

Strategies for Culturally Effective End-of-Life Care

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As a result of profound worldwide demographic change, physicians will increasingly care for patients from cultural backgrounds other than their own. Differences in beliefs, values, and traditional health care practices are of particular relevance at the end of life. Health care providers and patients and families may not have shared understandings of the meaning of illness or death and may not agree on the best strategies to plan for the end of life or to alleviate pain and suffering. Good end-of-life care may be complicated by disagreements between physicians and patients, difficult interactions, or decisions the physician does not understand. Challenges may result from cultural differences between the patient's background and traditional medical practice. Values so ingrained in physicians as to be unquestioned may be alien to patients from different backgrounds. Physicians need to be sensitive to cultural differences and to develop the skills necessary to

work with patients from diverse backgrounds.

Community and cultural ties provide a source of great comfort as patients and families prepare for death. This paper describes two cases that raise issues about cross-cultural end-of-life practice and suggests strategies for negotiating common problems. Physicians should assess the cultural background of each patient and inquire about values that may affect care at the end of life. They should become aware of the specific beliefs and practices of the populations they serve, always remembering to inquire whether an individual patient adheres to these cultural beliefs. Attention to cultural difference enables the physician to provide comprehensive and compassionate palliative care at the end of life.

Ann Intern Med. 2002;136:673-679.

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Providing good end-of-life care may be complicated by disagreements between physicians and patients, difficult interactions, or patient actions and decisions that the physician does not understand. In some cases, challenges may result from cultural differences between the patient's background and traditional medical practice. Values and social expectations that are so ingrained in physicians as to be unquestioned may be alien to patients from different cultural backgrounds. Physicians need to be sensitive to cultural differences and to develop the skills necessary to clarify and resolve end-of-life care involving patients from different cultures. We describe two cases that illustrate how cultural differences may affect specific aspects of end-of-life care.

CASE DESCRIPTIONS

Case 1. Advance Directives in a Patient with Congestive Heart Failure.

Wilma Martinez, a 67-year-old Spanish-speaking woman, has congestive heart failure due to inoperable coronary artery disease. She has been hospitalized three times

during the past 6 months, even though she has reliably taken five medications daily. Her ejection fraction is 25%. She seems distressed when her physician discusses advance directives and encourages her to designate a health care proxy. She says she wants "everything" done to help her survive. The patient's daughter usually accompanies her to clinic appointments and serves as translator.

A few months after the discussion about advance directives, the physician asks more specifically about Mrs. Martinez's preferences for end-of-life care. This time, Mrs. Martinez's daughter expresses a strong desire that her mother not receive mechanical ventilation or cardiopulmonary resuscitation. It is unclear whether this represents a change in the patient's preferences or the daughter's wishes.

Case 2. Insistence on Life-Sustaining Interventions by a Patient with Metastatic Cancer.

Lawrence Byrd, a 59-year-old African-American man, has metastatic colon cancer. He had surgery for Duke's stage D adenocarcinoma of the colon and adjuvant chemotherapy with 5-fluorouracil and leucovorin. Four months ago, he

*This paper was written by LaVera M. Crawley, MD; Patricia A. Marshall, PhD; Bernard Lo, MD; and Barbara A. Koenig, PhD, for the American College of Physicians–American Society of Internal Medicine (ACP–ASIM) End-of-Life Care Consensus Panel. Members of the ACP–ASIM End-of-Life Care Consensus Panel were Bernard Lo, MD (*Chair*); Janet Abraham, MD; Susan Block, MD; William Breitbart, MD; Ira R. Byock, MD; Kathy Faber-Langendoen, MD; Lloyd W. Kitchens Jr., MD; Paul Lanken, MD; Joanne Lynn, MD; Diane Meier, MD; Timothy E. Quill, MD; George Thibault, MD; and James Tulsky, MD. Primary staff to the Panel were Lois Snyder, JD (*Project Director*); Jason Karlawish, MD; and David Casarett, MD. This paper was reviewed and approved by the Ethics and Human Rights Committee, although it does not represent official College policy. Members of the Ethics and Human Rights Committee were Risa Lavizzo-Mourey, MD (*Chair*); Susan Dorr Gould, MD; Joanne Lynn, MD; David A. Fleming, MD; William E. Golden, MD; Jay A. Jacobson, MD; David W. Potts, MD; Daniel P. Sulmasy, OFM, MD, PhD; Vincent Herrin, MD; and Lee J. Dunn Jr., JD, LL.M.

