Negotiating Cross-Cultural Issues at the End of Life
“You Got to Go Where He Lives”

Marjorie Kagawa-Singer, PhD, MN, RN
Leslie J. Blackhall, MD, MTS

THE PATIENTS’ STORIES
Mr and Mrs G, an African American Couple

Mr G is a 66-year-old African American man diagnosed with stage IV squamous cell cancer of the lung in October of 1999. He has chronic obstructive pulmonary disease and has a 40 pack-year smoking history. A retired factory worker, he lives at home with his wife in a large city in Alabama. After diagnosis, he received radiation therapy and a trial of chemotherapy with vinorelbine and cisplatin. In the fall of 2000, with evident progression of the disease, his pain and dyspnea increased, adding to the symptom burden of asthenia, anorexia, and delirium. On December 6, 2000, he was admitted to an inpatient palliative care unit with symptomatic hypercalcaemia. He was treated with fluids and pamidronate, and approximately 1 week later was discharged home with hospice services. He and his wife were interviewed on December 7, 2000 by Dr C, Mr G’s European American physician.

Ms Z, a Chinese American Woman

Ms Z is a 38-year-old Chinese American woman who, along with her older sister, was the primary caretaker for both parents over extended illnesses. She, her older sister, and both parents were born and raised in Hawaii. Her college-educated mother was diagnosed with stage IIIB adenocarcinoma of the lung in December 1994. In the 6 months following her diagnosis she underwent 6 rounds of chemotherapy, followed by radiation. Despite treatment, the disease metastasized to the liver, brain, and bones. During a final 10-day hospital stay she continued to undergo radiation treatment. Still hospitalized while hospice was being considered, she died in January 1996 at the age of 73 years. Ms Z’s father was a prominent business executive and community leader. He was diagnosed with Parkinson disease in the early 1990s and was treated with Sinemet (levodopa and carbidopa) and other medications. He died of complications from Parkinson disease in February 1997 at the age of 78 years, following a brief admission for aspiration pneumonia. Throughout her parents’ illnesses Ms Z lived in California and commuted to Hawaii every few months, where her parents, her 40-year-old sister, and several relatives lived. Ms Z was interviewed by a Perspectives editor on January 12, 2001.

Culture fundamentally shapes how individuals make meaning out of illness, suffering, and dying. With increasing diversity in the United States, encounters between patients and physicians of different backgrounds are becoming more common. Thus the risk for cross-cultural misunderstandings surrounding care at the end of life is also increasing. Studies have shown cultural differences in attitudes toward truth telling, life-prolonging technology, and decision-making styles at the end of life. Using 2 case studies of patients, one of an African American couple in the southern United States and the other of a Chinese-American family in Hawaii, we outline some of the major issues involved in cross-cultural care and indicate how the patient, family, and clinician can navigate among differing cultural beliefs, values, and practices. Skilled use of cross-cultural understanding and communication techniques increases the likelihood that both the process and outcomes of care are satisfactory for all involved.

JAMA. 2001;286:2993-3001 www.jama.com

PERPECTIVES

In the interview between Mr G and his physician, Dr C, for this article, Mr G suggested how physicians could improve their relationship with patients, especially when the cultural background of the 2 are different.

Mr G: Well, you know, you got to find out the identity of a person to even get to know them. So I think that’s a big “if” right there. Because if you don’t know a person, you got to find out his identity, go where he lives, where he goes, where he was born, who’s in his family. And he’s got to open up, and tell you these things. Because the more you know about this person, his family, then that’ll make you know more about you.

Author Affiliations: Community Health Sciences, University of California, Los Angeles School of Public Health and Asian American Studies (Dr Kagawa-Singer); Center for Palliative Care and Research, and Center for Biomedical Ethics, University of Virginia, Charlottesville (Dr Blackhall). Corresponding Author and Reprints: Marjorie Kagawa-Singer, PhD, MN, RN, University of California, Los Angeles School of Public Health and Asian American Studies, 650 Charles E. Young Dr, Los Angeles, CA 90095. Perspectives on Care at the Close of Life is produced and edited at the University of California, San Francisco, by Stephen J. McPhee, MD, Michael W. Rabow, MD, and Steven Z. Pantilat, MD; Amy J. Markowitz, JD, is managing editor. Perspectives on Care at the Close of Life Section Editor: Margaret A. Winker, MD, Deputy Editor, JAMA.

