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Cultural Diversity at the End of Life: Issues and Guidelines for Family Physicians

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Ethnic minorities currently compose approximately one third of the population of the United States. The U.S. model of health care, which values autonomy in medical decision making, is not easily applied to members of some racial or ethnic groups. Cultural factors strongly influence patients' reactions to serious illness and decisions about end-of-life care. Research has identified three basic dimensions in end-of-life treatment that vary culturally: communication of "bad news"; locus of decision making; and attitudes toward advance directives and end-of-life care. In

contrast to the emphasis on "truth telling" in the United States, it is not uncommon for health care professionals outside the United States to conceal serious diagnoses from patients, because disclosure of serious illness may be viewed as disrespectful, impolite, or even harmful to the patient. Similarly, with regard to decision making, the U.S. emphasis on patient autonomy may contrast with preferences for more family-based, physician-based, or shared physician- and family-based decision making among some cultures. Finally, survey data suggest lower rates of advance directive completion among patients of specific ethnic backgrounds, which may reflect distrust of the U.S. health care system, current health care disparities, cultural perspectives on death and suffering, and family dynamics. By paying attention to the patient's values, spirituality, and relationship dynamics, the family physician can elicit and follow cultural preferences. (Am Fam Physician 2005;71:515-22. Copyright© 2005 American Academy of Family Physicians.)

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Ethnic minorities compose an increasingly large proportion of the population of the United States. In the 2000 census, about 65 percent of the U.S. population identified themselves as white, with the remaining percentage representing the following ethnic groups: black (13 percent); Hispanic (13 percent); Asian-Pacific Islander (4.5 percent); and American-Indian/Alaskan native (1.5 percent). About 2.5 percent of the population identify themselves as bi-ethnic, and this figure is likely to continue to grow.¹

The challenge for family physicians in an increasingly diverse society is to learn how cultural factors influence patients' responses to medical issues such as healing and suffering, as well as the physician-patient relationship. The American Academy of Family Physicians (AAFP) has published cultural proficiency guidelines² and policy and advocacy statements about diversity in AAFP educational activities.³ In addition, sensitivity to cultural diversity is integrated within the AAFP's policy statement on ethical principles for end-of-life care.⁴ Specifically, principle 5 states: "Care at the end of life should recognize, assess, and address the psychological, social, spiritual/religious issues, and cultural taboos realizing that different cultures may require significantly different approaches."

Although cultural proficiency guidelines exist,⁵ few

resources are available to family physicians regarding ways to apply these guidelines to direct patient care. Many physicians are unfamiliar with common cultural variations regarding physician-patient communication, medical decision making, and attitudes about formal documents such as code status guidelines and advance directives. End-of-life discussions are particularly challenging because of their emotional and interpersonal intensity.

Although patients in the United States tend to value autonomy, some cultures value beneficence.

Physicians also are challenged by the tremendous diversity within specific ethnic minority groups (*Table 1*).^{6,7} In fact, research suggests that when compared with whites of European descent, ethnic minorities exhibit greater variability in their preferences.⁸ Therefore, while certain styles of communication and decision making may be more common in some cultures, stereotyping should be avoided. Generalizations about specific cultures are not always applicable to specific patients.

TABLE 1
Points of Cultural Diversity in Health Care

- Emphasis on individualism versus collectivism
- Definition of family (extended, nuclear, nonblood kinship)
- Common views of gender roles, child-rearing practices, and care of older adults
- Views of marriage and relationships
- Communication patterns (direct versus indirect; relative emphasis on nonverbal communication; meanings of nonverbal gestures)
- Common religious and spiritual-belief systems
- Views of physicians
- Views of suffering
- Views of afterlife

Information from references 6 and 7.

Principlism, a well-established ethical framework for medical decisions in the United States and Western Europe, highlights cross-cultural differences that occur along four dimensions: autonomy, beneficence, nonmaleficence, and justice.^{9,10} Although many patients in the United States value autonomy, other cultures emphasize beneficence. In the United States, legal documents such as advance directives and durable powers of attorney are strategies to prolong autonomy in situations in which patients can no longer represent themselves. Other cultures, however, de-emphasize autonomy, perceiving it as isolating rather than empowering. These non-Western cultures believe that communities and families, not individuals alone, are affected by life-threatening illnesses and the accompanying medical decisions.¹¹ Cultures valuing nonmaleficence (doing no harm) protect patients from the emotional and physical harm caused by directly addressing death and end-of-life care. Many Asian and Native American cultures value beneficence (physicians' obligation to promote patient welfare) by encouraging patient hope, even in the face of terminal illness.

