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ELDER CARE

A Resource for Interprofessional Providers

Ethnic, Racial, and Cultural Perceptions in End-of-Life Issues

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Ethnic and racial groups that share a sense of history, tradition, identity, languages, and dialects exist within cultures that are comprised of behavior patterns, symbols, and values that differentiate them from other groups. An individual's sense of racial and ethnic identity, however, can fluctuate across the lifespan according to a variety of factors, including socioeconomic status and setting. As a result, ethnic and racial groups are not monolithic. In fact, there may often be more intra-group, than inter-group, variation.

Ethnicity, race, and culture are often omitted in discussions about end of life (EOL) issues. Including them can be challenging because of the aforementioned intra-group variations, which makes it difficult to characterize these differences in EOL perceptions into tidy boxes.

Nevertheless, as a "shorthand" measure for clinicians, we can compare the general, overall current knowledge about the EOL perceptions of four groups (African Americans, Hispanic/Latino Americans, Asian Americans, and Native Americans (Table 1). It is notable, however, that little quality research is available about perceptions of some aspects of EOL issues in these groups, so some cells in Table 2 indicate a lack of available data or lack of applicability.

Perceptions of End-of-Life Issues

Like many underserved populations, the four major ethnic/racial/cultural minority groups discussed here tend to prefer family-centered collective decision-making and that family members provide care for aging family. They are less likely than Anglos (non-Hispanic Whites) to complete advance directives.

Hispanic/Latinos fall between Anglos and African Americans in their attitudes toward aggressive treatments such as life support.

Asian American families may not disclose a terminal illness because they believe that talking about death may cause it, and their preferences for aggressive treatment vary with acculturation. They are less knowledgeable about advanced directives, and are less likely to complete them than Anglos.

While tribal communities vary, Native American families also tend to avoid discussions of death and dying but will provide tribal support of patients and families at the EOL. They will also normalize death as part of the life cycle, and incorporate traditional knowledge and ceremonies into the EOL through home and community-based care.

Table 1. Perceptions Regarding Key EOL Issues in Four American Groups

Ethnic/Racial/Cultural Group	*Family-Centered Decision Making*	*Non-Disclosure of Illness to Others*	*Preferred Caregiver*	*Advanced Directives (Compared to Anglos)*	*Desire for Aggressive Treatment*
African American	Yes	Yes	Family	Less likely	Yes
Hispanic/Latino American	Yes	Yes	Family	Less likely	Yes
Asian American	Yes	Yes	Family	Less likely	Varies with acculturation Wish for a natural death
Native American	Yes	Yes	Family	Less likely	Traditional treatment Wish for a natural death

TIPS FOR SUPPORTING ETHNICALLY, RACIALLY, AND CULTURALLY DIVERSE PATENTS AND FAMILIES AT THE END OF LIFE

- Recognize the impact of race, ethnicity, and culture on the worldview of patients and families
- Become familiar with the cultural practices and beliefs of underserved groups represented in your practice.
- Recognize your own ideas and biases about EOL issues that may affect your interactions with patients.
- Avoid mainstream assumptions about autonomous decision-making and homogeneity of ethnic group characteristics.
- Listen closely to the needs of patients and family caregivers to assure all voices are heard during clinical encounters.
- Use cultural brokers or patient navigators to help tailor culturally-relevant, family-centered treatment.
- Use certified medical interpreters when interacting with patients and families with limited English proficiency.
- Support ongoing, meaningful conversations about advanced directives.

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Table 2. Comparison of Perceptions: Caregiver Stress/Benefits, Religious Faith, and Suffering

Group	*Caregiver Stress*	*Benefits of Caregiving*	*Emphasis on Religious Faith*	*View of Suffering*
African Americans	Yes, but less than Anglos	Yes	More than Anglos or Hispanic/Latinos	God's plan
Hispanic/Latino Americans	Yes, but less than Anglos	Yes	Yes	God's plan
Asian Americans	Yes; similar to Anglos	Yes	No data available	No data available
Native Americans	Yes; similar to Anglos	Yes	Traditional ceremonies	No data available

Perceptions of the Health Care System

Trust in the health care system is often low for African American and Hispanic/Latinos, and this lack of trust may extend to poor quality patient-clinician relationships. Fear of denial of treatment or experimentation during routine care stems from a long history of societal discrimination, health disparities, and unpleasant experiences such as inadequate pain management or stereotyping. Successful patient-clinician communication about EOL treatment and caregiver needs is thought to rest on racial and ethnic concordance with clinicians, but many individuals from ethnic or racial minorities have little or no experience with clinicians of their own background.

Additionally, the Hispanic/Latino experience is affected by acculturation, with less acculturated families preferring more aggressive services.

Similar to African Americans and Hispanic/Latinos, Native Americans fear being denied treatment, particularly in certain regions of the country, and may have little contact with ethnically or racially concordant clinicians. In addition, aggressive treatment varies with acculturation in Asian Americans.

All four groups report experiencing communication problems with clinicians based on language and/or culture. In general, underserved patients and families with limited English proficiency achieve better clinical outcomes and greater patient satisfaction when professional interpreters are used to promote accurate communication.

Caregiving, Religious Faith, and Suffering

African Americans may emphasize faith and spirituality more than Hispanic/Latinos or Anglos and they may view suffering as an act of faith or part of God's plan. Like African Americans, Hispanic/Latinos report family caregiving as less stressful and more satisfying than do Anglos, using religious activities, often a part of daily life, as a coping strategy. Asian Americans and Native Americans, while accepting the stressful role of caregiving, also acknowledge greater rewards than Anglo counterparts (Table 2).

What to Do?

When discussing EOL issues with patients of different backgrounds, reflect on your own biases that may affect your interactions. Learn about cultural practices and beliefs of your patient population, elicit the perceptions and needs of individual patients, and avoid generalized assumptions.

Use certified interpreters when interacting with patients who are not proficient in your language. It is not appropriate to use relatives, especially minors, or those who might benefit financially from a person's death, as interpreters in EOL discussions.

Finally, be sure to explain complex EOL issues in simple terms so that patients and families can make informed decisions about EOL care. Other suggestions about what to do are shown in the "Tips."

References and Resources

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