©2001 American Medical Association. All rights reserved.
Ms Z related to the Perspectives editor her communication with her mother after the doctor indicated to them that the prognosis for survival was poor.

Ms Z: We never discussed it [my mother’s prognosis] after [the doctor told us] . . . My father never discussed his prognosis either . . . my father knew he had Parkinson’s. There was certainly [material] available for him to read if he so chose. I don’t think he read it. And there does seem to be a barrier discussing it, especially about the course of treatment. I think there are 2 issues: one is the actual discussion about death, and one is the discussion about treatment and care up to that point. And both of my parents were resistant to discuss either issue.

CULTURE AND MEDICAL CARE

The United States is home to an increasingly diverse population, where the former dominant culture—European American (white)—is no longer a majority in some places. Encounters between patients and physicians of dissimilar ethnicities are becoming more common, yet the literature in end-of-life care has only recently begun to investigate the influence of cultural differences on the clinical encounter. The recent President’s Race Initiative (1997)1 to eliminate racial disparities in health outcomes indicates that cultural differences significantly affect the provision of healthcare, including at the end of life. Without concerted attention to resolve cultural differences, disparities are likely to increase.2

Culture is an important part of the context within which people (including health care professionals) understand their world and make decisions about how to act. Although each individual has a perspective that is influenced by many factors such as personal psychology, gender, and life experiences, culture fundamentally shapes the way people make meaning out of illness, suffering, and dying, and therefore also influences how they make use of medical services at the end of life. However, culture is not an independent, homogeneous, dichotomous variable.3 If “culture” is simply reduced to a series of isolated acontextual beliefs or practices categorized by ethnic origin, we run the risk of stereotyping or believing we know what people of that group tend to think. In fact, there is wide variation of beliefs and behaviors within any ethnic population. The other extreme is to disregard culture’s fundamental function of giving meaning to life and of providing guidelines for living.4 Failure to take culture seriously means we elevate our own values and fail to understand the value systems held by those of different backgrounds. Dana labels this posture “culturally destructive,” as compared with “culturally skilled,” behavior.5 Assuming a Chinese woman would not want to be told her diagnosis because she is Chinese is stereotyping. Insisting that she must be told, even at the risk of violating her rights, is a form of cultural imperialism. The challenge is to navigate between these poles.

Misperceptions caused by lack of cultural sensitivity and skills can lead to unwanted or inappropriate clinical outcomes and poor interaction with patients and their families at critical junctures as life comes to a close.6,7 If the Chinese family mentioned in the opening scenario believes that knowing the truth is harmful to the patient, a physician who persists in telling them the direct “truth” may be perceived as cruel, uncaring, and ignorant. The result is mistrust and anger, and may even precipitate the removal of the patient from medical care altogether.8

Patients bring to the medical encounter different languages, explanatory models concerning the cause and treatment of illness, religious beliefs, and ways of understanding the experience of suffering and dying.2 Styles of communication and beliefs about the role of physician, patient, and family also vary, and such differences may occur against the backdrop of experiences of societal oppression or inequities in medical care.9 For this reason, the clinical encounter often requires a negotiation between the worldviews or cultures of the clinician and the patient and family to reach mutually acceptable goals.2,10,11 In the end, addressing and respecting cultural differences will likely increase trust, leading to better clinical outcomes and more satisfactory care for patients and their families.12

Using 2 case studies as examples of cross-cultural encounters—an African American couple in the southern United States and a Chinese American family in Hawaii and California—we examine 6 specific issues for end-of-life care (TABLE 1). These families, from 2 different ethnic groups, share some views more aligned with each other than with the dominant culture, such as the reluctance to accept hospice and the dynamics of extended family involvement. The issues presented, and the views of each of the interviewees, however, are by no means exhaustive or generalizable to their entire ethnic group. Cultures are not monolithic, and a range of potential responses to each issue is likely to occur in every ethnic group. Careful examination of within-group variations, such as those attributed to acculturation differences, have not yet been applied to most studies of cultural diversity at the end of life. As the science in this area moves forward, we will be able to better understand not only differences between groups, but those within groups due to education, age, gender, geographic location, degree of ethnic homogeneity, social context, and individual acculturation.13 References and the list of Web sites at the JAMA Web site (http://jama.ama-assn.org/issues/v286n23/abs/jel10001.html) provide more nuanced variations and ranges of responses among and within different ethnic populations.