Cultural influences in late-life care became particularly evident with the passing of the 1990 Federal Patient Self Determination Act (PSDA).¹² Case studies appeared that highlighted unforeseen

dilemmas in the PSDA's implementation among some ethnic and cultural groups.^{13,14} Subsequent research and case studies identified three basic dimensions in end-of-life treatment that may vary culturally: communication of "bad news," locus of decision making, and attitudes toward advance directives and end-of-life care.

Communicating Bad News

The consumer movement, legal requirements, an emphasis on patient informed consent, and reduced physician authority have contributed to health-related "truth telling" in the United States. Outside the United States, health care professionals often conceal serious diagnoses from patients. Physician strategies commonly employed to minimize direct disclosure include using terminology that obscures the seriousness of a condition or communicating diagnostic and treatment information only to the patient's family members. Many African and Japanese physicians, when discussing cancer with patients or family members, choose terms such as "growth," "mass," "blood disease," or "unclean tissue,"¹⁵ rather than specifically describing a potentially terminal condition. In Hispanic, Chinese, and Pakistani communities, family members actively protect terminally ill patients from knowledge of their condition. In the United States, this protection may include deliberately not translating diagnosis and treatment information to patients,¹⁶ a situation that is less likely to arise with appropriate use of a translator (*Table 2*).^{17,18}

TABLE 2

Guidelines for Medical Interviews with Translators

Ideally, the translator should not be a family member.

Translators should be trained to respect patient confidentiality.

Physicians should orient the translator to the process of the medical encounter.

Physicians should request a literal, word-for-word translation.

Physicians should request the translator to ask the physician to restate or clarify unfamiliar terms.

After making a complete statement, the physician should pause for translation.

The physician should look directly at the patient, rather than at the translator, when either the physician or patient is speaking.

The physician should speak in the second person. For example, he or she might ask, "Where is your pain?" rather than "Can you ask him where he hurts?"

Information from references 17 and 18.

There are four primary reasons for nondisclosure: (1) certain cultures specifically view discussion of serious illness and death as disrespectful or impolite^{5,19,20}; (2) some cultures believe that open discussion of serious illness may provoke unnecessary depression or anxiety in the patient; (3) some cultures believe that direct disclosure may eliminate hope; and (4) some cultures believe that speaking aloud about a condition, even in a hypothetical sense, makes death or terminal illness real because of the power of the spoken word.

In many Asian cultures, it is perceived as unnecessarily cruel to directly inform a patient of a cancer diagnosis.^{15,21} Even among people of European background, Bosnian-Americans and Italian-Americans perceive direct disclosure of illness as, at minimum, disrespectful, and more significantly, inhumane.^{15,22} Recent immigrants to the United States described Bosnian physicians as "going

around” the diagnosis and being indirect about serious illness in contrast to American physicians, whose directness they described as hurtful.²²

Emotional reaction to news of serious illness is also considered directly harmful to health. It is thought that a patient who is already in pain should not have to grapple with feelings of depression as well.²¹ This negative emotional impact on health also appears to be one of the primary reasons that Chinese patients are less likely to sign their own do-not-resuscitate (DNR) orders.²³ This concern, together with Asian values of reverence for aging family members,⁷ may be especially pronounced in elderly patients who, because of their frailty, are perceived as more vulnerable to being upset by bad news. In addition, the special status of the elderly in Asian culture includes a value that they should not be burdened unnecessarily when they are ill.^{11,15,24}

Direct disclosure of bad health news may eliminate patient hope. Bosnian respondents indicated that they expected physicians to maintain patients' optimism by not revealing terminal diagnoses.²² Among other ethnic groups emphasizing this perspective of hope, there is the notion that factors outside of medical technology, such as a divine plan and personal coping skills, may be more important for survival than physician intervention.⁵ Filipino patients may not want to discuss end-of-life care because these exchanges demonstrate a lack of respect for the belief that individual fate is determined by God.²⁴ If their hope is shattered, patients are no longer able to enjoy their daily lives and may feel they are "...among the dead while still alive."^{11(p213)}

