribe to the value of an individual's power for self-determination share this belief (Meleis and Jonsen 1983; Klessig 1992).

Professional Caregivers and Advance Directives

Hospital personnel who have initial contact with patients are generally involved in discussing Advance Directives. Nurses are often involved in providing patients with information about Advance Directives and other end-of-life care decisions (Hague and Moody 1993); yet, there is minimal information documenting their knowledge and attitudes toward Advance Directives

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(Jarr, Henderson, and Henley 1998). Nurses are uncomfortable and often feel inadequate discussing end-of-life issues (Barta and Neighbors 1993; Mezey et al. 1994), and often experience personal conflict about Advance Directives. Indeed, we interviewed Chinese and Filipino nurses who believe that it is inappropriate to talk with patients about Advance Directives. One nurse who is Chinese stated, "Death is God's will. We are given the technology to save life and not end it" (Pacquiao 1993).

Socialization to the professional caring culture makes it difficult for some nurses to discuss Advance Directives with their patients. Many consider a hospital stay or a time when patients are quite ill as the most inappropriate time for making

end-of-life decisions. Although cognitively, they believe in the value of self-determination, they express ambivalence about the subject and discomfort in initiating in-depth discussions about Advance Directives. Many of them would prefer to refer these discussions to pastoral staff and the clergy.

Culture and Life Transitions

For some groups, discussions about Advance Directives are not confined to one aspect of decision making. The concept gives rise to other relevant issues, for example, family relationships and obligations, religion, respect, cremation, burial, organ donation, and treatment preferences (Dupree 2000). Advance Directives trigger a complex of religious, cultural, and social meanings that cannot be reduced or compartmentalized to the biologic aspects of life. The enormity of the ramifications makes the task daunting for most healthcare professionals.

Life transitions in all cultures are marked by rituals and symbols that reflect the core values of the group. Beliefs and practices surrounding dying attempt to promote value continuity among the living and to ensure the memory and rightful place of the dying person with his or her loved ones. In cultures that emphasize

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the survival of the group over individual self-determination, group cohesiveness and the maintenance of smooth interpersonal relationships among members are paramount. Decisions follow a consistent pattern of social hierarchy and may be confidently delegated to others who

have the status and privilege to make decisions on behalf of the group and its sick and dying members. It makes sense therefore that some patients will not make decisions or discuss Advance Directives with their professional caregivers who are outsiders. It is also not surprising to find that some patients do not want to know their prognosis or that family members will strive to prevent patients from knowing the finality of their situation.

Culturally Congruent End-of-Life Care

Indeed, many authors question the logic of Advance Directives as currently conceptualized. Teno, Hill, and O'Connor (1994) question the emphasis on Advance Directives as a written document. Hill (1994) suggests that Advance Directives should be reserved for patients without family or who may not want their family to make decisions for them. Dresser (1994) also questions the advantage of Advance Directives over allowing family members to make decisions. Studies have shown that a person's response to end-of-life decisions is influenced by age, religion (Grodin 1993), education (Schonwetter et al. 1991), knowledge of Advance Directives, and cultural and ethnic values (Caralis et al. 1993; Eleazar et al. 1996).

Life transitions are universal phenomena cross culturally. However, the context for guiding actions and interpreting the meaning of life experiences is socially and culturally constituted. The challenge for professional caregivers is to strike a balance between fulfilling PSDA's universal mandate and rendering culturally congruent end-of-life care. Leininger (1991) articulated this task of caring in *Culture Care Diversity and Universality*. She recommends that we become aware of the cultural background and the inherent differences between the patients' indigenous lifeways and the professional caregiving culture, and suggests three action strategies for achieving culturally congruent care:

Cultural preservation or maintenance – professional actions and decisions that facilitate the preservation of relevant care

values that enable people of particular cultures to face death.

Cultural accommodation or negotiation – professional actions and decisions that help people of a designated culture to adapt or negotiate with others to achieve satisfying health outcomes.

Cultural repatterning or restructuring – professional actions and decisions that help people reorder, change or greatly modify their lifeways for a new, different, and beneficial health care pattern (p. 49).

In cultural preservation, it is expected that professional caregivers will develop cultural knowledge about their patients and understand the significance of their core values. Hence, if filial obligation is a culture's central value premise, professional decisions should support the family members' need to care for the sick and include all members of the accepted social hierarchy in decision making. Professional actions relevant to cultural accommodation will be needed whenever a cultural value conflicts with ethical and legal mandates of the professional culture. For instance, if discussion of Advance Directives is a cultural taboo, practitioners can seek the mediation of spiritual leaders such as the rabbi, imam, or priest. Cultural brokers are effective when they represent congruent status and authority within the culture of the patient. Leininger believes that cultural repatterning is often required to change the mind-set of professional caregivers. Indeed, many protocols that are legally mandated can be adapted to the lifeways of diverse communities.

Using members of the group to facilitate end-of-life decisions requires that institutions develop a social network with the communities they serve. Professionals can collaborate with gatekeepers in the community to disseminate knowledge about the professional culture, and to learn and work with the cultural values and norms of the community. Relationship building is a prerequisite to trust between outsiders and the group. Developing trust is especially important

when dealing with group-centered cultures whose members are markedly distinct from outsiders. Institutional protocols can be designed inductively with real input from the community.

Conclusion

Population-based care is built on knowledge of our patients and communities as cultural entities with constituted values and realities that are the context for interpreting caregiving both inside and outside healthcare institutions. Professionals need to be practitioners of biculturalism. Bicultural practice is rooted in the ability to adopt institutional and professional lifeways appropriate to the culture-specific end-of-life needs and values of the communities. It is practice that attempts to provide meaningful and satisfying care as defined by the care recipients. Practitioners also need to be sensitized to differences both within and across cultural groups. Sensitivity to cultural variability prevents stereotypes and cultural imposition that negates diversity by prescribing a set of standards for all.

Culture prescribes the meaning and artful process of dying for its members. Death reminds us of the limitations of science and technology. Faced with these limitations, our challenge is to facilitate the experience of patients and their families with a tradition that represents comfort and respect for beliefs that transcend the physical and existential aspects of their being. In the implementation of the PSDA, the cultural system of meanings should become the context for discussing Advance Directives with patients. This context necessitates a humanistic approach that enables one to appreciate the holistic complexity of issues surrounding death. Failure to include this context is tantamount to making our best intentions irrelevant and disrespectful.

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