

# Culturally Diverse Communities and End-of-Life Care



AMERICAN  
PSYCHOLOGICAL  
ASSOCIATION

## WHY IS CULTURE IMPORTANT?

Many factors including culture and ethnicity determine thoughts about death. Culture is a group's worldview and values (Breslin, 1993). Ethnicity is one's self-identified group and may include subgroups that share common values. Culture shapes choices for life support (e.g., resuscitation, feeding tubes) and preferences: to know a terminal diagnosis; to die at home, in the hospital, or in a hospice; and to promote quality during the last days. In some cultures talking of death is taboo. Among the Zuni and Koreans, speaking of a person's death is taboo because it might bring sadness or hasten the demise (Hern, Koenig, Moore, & Marshall, 1998). Clinicians need to respect culture and learn culturally competent strategies to explain a person's illness and health care.

Lack of open and culturally sensitive discussion may mean that the patient's choice for life support is ignored. Ethnic groups have different values about using treatment or artificial nutrition with a feeding tube, trusting physicians, and participating in decisions. Some cultures (e.g., Korean) expect the eldest son to decide about a parent's end-of-life care (Murphy, Blackhall, Michel & Azen, 1995). African Americans typically want aggressive treatment (Mouton, 2000). Groups of African American, Latino, Asian, and Russian Philadelphians initially wanted resuscitation (CPR) and feeding tubes but poorly understood either choice. Many people in all groups distrusted the health care system and providers (Phipps, True, & Pomerantz, 2000).

## HOW DOES ETHNICITY INFLUENCE ADVANCE PLANNING?

People can plan end-of-life treatment in an advance directive (AD) and choose a spokesperson. ADs can reduce distress in end of life decisions because families know their loved one's wishes. ADs can specify choices for life-support and hospice care (Barry & Henderson, 1996). In surveys, Latinos held different views about life support. One-third opposed life support that prolonged suffering and most were unfamiliar with hospice (Sullivan, <http://www.lastacts.org>). In one study, Latinos differed in wanting to know a terminal diagnosis (Sullivan, 2001). Hospices serve primarily Whites (83%), and few Native Americans (6%), African Americans (8%) and Hispanics (3%) (National Palliative Care and Hospice Organization, 1995). African Americans may believe that hospice and palliative care mean "denial of care."

Ethnic groups differ in their use of ADs. Caucasian and Asian Americans more often use ADs than others (Ersek, Kagawa-Singer & Barnes, 1998). Some older Korean-Americans support ADs and wish to forego life support, but worry that ADs could create inter-generational conflict if their eldest son disapproved (Phipps, True, & Pomerantz, 2000). Cultural traditions that involve karma may be at odds with ADs (Braun, Pietsch, & Blanchette, 2000). For Muslims, treatment that becomes futile is no longer mandatory. The Islamic Medical Association of North America encourages a living will

## Who?

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# Says Who?

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**Patient Self Determination Act**, Public Law 101-508; 42 U.S.C. Sections 1395 cc.1396 *d learn culturally competent strategies to explain a person's illness and health care.*

with do not resuscitate orders if brain death occurs (Lawrence & Rozmus, 2001). Many people think ADs are a good idea, but believe they are not needed because family or physicians know their wishes (Caralis, Davis, Wright, Marcial, 1993). However, physicians and families are poor predictors of a patient's wishes (Haidet et al, 1998).

## WHAT ARE THE BARRIERS TO COMMUNICATION?

Talking to physicians and deciding about treatment is challenging. Critical messages may be lost in translation or in unfamiliar terms. For instance, asking, "Do you want me to do everything to cure your parent?" will elicit agreement. However, some families may think, "If I say no, I am a bad person." Translations and culturally sensitive written information in native languages are lacking. Physicians typically talk too briefly about end-of-life options and neglect culture or values (Tulsky, Fischer, Rose, & Arnold, 1998).

Speaking another language or having limited English skills may complicate interactions and speaking up (Phipps True & Pomerantz, 2000). For example, one person said, "I'd rather take the pain than speak up because of my language" (Phipps, True & Pomerantz, 2000). For many reasons, Koreans and Cambodians were afraid to ask for anything in the hospital to improve the patient's comfort. When a family member translates for an adult relative, the person's status, knowledge of private information, and exposure to stressful issues changes. Minority cultural groups often believe that the health care staff have negative attitudes toward them, use unclear technical terms, and treat them differently.

Medical culture emphasizes a curative focus and a view of death as the enemy or a failure (Christakis, 2001). According to Christakis, many physicians have difficulty disclosing terminal illness or futility. They report they do not have much education or expertise in talking about death with people from diverse cultures (Christakis, 2001). In their study, Tulsky et al reported that physicians spoke briefly about death with patients but did not thoroughly consider the patient's values or culture.

## WHAT IS THE ROLE OF FAMILY?

Family members often make sacrifices to care for relatives. Families provide care, pain management, and protect the patient. Although they may lack knowledge, caregivers gain satisfaction and pride from providing care, but are also at risk for depression and health problems related to caregiver stress (Haley & Bailey, 1999; Haley et al., 2001; Weitzner, Haley, & Chen, 2000). Some cultures may believe caring is the community's duty and obligation. Caregivers benefit from social support, maintaining social activities and roles, and psychological interventions that teach coping skills. Most people want their family to be given choices about treatment and few wanted the physician to decide alone (Bradley, 1998).

## WHAT IS WORKING?

Mental health providers with palliative expertise can improve communication and resources. Mental health experts help providers understand the patient's concerns and culture. They explain confusing medical terms and clarify CPR, pain management, and other treatments and encourage collaboration. Mental health providers also help relieve the common emotional distress and grief resulting from a terminal illness or care giving.

## WHAT NEEDS TO BE DONE?

We need research about culture, communication, and dying to prevent unwanted, treatments that reduce quality of life and increase suffering. We need to understand how culture and socioeconomics influence quality care. Professionals need to explore what the family wants. For example, "If your heart stops, do you want CPR? Let me tell you what CPR is." Education about culturally competent strategies for communication and end of life care is needed. Providers should avoid technical jargon and use clear explanations. Policies need to offer AD options and palliative care centers that honor rich cultural traditions.