Finally, Native American, Filipino, and Bosnian cultures emphasize that words should be carefully chosen because once spoken, they may become a reality. For example, a commonly held Navajo belief is that negative words and thoughts about health become self-fulfilling. Carrese and Rhodes¹⁴ noted that Navajo informants place a particularly prominent value on thinking and speaking in a "positive way." About one half of their Navajo informants would not even discuss advance directives or anticipated therapeutic support status with patients because these verbal exchanges were considered potentially injurious. Similarly, the reluctance of Chinese patients and their families to discuss possible death is based on the belief that direct acknowledgement of mortality may be self-fulfilling.²³

In some ethnic groups, factors outside medical technology, such as a divine plan and personal coping skills, may be more important for survival than physician intervention.

Locus of Decision Making

In the past 30 years, the U.S. system of medical ethics has de-emphasized physician beneficence and increasingly emphasized patient autonomy. A patient's capacity for making independent decisions is questioned only if cognitive function or patient judgment appears to be impaired by medical or psychiatric illness. In contrast, many ethnic communities view it as appropriate to withhold potentially distressing information from cognitively intact, competent patients. Therefore, the North American cultural norm of individual decision making about medical care may have to be altered when physicians care for ethnically diverse patients. Alternate models of decision making include family-based, physician-based, and shared physician-family decision making (*Table 3*).^{5,19,25}

TABLE 3

Cross-Cultural Interview Questions Regarding Serious Illness and End-of-Life Care

"Some people want to know everything about their medical condition, and others do not. What is your

preference?"

"Do you prefer to make medical decisions about future tests or treatments for yourself, or would you prefer that someone else make them for you?"

To patients who request that the physician discuss their condition with family members: "Would you be more comfortable if I spoke with your (brother, son, daughter) alone, or would you like to be present?" If the patient chooses not to be present: "If you change your mind at any point and would like more information, please let me know. I will answer any questions you have." (This exchange should be documented in the medical record.)

When discussing medical issues with family members, particularly through a translator, it is often helpful to confirm their understanding: "I want to be sure that I am explaining your mother's treatment options accurately. Could you explain to me what you understand about your mother's condition and the treatment that we are recommending?"

"Is there anything that would be helpful for me to know about how your family/community/religious faith views serious illness and treatment?"

"Sometimes people are uncomfortable discussing these issues with a doctor who is of a different race or cultural background. Are you comfortable with me treating you? Will you please let me know if there is anything about your background that would be helpful for me to know in working with you or your (mother, father, sister, brother)?"

Information from references 5, 19, and 25.

Cultures that place a higher value on beneficence and nonmaleficence relative to autonomy have a long tradition of family-centered health care decisions. In this collective decision process, relatives receive information about the patient's diagnosis and prognosis and make treatment choices, often without the patient's input. Compared with persons of black and European descent, Koreans and Mexican-Americans were more likely to consider family members, rather than the patient alone, as holding the decision-making power regarding life support.⁹ With acculturation, Mexican-Americans were more likely to agree that patients should be directly informed of their conditions. However, acculturated Mexican-Americans continued to view decision making as a family-centered process.^{5,8} Blacks may view an overly individualistic focus as disrespectful to their family heritage.^{5,26,27}

Among Asian cultures, family-based medical decisions are a function of filial piety—an orientation toward the extended family as opposed to individual patient self-interest.²⁴ Illness is considered a family event rather than an individual occurrence.¹¹ Interests in Asian families are often bi-directional—there is an equivalent concern about the impact of the elderly person's death on the family.