developed liver metastases and did not respond to two cycles of chemotherapy. At his last visit, the patient declined to discuss hospice when his physician raised this option. He has a living will indicating his desire for aggressive treatment if artificial means are required to sustain his life. The physician suspects that the patient's insistence on aggressive care may stem from his failure to understand the limits of available interventions.

The physicians in these cases were perplexed by their patients' seemingly inconsistent or unreasonable actions and decisions. In typical cases, physicians have little information about the patient's cultural and social background even though these characteristics shape end-of-life preferences. In this discussion, we argue that quality end-of-life care requires attention to cultural differences. Only through knowing the cultural background can clinicians make sense of a patient's explanatory models about illness, expectations about care, hopes for the future, and views regarding death (1). Building on many useful general articles on cross-cultural care and the culture of medicine (1–9), we focus on end-of-life care. Attention to cultural differences is particularly important because demographic changes increase the likelihood that U.S. physicians will care for patients from cultural backgrounds other than their own (10).

STRATEGIES FOR CROSS-CULTURAL END-OF-LIFE CARE

We revisit the cases introduced earlier to more fully describe the patients' cultural backgrounds and the impact of cultural differences on their care. The cases are composites, drawn from research or clinical experience. All names used are pseudonyms. Case 1 raises important issues about communication across cultural differences and misunderstandings over such basic issues as the role of the patient in decision making. Case 2 raises issues of patient mistrust with deep roots in cultural history and personal experiences.

Case 1. Wilma Martinez is a 67-year-old immigrant from El Salvador who moved to the United States to live with her daughter. Mrs. Martinez speaks only Spanish. Through her daughter's translations, the patient appears to comprehend details of her illness and treatment. When asked if she understands what the doctor is saying, she invariably nods affirmatively.

During a clinic visit when the patient's daughter is not

present, the physician arranges for a trained medical interpreter to be present. When the physician discusses end-of-life preferences, the interpreter reports that Mrs. Martinez thought that ventilatory support and cardiopulmonary resuscitation would hasten her death. Later, the interpreter explains that Mrs. Martinez could not understand why staff were insistent that she, rather than her daughter, make decisions. Mrs. Martinez stated, "In my country, the family decides." Assuming that her daughter would make decisions for her, she saw no reason to sign forms. She worried that signing forms would cause legal problems because of her immigration status. The interpreter also suggests that Mrs. Martinez's nodding indicates politeness and respect for the physician, not assent.

The physician arranges for a trained interpreter to be present at subsequent clinic visits. By probing—for example, asking, "Tell me what you believe is going on in your illness"—the physician ascertains that Mrs. Martinez does not expect to survive her illness. By asking, "How would you like decisions to be made about your medical care?" the physician confirms that Mrs. Martinez wants her daughter to make decisions for her. Rather than assuming that Mrs. Martinez's nods signify assent, the physician asks her specifically whether she has any questions or disagreement with the care plans.

Case 1 illustrates how the emphasis on patient autonomy and informed consent that is common in U.S. health care and bioethics is alien to many. Among some cultural traditions, disclosure of a serious diagnosis and decisions about treatment are sometimes made through discussions with family members, not the patient (11, 12). The cultural belief is that families should spare patients the suffering that accompanies the responsibility of decision making (13).

The ethical principle of respect for patients does not require physicians to insist that patients make decisions about their care (14). The physician should offer competent patients the opportunity to make these choices but accept preferences to have someone else make decisions for them. The patient's wishes may guide decisions, but the patient may want family to assess the benefits and burdens of interventions.