Patient Autonomy—The Dominant Culture, the Dominant Mode

In the European American model, patient autonomy is the primary focus of decision making at the end of life. Patient autonomy emphasizes the rights of patients to be informed about their condition, its possible treatments, and their ability to choose or refuse life-prolonging medical care. Advance care directives (ACDs) are meant to ensure that pa-

©2001 American Medical Association. All rights reserved.
Table 1. Techniques for Negotiating Issues Influenced by Culture That Are Important in End-of-Life Care

<table>
<thead>
<tr>
<th>Issue</th>
<th>Possible Consequences of Ignoring the Issue</th>
<th>Techniques and Strategies to Address the Issue</th>
</tr>
</thead>
<tbody>
<tr>
<td>Responses to inequities in care.</td>
<td>Lack of trust</td>
<td>Address directly: &quot;I wonder whether it’s hard for you to trust a physician who is not [of your same background]?&quot;</td>
</tr>
<tr>
<td></td>
<td>Increased desire for futile aggressive care at the end of life</td>
<td>Make explicit that you and the patient and their family will work together in achieving the best care possible</td>
</tr>
<tr>
<td></td>
<td>Lack of collaboration with patient and the family</td>
<td>Work to improve access and reduce inequities</td>
</tr>
<tr>
<td></td>
<td>Dissatisfaction with care by all parties involved</td>
<td>Understand and accommodate desires for more aggressive care, and use respectful negotiation when this is</td>
</tr>
<tr>
<td></td>
<td></td>
<td>contraindicated or medically futile</td>
</tr>
<tr>
<td>Communication/language barriers</td>
<td>Bidirectional misunderstanding</td>
<td>Take time to:</td>
</tr>
<tr>
<td></td>
<td>Unnecessary physical, emotional, and spiritual suffering</td>
<td>Avoid medical or complex jargon</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Check for understanding: &quot;So I can make sure I’m explaining this well for you, please tell me what your</td>
</tr>
<tr>
<td></td>
<td></td>
<td>understanding is about your illness and the treatment we’re considering&quot;</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Hire bilingual, bicultural staff and train in medical translation to be bridges across cultures. Translators</td>
</tr>
<tr>
<td></td>
<td></td>
<td>are preferable in person, but use AT&amp;T language line or similar services, if trained staff unavailable</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Avoid use of family as translators, especially minors</td>
</tr>
<tr>
<td>Religion and spirituality</td>
<td>Lack of faith in the physician</td>
<td>“Spiritual or religious strength sustains many people in times of distress. What is important for us to</td>
</tr>
<tr>
<td></td>
<td>Lack of adherence to the treatment regimen</td>
<td>know about your faith or spiritual needs?”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“How can we support your needs and practices?”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“Where do you find your strength to make sense of this experience?”</td>
</tr>
<tr>
<td>Truth telling</td>
<td>Anger, mistrust, or even removal of patient from health care system if team insists on informing the</td>
<td>Informed refusal:</td>
</tr>
<tr>
<td></td>
<td>patient against the wishes of the family</td>
<td>“Some patients want to know everything about their condition, others prefer that the doctors mainly talk to</td>
</tr>
<tr>
<td></td>
<td>Hopelessness in the patient if he or she misunderstands your reason for telling him or her directly</td>
<td>their families. How would you prefer to get this information?”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Use a hypothetical case, eg, &quot;Others who have conditions similar to yours have found it helpful to consider</td>
</tr>
<tr>
<td></td>
<td></td>
<td>several options for care, such as nutrition, to keep them feeling as well as possible”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Be cognizant of nonverbal or indirect communication when discussing serious information</td>
</tr>
<tr>
<td>Family involvement in decision-making</td>
<td>Disagreement and conflict between family and medical staﬀ when the family, rather than the patient, insists on making decisions</td>
<td>Ascertain the key members of the family and ensure that all are included in discussions as desired by the patient:</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“Is there anyone else that I should talk to about your condition?”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Talk with whomever accompanies the patient and ask the patient about this individual’s involvement in</td>
</tr>
<tr>
<td></td>
<td></td>
<td>receiving information and decision-making</td>
</tr>
<tr>
<td>Hospice care</td>
<td>Reduced use of hospice services, leading to decreased quality of end-of-life care</td>
<td>Emphasize hospice as an adjunct or assistance to the family but not as a replacement: “When the family is</td>
</tr>
<tr>
<td></td>
<td></td>
<td>taking care of the patient at home, hospice can help them do that”</td>
</tr>
</tbody>
</table>