Many societies attribute a high degree of authority, respect, and deference to physicians.²⁸⁻³⁰ Patients and families defer end-of-life decisions to the physician, who is seen as an expert. Eastern European medicine has had a long tradition of physician-centered, paternalistic decision making. In Russian medicine, the physician rather than the patient or patient's family often unilaterally determines a patient's level of life support.²⁹ Recent Bosnian immigrants to the United States reported that they would prefer that physicians, because of their expert knowledge, make independent decisions to reduce the burden on patients and their families.²²

In Asian, Indian, and Pakistani cultures, family members and physicians may share decisional duties. Family care of the terminally ill in Asian and Indian cultures is a shared responsibility for cognitively intact and incapacitated relatives. Physicians in Pakistan may be adopted into the family unit and addressed as parent, aunt, uncle, or sibling.³⁰ This family status provides the physician with a role sanctioning his or her involvement in intimate discussions.³⁰

Advance Directives and End-of-Life Care

Survey data suggest that about 20 percent of the U.S. population has advance directives.^{31,32} Most investigators find significantly lower rates of advance directive completion among Asians, Hispanics, and blacks.^{31,32} For example, about 40 percent of elderly white patients indicated that they had an advance directive, compared with only 16 percent of elderly blacks.³³ In one study,⁸ none of the Korean respondents had advance directives, and relatively few of the Hispanics had completed these documents. The low rates of advance directive completion among nonwhites may reflect distrust of the health care system, health care disparities, cultural perspectives on death and suffering, and family dynamics such as parent-child relationships (*Tables 3^{5,19,25} and 4^{34,35}*).

Among blacks, nonacceptance of advance directives appears to be part of a much broader pattern of values regarding quality of life, as well as a historical legacy of segregation. DNR orders may be viewed as a way of limiting expensive health care or as cutting costs by ceasing care prematurely.¹¹ Historically, this perspective may stem from a long history of distrust of the white-dominated health care system. The Tuskegee syphilis study,³⁶ in which infected black men were followed for 40 years but were not informed of the availability of penicillin treatment, is well known in the black community.

The reluctance of blacks to formally address end-of-life care also may stem from a history of health care discrimination. Although individual studies vary, the preponderance of evidence indicates that nonwhites, even after controlling for income, insurance status, and age, are less likely to receive a range of common medical interventions such as cardiac catheterization, immunizations, and analgesics for acute pain.^{37,38} Although issues such as geographic patterns of medical care play some role in these disparities,³⁹ mistrust of the health care system is likely to be a factor in the lower rates of organ donation among blacks, as well as a reduced acceptance of hospice care.^{40,41} Blacks with colon cancer were more likely than comparably ill white patients to want artificial nutrition, mechanical ventilation, and cardiopulmonary resuscitation.⁴¹ Similarly, black patients overall are about one half as likely to accept DNR status and are more likely than whites to later change DNR orders to more aggressive levels of care.⁴² These attitudes also carry over to black physicians, who are significantly more likely than their white colleagues to recommend aggressive treatment to patients with brain damage and known terminal illness.⁴³ Similarly, black physicians are less likely to accept physician-assisted suicide as an acceptable intervention.⁴³

In addition to a historical legacy of unequal care, black patients also appear to view suffering somewhat differently than whites of European background. While whites may be concerned about dying patients undergoing needless suffering, black physicians and patients are more likely to think of suffering as spiritually meaningful, and life as always having some value.^{11,44} Survival alone, even if it involves significant pain, may be an important demonstration of religious faith.⁵

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Among Hispanics, the lack of acceptance of advance directives may stem from a view of collective family responsibility.⁴⁵ Hispanic patients may be reluctant to formally appoint a specific family member to be in charge because of concerns about isolating these persons or offending other relatives. Instead, a consensually oriented decision-making approach appears to be more acceptable in this population. Formalization of this process is seen as unnecessary and potentially harmful, because

it may lead to increased and extended family conflict.⁴⁵

Finally, among Asians, aggressive treatment for elderly family members is likely to be guided by filial piety. Asian adults feel a responsibility to reverently care for aging parents. This sense of obligation makes it difficult for relatives to request other than extraordinary measures.²⁰ Similarly, elderly Asian parents may experience a reciprocal obligation to continue living for the emotional well-being of their adult children.²⁰

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Guidelines for Cross-Cultural Communication

Physicians can actively develop rapport with ethnically diverse patients simply by demonstrating an interest in their cultural heritage. Attention to dimensions such as those listed in *Table 1*^{6,7} should help physicians develop a more detailed understanding of important cultural issues. The power imbalance of physician-patient interaction may make it particularly difficult for ethnic minority patients to directly request culturally sensitive care. Through skillful use of patient-centered questions (*Table 3*)^{5,19,25} and by including interpreters as necessary (*Table 2*),^{17,18} physicians can develop a richer understanding of patients' health care preferences.