Mrs. Martinez's case also raises issues about communication. Behaviors such as nodding one's head may have different meanings in various cultures. Particularly when discussions with the patient are not smooth, physicians need to consider whether they are misinterpret-

ing nonverbal cues. Rather than indicating agreement, Mrs. Martinez's nod might be merely a social custom, showing politeness and respect for a person in authority (15). Recognizing this possibility, the physician asked specific questions that required the patient to express her wishes.

Language differences, even those that exist within the provider's own language (for example, black vernacular English or other dialects), should signal the need to seek clarity (4). Trained medical interpreters can ensure effective, efficient, and reliable communication between providers and patients (16). Physicians need to bear in mind that interpreters may themselves influence the content of messages conveyed during translations (17). When professional interpreters are unavailable, physicians may need to use family members or bilingual health care workers for translation. Family or untrained interpreters may, however, misinterpret medical phrases, censor sensitive or taboo topics, or filter and summarize discussions rather than translating them completely (17, 18). In case 1, Mrs. Martinez's daughter may not have translated information about mechanical ventilation and cardiopulmonary resuscitation accurately or may have been reluctant to tell the doctor that her mother did not understand or that the doctor's words were unclear.

Case 2. Communication between Lawrence Byrd, an African American, and his physician, a European American, has been difficult. In an effort to improve their relationship, the physician suggests using first names. Mr. Byrd does not use the doctor's first name, although the physician calls him "Lawrence." The doctor says, "Lawrence, I am worried about what happens when we reach the point where these interventions you are asking for would be costly and serve only to prolong your suffering." Mr. Byrd angrily demands that he receive "every medical test and procedure you've got—regardless of the cost."

The physician asks for advice from an African-American colleague, who suggests that the physician's well-meaning behavior might have seemed disrespectful. Calling an older African-American man by his first name is impolite. African-American persons who have suffered discrimination may fear neglect if they do not insist on maximal care. Many patients seek aggressive treatment because they value the sanctity of life, not because they misunderstand the limits of technology. Mr. Byrd may have perceived discussions of costs and the ineffectiveness of treatment as a devaluation of his life.

At the next visit, the physician asks Mr. Byrd whether he has experienced disrespect or racism: "Mr. Byrd, it is important for me to know if you have ever felt unfairly treated by me or anyone else involved in your care." Mr. Byrd relates incidents when his requests for pain medication went unanswered. The physician responds apologetically, "I am truly sorry if I have failed to communicate clearly in the past; I never intended to be disrespectful." The physician addresses the issue of pain directly: "Mr. Byrd, I would like to talk with you about your pain medication. Are we failing to treat your pain adequately?" Mr. Byrd reports that pain interferes with his sleep. The doctor continues, "Your well-being is important to me. Let's figure out how we can get the pain under better control." The doctor asks the patient to quantify his pain on a 10-point scale and to indicate what point would represent desired relief. With this information, the doctor increases the dose of analgesics and switches to sustained-release preparations.

The physician's well-intentioned efforts to transition to palliative care seemed at first to be met with hostility and mistrust. However, he was able to identify how his actions created barriers to optimal care by consulting a cultural "insider," who understood both the medical and cultural issues involved. A respectful inquiry, followed by a willingness to listen to the patient's story and acknowledge his experience, helped restore a trusting relationship.

Minorities' mistrust of physicians or of the health care system has been related to historical events, most notably the legacy of slavery and abuses in medical research (19–24). However, dealing with problems associated with trust in the past without considering the present institutional context or the contemporary framework fails to recognize the influence of physician and medical staff behaviors on patient trust (25–27). Data from a survey by van Ryn and Burke suggest that physicians' perceptions of patients are influenced by patients' ethnicity (28). According to the survey, physicians have negative stereotypes about black patients, including higher risks for nonadherence and substance abuse and lower intelligence compared with white patients. These stereotypes may exist unconsciously in physicians who are otherwise deeply opposed to discrimination, thereby subtly affecting their behavior (29). When asking about past incidents of discrimination or abuse, physicians should avoid responding defensively, even though they may be included in the patient's crit-

icisms of the medical system. When specific incidents that engender mistrust are reported, follow-up through appropriate quality assurance committees may be necessary to correct systemic problems (30).