Patients’ wishes concerning end-of-life care are enforced, even when they are no longer able to speak for themselves. 14-16 This framework reflects core values of the dominant culture—dependence, individual rights, and even fears of receiving too much care at the end of life. While the emphasis on patient autonomy has clarified the legal status of patients to refuse therapy and increased the comfort of physicians to make these decisions, patients and families from other cultures may not share these values and concerns.17,18

**FINAL CHOICES BY AN ELDERLY AFRICAN AMERICAN COUPLE**

**Responses to Inequities: Social and Historical Context of Trust in the Clinical Encounter**

Mrs G: *Because [an African American] doctor is the same nationality as myself, that causes me to want to trust him more, because he could relate better. Most of them have been there, even though they are above [it]—they’ve moved away from it. That helps, but like I said, as long as I know he’s qualified, it would make a difference [whether he is African American or not].* 4

Although Mr G has a do-not-resuscitate (DNR) order, opted for a palliative approach to his lung cancer, and accepted home hospice, several studies in diverse regions of the country and across practice settings have shown that African American patients are more likely to want aggressive medical care at the end of life and are less likely to have DNR orders or ACDs than European American patients.19-23 For example, one study of elderly outpatients in North Carolina found that African Americans were almost 3 times as likely as white patients to want more treatment (42% vs 15%), a choice that did not vary with education level.24 Similarly, African American outpatients in Miami were more likely to want life-prolonging therapy than white patients (37% vs 14%).25 McKinley et al found that 37% of African American cancer patients wanted cardiopulmonary resuscitation when terminally ill, while only 16% of white patients would desire such treatment. Only 3% of Af-
African Americans in this study had completed an ACD vs 34% of white patients. Murphy et al,22 in a study of elderly patients from 4 different ethnic groups in Los Angeles, reported that only 2% of African American elders studied had an ACD (17% of those with knowledge about ACDs) vs 28% of white subjects (40% of those with knowledge about ACDs). Morrison et al24 also found that Hispanic and African American patients were less likely to have appointed a health care proxy than white patients (20% and 31% vs 46%). In this study, however, ethnicity was not significantly associated with ACD completion after controlling for knowledge, age, availability of a health care proxy, experience with life support, and attitudes toward family involvement.25 Although African Americans represent 12.3% of the US population, they comprise only 8% of patients enrolled in hospice.25

Some have attributed these differences to mistrust of the medical system by African American patients, and evidence exists to support the contention that African Americans are less likely than white patients to trust the motivations of physicians who discuss end-of-life care with them. In the Miami study, Caralis et al19 found that African American patients were more likely to feel that they would be treated differently and receive lower-quality treatment if they completed an ACD. Other studies have also suggested that mistrust acts as a barrier to organ donation,26 and as a reason not to participate in medical research.27 In the Los Angeles study mentioned above, African American elderly persons were more likely than other groups to want life support under various conditions (for example, 27% wanted CPR in the event of a coma with no chance of recovery vs 13% of whites, 22% of Mexican Americans, and 14% of Korean Americans).20 Post survey interviews to probe the reason behind the increased desire for life support uncovered the belief that economic motivations were behind clinicians’ decisions to remove life support. Several subjects cited personal experience with relatives prematurely removed from life support, or not placed on it, including one woman whose son died of acquired immunodeficiency syndrome. He was not placed on life support and her conclusion was, “They figured out, or assumed, that I didn’t have money so they weren’t going to bother.”

Mrs G: We always think we know what’s best for us. And because we might not understand the explanations and what’s going on, we choose the easier way. I’m not saying it’s the better way—but because we don’t really fully understand, we just kind of stay in those same ways or traditions.

Although Mr and Mrs G appear to be blaming themselves for not understanding medical information, research has shown that African American patients have unmet needs for communication. African American patients generally want to be informed about the diagnosis and prognosis of a terminal illness, and want to make decisions about medical care.40

We have a tendency to want to treat ourselves, but we don’t have enough trust. . . . You know, most [doctors] use medical terms and big terminology that’s beyond us, and that tends to frighten us because we don’t know what they’re talking about—we might think one thing and feel misled to a point. We hear, but experience is different. . . . Sometimes experience can be detrimental—you don’t want to keep doing that.