Patient preferences for nondisclosure of medical information and family-centered decision making may be disorienting initially to American-trained physicians. When treating patients from cultures with norms of nondisclosure, physicians might describe the dimensions of informed consent and offer to provide diagnostic and treatment information (*Table 4*).^{34,35} By offering autonomy to patients, cultural norms are respected while rights to independent decisions are simultaneously acknowledged.^{46,47} A patient who refuses diagnostic information and prefers family-or physician-centered decision making has made a clear, voluntary choice. Physicians should also appreciate that, in certain cultures, while communication about serious illness and death may not be overt, information may be conveyed with subtlety. Facial expressions, voice tone, and other nonverbal cues may convey the seriousness of a patient's status without the necessity for explicit statements. In addition, stories about "good" deaths of family and community members may be shared with seriously ill patients.¹⁴

TABLE 4

Cross-Cultural Communication for Serious Illnesses and End-of-Life Care

<i>Issue</i>	<i>Potential solution</i>
Ethnic minorities, which compose about one third of the U.S. population, often have distinct norms for physician-patient communication and decision making for seriously ill patients.	Physicians can become knowledgeable about cultural norms in patients they commonly treat. They can describe the dimensions as they apply to specific ethnic groups (see Table 1). Physicians should ask patients directly about cultural issues that may affect communication patterns and treatment.
Up to 17 percent of the U.S. population speaks a primary language other than English.	Physicians must find accessible, trained translators. Untrained translators should be briefly oriented to their role (see Table 2).
Some cultures view directly informing patients of a serious diagnosis as harmful.	Physicians can ask patients if they would like to be directly informed of the results of medical investigations. Physicians can let patients know that they will discuss the patient's

	condition with the patient at any time. These exchanges should be documented in the medical record (see Table 3).
Patients may prefer that their family members be the recipients of diagnostic and treatment information.	If a patient prefers that family members receive information, find out which family member(s).
Treatment decisions may be made by an informally appointed family member, family-wide consensus, or physician-family collaboration.	Physicians should ask patients how they would like treatment decisions to be made. At this point, the physician can determine the extent to which patients/ family members wish to be involved in treatment decisions.
When compared with whites of Northern European background, patients who belong to other ethnic groups are less likely to complete formal advance directives.	Physicians should inform patients and/or family members about the availability of written advance directives and durable powers-of-attorney. They can ask the patient or family if there is a preferred approach for making decisions on the patient's behalf.
Patients from some cultures, particularly those with histories of health care discrimination, may not trust physicians who are of a different ethnic background.	In this situation, it is good to ask patients directly if they are comfortable working with a physician of a different ethnic background. When appropriate, physicians can acknowledge that members of a particular ethnicity have had histories of less than optimal care. Patients and family members can be encouraged to inform the physician immediately if they have quality-of-care concerns.

Information from references 34 and 35.

The physician's partnership with his or her patients and their families provides unique insight into their values, spirituality, and relationship dynamics, and may be especially helpful at the end of life. By eliciting and following cultural preferences regarding disclosure, advance planning, and decisional processes that relate to seriously ill patients, family physicians can provide culturally sensitive end-of-life care.

Strength of Recommendations

<i>Key clinical recommendation</i>	<i>Label</i>	<i>References</i>
Many ethnic groups prefer not to be directly informed of a life-threatening diagnosis.	C	6
In cultural groups in which patients are not directly informed about a serious prognosis, family members may want the physician to discuss the patient's condition with family members only.	C	6, 34
When considering therapeutic options, physicians should consider that members of many cultural groups prefer that family members, rather than patients, make treatment decisions.	C	6, 34
Direct discussion of advance directives and therapeutic support levels may be undesirable in situations in which they are viewed as potentially harmful to patients' well being.	C	14
When physician-patient communication occurs through a translator, trained health care translators make fewer errors than untrained translators.	C	35

A = consistent, good-quality patient-oriented evidence; B = inconsistent or limited-quality patient-

oriented evidence; C = consensus, disease-oriented evidence, usual practice, opinion, or case series.
See page 409 for more information.

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