After addressing the fundamental issues of mistrust and misunderstanding, Mr. Byrd's physician dealt with the specific problem (inadequate pain control) troubling his patient. African Americans in the U.S. health care system continue to experience serious inequalities in treatment across a broad spectrum of clinical conditions, from cardiac disease to cancer, diabetes, renal disease, asthma, HIV and AIDS, and pneumonia; pain relief is an additional area of inequality (31–36). Minorities are less likely than other patients to receive adequate pain relief (37–39). Pharmacies in minority neighborhoods are less likely to stock and fill prescriptions for narcotics (40). Aware of these disparities, the physician expressed his commitment to pain relief and ensured that he understood how Mr. Byrd was reporting pain levels by asking him to indicate the level of relief he wanted.

Like Mr. Byrd, patients who have experienced poor access to care may be concerned that palliative medicine represents “giving up,” or second-rate care (41, 42). Belief in the sanctity of life may make it difficult for patients to accept the philosophy of care offered through hospice and palliative medicine (43). In response to this concern, Mr. Byrd's physician assured him that he, the patient, was in control. The doctor might also consider exploring other symptoms and functional limitations experienced by Mr. Byrd and how his family was coping with his illness, thus opening discussion to further clarify the philosophy and services of hospice care. Once Mr. Byrd understood that his physician's disrespectful behavior had been unintentional, he was able to hear offers of palliative care more openly.

BASIC CONCEPTS OF CULTURALLY EFFECTIVE CARE

These cases suggest how physicians can better provide culturally effective care in societies characterized by diversity. To do so, physicians need the appropriate attitudes and skills, which have been termed *cultural sensitivity* and *cultural competence* (7, 9).

Cultural sensitivity requires that physicians be aware of how culture shapes patients' values, beliefs, and world views; acknowledge that differences exist; and respect these differences (6). Physicians need to maintain a non-

judgmental attitude toward unfamiliar beliefs and practices and be willing to negotiate and compromise when world views conflict. In case 1, the physician recognized that, for some people, decision-making authority is the responsibility of the larger family unit rather than the individual. In case 2, the physician realized that the history of racism in the United States and contemporary institutional and attitudinal barriers may lead some to view the health care system as untrustworthy. In both cases, physicians needed to accept the patients' values and world views as starting points for the physician–patient relationship.

Physicians also need to be aware of values, perspectives, and biases that are derived from their own culture of origin and from the biomedical world view of their professional training. Medicine itself is a cultural system with its own specific language, values, and practices that must be translated, interpreted, and negotiated with patients and their families (44, 45). For the physician, a patient's death may be regarded as a failure to achieve the goal of saving life rather than as the inevitable consequence of illness; this denial may contribute to the documented problems of inadequate treatment of pain and delays in referring patients to hospice care.

Cultural competence refers to knowledge and skills rather than attitudes. Physicians need a sound knowledge base regarding patients' cultural values, beliefs, and health behaviors. Cultural competence requires skills in communication, use of interpreters, and attention to nonverbal communication. In case 1, the physician recognized the importance of cultural etiquette and learned through the interpreter that the patient's nodding may have indicated respect and politeness rather than agreement. The physician used communication skills to advantage, asking in an open-ended manner about Mrs. Martinez's preferences for decision making. For example, he asked, “How would you like decisions to be made about your medical care?” In case 2, the physician learned that many African Americans are offended when addressed by their first name. This physician also might use communication techniques to encourage Mr. Byrd to express his emotions, for example, “How do you feel when that happens?” Such empathic questions strengthen the physician–patient relationship because a patient whose physician has listened to his story is likely to feel that the physician cares about him and understands him (46, 47).