Dr C: I don’t think we have the institutional racism that we had 30 years ago with the Jim Crow laws. But we have informal institutional racism, particularly here in the South. The way we decide how we’re going to fund medical care and other kinds of services for people. And people are smart—they know that.

Framing this whole issue as one of mistrust, however, is problematic. McKinley et al31 found that although African American cancer patients wanted more life-sustaining treatment than white patients, 96% trusted the medical system and less than 20% feared inadequate medical care. More importantly, as Crawley et al28 point out, framing the issue as one of mistrust implies that the main problem is the attitude of African Americans. In fact, health care institutions, both historically and in the present, have not always shown themselves to be worthy of trust.29,30 Trust is a critical element in cross-cultural cooperation. The historical context of African Americans’ experience within the dominant medical culture in the United States is the backdrop against which any discussion of trust must take place. The Tuskegee syphilis study31,32 and segregated hospitals are in the historic memory of most older African Americans, and current treatment disparities between African American and European American patients are extensively documented.33 Studies report less use of cardiac procedures,34–36 fewer surgeries for lung cancer,37 and reduced access to renal transplantation for African Americans.38 Similar disparities exist for Hispanics, Asian Americans, and Native Americans.39 Ultimately, until disparities in access and quality of care are eliminated or at least greatly reduced, simply encouraging African Americans and other ethnic minorities to be more “trusting” of recommendations provided by European American physicians is doomed to failure. Physicians can take steps outlined in Table 1 to constructively address this issue.

Communication

Mrs G: We always think we know what’s best for us. And because we might not understand the explanations and what’s going on, we choose the easier way. I’m not saying it’s the better way—but because we don’t really fully understand, we just kind of stay in those same ways or traditions.

Mrs G: We’re just ignorant to the facts that we don’t understand.

Although Mr and Mrs G appear to be blaming themselves for not understanding medical information, research has shown that African American patients have unmet needs for communication. African American patients generally want to be informed about the diagnosis and prognosis of a terminal illness, and want to make decisions about medical care.40

In the Study to Understand Prognoses and Preference for Outcomes and Risks of Treatment (SUPPORT),35 African Americans were among those most likely to want to discuss preferences for CPR, but not to have done so (odds ratio, 1.53; 95% confidence interval, 1.11–2.11). A 1986 telephone survey found that African American patients were more likely than European American patients to report that their physician did not sufficiently explain test results, medical conditions, and treatments.41 A more recent study42 found that African American patients were less likely than European Americans to feel that their physicians included them in decision making. This was particularly true for those in race-discordant patient-physician relationships.

Of course African American patients are by no means alone in their desire for better communication. Avoiding the use...
of medical jargon and checking for understanding are 2 easy ways to reduce misunderstandings with patients of any culture. When the patient speaks a language not understood by the physician, adequate translation is vital. See Table 1 for further details and suggestions on this topic.

Religion and Spirituality

Attitudes toward end-of-life care also may be influenced by religious or spiritual concerns. In one study, African American participants revealed their beliefs that only God has knowledge about—and power over—life and death, and that physicians cannot have access to this type of knowledge. One participant said “The doctor don’t know everything. God might come into it . . . He can do more for us than the doctor can.” Participants cited this belief as a reason for trying life support. Similarly, Koenig and Gates-Williams describe an African American woman with advanced pancreatic cancer who rejected hospice and DNR orders. She stated, “only God has priority over living. That’s something man can’t tell you—how long you got to live.” Crawley et al point out that the Christian religious view embraced by many in the African American community holds that suffering is redemptive. It is to be endured, rather than avoided. In this setting, forgoing life support in order to avoid pain and suffering might be seen as failing a test of faith. Denial of death and a willingness to undergo potentially painful and/or futile life support may in fact be part of an “ethic of struggle.” This ethic of struggle can be considered part of a moral strength that ensures a better place than this one in a world in which African Americans often die younger than their white counterparts.

FINAL CHOICES BY A CHINESE AMERICAN FAMILY

Truth Telling: Prognosis and Informed Refusal

Ms Z: The prognosis for my mother was given very gently. And given in the form of statistics. [The doctor] had a book of statistics out and said, “This is the percentage of people who are still living after 1, 2, 3 years . . . .” So it wasn’t given verbally. I think it was mentioned very delicately and I’m not sure how much of that information she actually took in at the time. . . . We never discussed it after that.

Although informed consent is a major tenet of US health care, truth telling about diagnosis, and especially about the prognosis of potentially fatal illnesses like cancer, is not the norm in much of the world. In Italy, France, and Eastern Europe, as well as much of Asia, Central and South America, and the Middle East, physicians and patients often feel that withholding medical information is more humane and ethical. A report by an Italian oncolgist in 1992, for example, describes the decision-making style in Italy as one in which the patient is “protected” from bad news by physicians and family. In a Greek population survey, only a third of the respondents believed that patients should be told of a terminal illness. Older respondents and those with less education were less likely to favor truth telling. Patients who have emigrated from countries where truth telling is not common often bring that perspective to medical encounters in this country. Even in the United States, as recently as the early 1970s physicians commonly withheld the diagnosis of cancer. Not until 1979 did the first article note the practice trend of disclosing a cancer diagnosis, and while open discussion of diagnosis has become the norm in this country, discussing prognosis remains difficult. One study of oncologists published in 2001 found that only 37% would give a truthful estimate of prognosis even when asked directly by the patient. The reason often given for withholding information about diagnosis or prognosis is that the truth may be cruel and is potentially harmful to the patient. Anecdotal reports note the tendency of Chinese and Ethiopian families to oppose truth telling because the patient would lose hope and suffer unnecessary physical and emotional distress. In the Los Angeles study cited above, 52% of Mexican American patients stated that patients should not be told the truth about a terminal prognosis. Within this ethnic group, older age, lower socioeconomic status, and less acculturation were associated with a desire for less truth telling. Ethnographic interviews revealed the belief that the truth should never be told because it hastens death. A Korean American subject from the same study reported keeping his wife’s cancer diagnosis a secret, saying, “We kept it a tight secret . . . . If she knew, she would not be able to live longer because of the fear.” Only 35% of the Korean American subjects in this study believed that a patient should be told of a terminal prognosis.

Ms Z reports that prognosis was discussed only indirectly with her mother, and, as noted above, several authors have described the tendency toward nondisclosure in Chinese society. One recent study of 1136 Chinese persons in Hong Kong, however, indicates that the patterns of preferences for patients desiring information about diagnosis (95%) and prognosis (97%) were similar to those in the United States. Such findings emphasize the importance of being specific about the group studied. For example, identifying all persons as “Chinese” whether they come from rural mainland China, Hong Kong, or Taiwan may miss important sources of variation.

The issue of truth telling is more complex than simply whether or not to tell the truth. It also includes the problem of how to tell and to whom. Even a patient who does not want direct disclosure may wish to know the truth through other means: indirectly, euphemistically, “delicately” (as Ms Z puts it), or nonverbally. In far east Asian cultures, such as Korean, Chinese, and Japanese, nonverbal communication is often acknowledged to be a vital means of interpersonal connection. “Zhih Yi” is the Chinese term that denotes nonverbal communication, “just knowing what the other thinks and feels,” and the Japanese term “inshin denshin” denotes a similar concept of
knowing without being told. The Korean word “nunchi” denotes understanding through social, nonverbal cues.

The purpose of indirect communication in these cultures is to preserve the “face” of the other; that is, never to put the person one is talking to into a position of embarrassment or loss of honor by directly posing potentially sensitive questions. “Face,” in the Asian sense, is the preservation of family and community honor more so than individual honor. This proscription against losing face applies to all verbal communication and conduct both within and outside the family or community setting. In these cultures, indirect or nonverbal communication may be preferable, because the ambiguity saves face and allows for the possibility of hope.

In situations in which the family insists that the patient not be told, but the clinician feels that some diagnostic or prognostic information needs to be provided (eg, before radiation therapy or chemotherapy), one strategy is to make an offer of information to the patient, allowing the patient “informed refusal” (see Table 1). The clinician establishes with the patient who should receive all medical information and make decisions regarding the patient’s care. If the patient designates that someone else be given this responsibility, this constitutes the patient’s informed refusal to be included in the discussions or decision making, and this preference should be documented.