It is unrealistic to suggest that health care providers should learn the common beliefs about illness and the practices of the many cultural groups in the United States. Nonetheless, it is reasonable for physicians to become informed about the needs of populations they see regularly in their practices. Guidebooks and Web-based resources that compile information about cultural differences can introduce physicians to beliefs and practices relevant to end-of-life care (48–50). Specific cultural issues include the appropriateness of openly naming a disease or discussing death, the expression of pain, attitudes toward suffering, and the role of family members (and professional caregivers) in serious illness.

A tendency to lump together large population groups under broad categories can obscure important differences. For example, the designation “black” could refer to West Indians, Africans, and American-born blacks, among others. “Hispanics” or “Latinos” may include Puerto Ricans, Mexican or Central Americans, Dominicans, Cubans, and others. “Asians” may include persons with ancestry from the Indian subcontinent, China, Korea, Japan, or other Pacific Rim countries. Furthermore, there is great diversity within ethnic and cultural groups. Patients are individuals, and all members of any group do not necessarily share the same cultural traits. For example, although survey and focus group data suggested that African Americans and members of certain Hispanic groups completed advance directives less frequently than European Americans, individual representatives of these groups did not necessarily hold these beliefs (51–55).

Concepts of culture and ethnicity may be useful for making generalizations about populations; however, if used to predict individual behavior, they may lead to stereotyping (28, 56, 57). Sex, socioeconomic class, education, immigrant status, and religion interact with patients’ cultural backgrounds in important ways. Physicians can avoid the risk for stereotyping by asking explicitly whether the patient holds a belief that is prevalent within a culture. As in any clinical situation, physicians can use open-ended questions, empathic comments, and probes to elicit the patients’ own perspectives on illness and their expectations for care (58, 59).

The influence of culture on the meaning and experience of death and dying may be applied to fundamental domains of end-of-life care, such as symptom

management, advance-care planning, and grief and bereavement counseling. Many areas of palliative care involve culturally mediated practices, including pain control, feeding, and nutrition (60). Symptom management in cross-cultural contexts requires attention to differences in the meaning and expression of pain and suffering and to the perceptions and customs related to touching or handling the body (61, 62). Although ethnicity may play a role in determining personal wishes for life support, feelings toward withholding or withdrawing treatment may follow seemingly contradictory patterns (54, 63). Physicians must develop advance-care planning strategies that reflect sensitivity to patient values and beliefs and emphasize shared goals, such as the relief of suffering. Understanding that mourning practices vary across cultural groups (62, 64, 65) will help physicians know how and when it is appropriate to intervene in the grieving process and when it is appropriate to assist in discussions about such issues as organ donation and autopsies.

Community and cultural ties may provide a source of great comfort as patients and families prepare for death. As stated earlier, physicians should assess the cultural background of each patient and inquire about values or preferences that may affect care at the end of life. Physicians should become aware of the specific beliefs and practices of the populations they serve, always remembering to inquire whether an individual patient adheres to these beliefs. With today’s managed care climate and with situations in which patient contact is episodic or sporadic, the lack of continuity of care can impede the opportunity to build cultural knowledge over time. Strategies that can enhance knowledge of a patient’s cultural beliefs, practices, or preferences, however, may save time in the long run. Knowing a fuller context of a patient’s life enables the physician to better provide comprehensive and compassionate palliative care at the end of life.

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Acknowledgments: The authors thank the funding sources for generous support of their work in cultural diversity, end-of-life care, and strengthening the doctor–patient relationship. They also thank the members of the ACP–ASIM End-of-Life Care Consensus Panel and the *Annals* re-

viewers for thoughtful and highly valuable comments on multiple drafts of this manuscript.

Grant Support: By the American Foundation for AIDS Research (1772); The Greenwall Foundation; National Institutes of Health (R01 NR029060); Open Society Institute Project on Death in America; the Robert Wood Johnson Foundation; State of California Universitywide AIDS Research Program (R95-ST-188); the University of California, San Francisco, AIDS Clinical Research Center; and the Robert Wood Johnson Foundation Initiative on Strengthening the Doctor–Patient Relationship.

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