Another strategy is to use a hypothetical case as described by Carrese and Rhodes in their article describing decision-making styles among Navajo patients and practitioners. This technique acknowledges the patient’s and/or the family’s realistic fears, respects the need for indirect discussion, and implicitly invites further questions. Apparently tangential statements by the patient or family may be indirect questions, and indicate the desire for more information. How the questions are answered requires sensitivity and skill to gauge the degree of information sought. Direct confrontation may frighten or offend the patient/family, and they may not pursue their inquiry. On the other hand, they may appreciate bringing the questions to light. Responses, therefore, may be indirect or couched as hypothetical, according to the capacity of the patient/family (Table 1). The physician should regularly seek feedback from the patient/family to assess their understanding of the progression of the disease and the treatment plan, and their desire for additional information.

Family Involvement in Decision Making

Ms Z: I know there’s often a great resistance to the idea of hospice or placing people in hospice. A lot of the resistance comes from admitting that the patient is dying. Or it feels like a failure of the medical system. I think one of the reasons that Asians are resistant to hospice is that it feels like a failure on the part of the caretaker . . . to take care. It seems almost like giving up or admitting that the caretakers can no longer take care of their own.

Consideration of hospice care places cultural values of families into bold relief, and differences with mainstream hospice approaches become apparent when we see that although ethnic minority populations now comprise over 25% of the US population, they represent less than 17% of patients enrolled in hospice. Very few of these are Asian Americans. Filial piety, which is an important concept in many parts of Asia including Korea, China, and Japan, may partly account for this.

Filial piety is the expectation that children will care for their parents without question in gratitude for their parent’s caring and sacrifices, and infuses all aspects of a parent’s care. Hospice, which constitutes accepting care from outsiders, may
EVALUATING AND ADDRESSING CULTURAL ISSUES AT THE END OF LIFE

Mr G’s perspective, noted in his opening quote, is the key to cross-cultural communication: “you got to find out the identity of a person to even get to know them . . . and he’s got to open up and tell you these things.” When the physician and patient are from different cultural backgrounds, the physician needs to ask questions that respectfully acknowledge these differences and build the trust necessary for the patient to confide in him or her. Physicians can use knowledge about particular cultural beliefs, values, and practices to respectfully recognize a person’s identity and to assess the degree to which their cultural background may influence their health care decisions. One way to begin this dialogue is by evaluating patients’ and families’ attitudes, beliefs, context, decision making, and environment (ABCDE) (Table 2). This approach is adapted from work by Koenig and Gates-Williams.65 The purpose of this mnemonic is to help avoid the dual pitfalls of cultural stereotyping or ignoring the potential influence of culture. In this way, the risk of miscommunication may be reduced.

While understanding the patient as an individual in the context of culture does not prevent conflicts over differing values, beliefs, or practices, information gained from such an assessment serves to identify areas for negotiation of conflicts should they occur.18 When the physician and the patient/family have some understanding of each other’s perspective, such negotiations can take place in an atmosphere of mutual respect rather than frustration and misunder-

Table 2. Assess ABCDE to Ascertain Level of Cultural Influence

| Attitudes of patients and families | What attitudes do this ethnic group in general, and the patient and family in particular, have toward truth telling about diagnosis and prognosis? What is their general attitude toward discussions of death and dying? How reflective are their practices of traditional beliefs and practices? | Educate yourself about attitudes common to the ethnic groups most frequently seen in your practice (see References). Determine attitudes of your patient and their family (see Table 1). For example, what is the symbolic meaning of the particular disease? |
| Beliefs | What are the patient’s and family’s religious and spiritual beliefs, especially those relating to the meaning of death, the afterlife, the possibility of miracles? | See Table 1 for strategies addressing the religious concerns of individuals and families. For general information, see list of Web resources at: http://jama.ama-assn.org/issues/v286n23/abs/jel10001.html. |
| Context | Questions about the historical and political context of their lives, including place of birth, refugee or immigration status, poverty, experience with discrimination or lack of access to care, languages spoken, and degree of integration within their ethnic community | Religious and community organizations may be able to provide general information about the relevant group (see below, “Environment”). Ascertain specific information by asking the following: “Where were you born and raised?” “When did you emigrate to the United States, and what has been your experience coming to a new country? How has your life changed?” “What language would you feel most comfortable speaking to discuss your health concerns?” Life history assessment: “What were other important times in your life and how might these experiences help us to understand your situation?” |
| Decision-making style | What decision-making styles are held by the group in general and by the patient and family in particular? Is the emphasis on the individual patient making his or her own decisions or is the approach family centered? | Learn about the dominant ethnic groups in your practice (see References): How are decisions made in this cultural group? Who is the head of the household? Does this family adhere to traditional cultural guidelines or do they adhere more to the Western model (see Table 1)? |
| Environment | What resources are available to aid the effort to interpret the significance of cultural dimensions of a case, including translators, health care workers from the same community, community or religious leaders, and family members? | Identify religious and community organizations associated with the ethnic groups common in your practice (hospital social worker and chaplains may be able to help you in this effort). See list of telephone translation services available at: http://jama.ama-assn.org/issues/v286n23/abs/jel10001.html. |

Adapted from work by Koenig and Gates-Williams.65
standing. In the cases above, we have discussed the context for potentially divisive issues such as “informed refusal” of diagnostic or prognostic information, delegation of decision-making power to the family, and increased desire for life support. Many other important areas, including end-of-life customs or religious rituals that give meaning, security, and solace in times of need and during life transitions such as death, have been addressed in detail elsewhere.45,73

As the suggested lines of inquiry provided in Tables 1 and 2 indicate, timely and sensitive investigation can begin to broaden options available to the physician to explore cross-cultural differences.3 When specific issues (such as differing desires about truth telling, or reluctance to sign informed consent documents) arise repeatedly, development of appropriate and respectful institutional protocols may help avoid laborious negotiations in each individual encounter.29,74 The suggestions in Tables 1 and 2 build on the basic communication skills presented by numerous authors with various mnemonics to promote more productive communication generally and at the end of life.33,73-77 The reader is directed to the growing literature in cultural competency that addresses this need and the many approaches being developed.5,78-81

“Cultural competence” is, however, not simply a moral or ethical obligation, or a “nice thing to do.” It is now the law. In December 2000, the Office of Minority Health of the US Department of Health and Human Services released national standards for culturally and linguistically appropriate health services.80 These standards are primarily directed at health care organizations, though individual providers are encouraged to use the same standards to make their practices more culturally and linguistically accessible.

Institutions such as hospitals, home care and hospice agencies, and nursing homes must take responsibility for facilitating culturally competent care. This includes knowing the groups that most frequently use the institution, seeking out and disseminating information about cultural beliefs that might affect attitudes toward illness and health care, providing adequate translation services, and identifying community resources. Hiring and training health care workers (at all levels) who are members of the ethnic group in question or knowledgeable about them, and who have credibility within these communities, may assist greatly in bridging the cultural chasm.

Finally, note Mr G’s comment about physicians eliciting a complete social history from the patient: “the more you [the physician] know about this person, his family, then that’ll make you know more about you.”

Reflecting on the ways culture shapes the patient’s worldview invites self-reflection about the physician’s own biases, values, beliefs, and practices. Cross-cultural experiences may also enrich the repertoire of the physician with alternative ways to ease the dying process for patients, families, and staff. Accepting this invitation enables the growth that is the hallmark of cross-cultural communication skills.30

Funding/Support: The Perspectives on Care at the Close of Life section is made possible by a grant from the Robert Wood Johnson Foundation.

Other Resources: For a list of relevant Web sites and telephone translation services, see the JAMA Web site at http://jama.ama-assn.org/issues/v286n23/abs/jel10001.01.html.

REFERENCES


©2001 American Medical Association. All rights reserved.


WEB SITES FOR CULTURAL HEALTH INFORMATION

EthnoMed
http://ethnomed.org
Ethnic medicine information from Harborview Medical Center

Last Acts
http://www.lastacts.org
An online community dedicated to improving end-of-life care

Montana Area Health Education Center
http://ahec.msu.montana.edu/students/culture.html
Culturally Competent Health Care Web site

Office of Minority Health Information Center
http://www.omhrc.gov/clas
Assuring Cultural Competence in Health Care: Recommendations for National Standards and Outcomes-Focused Research Agenda

Park Ridge Center for the Study of Health, Faith and Ethics
http://www.parkridgecenter.org
Offers a series of books (Health and Medicine in the Faith Traditions) giving general information about different religions

Resources for Cross-Cultural Health Care
(Julia Puebla Fortier, Director)
http://www.diversityrx.org
8915 Sudbury Rd, Silver Spring, MD 20901 (301/588-6051)

Telephone Services

Certified Languages International
http://www.clilang.com (800/237-8434)

Language Line Services
http://www/languageline.com (800/752-0093 x196)

Tele-Interpreters
http://www.teleinterpreters.com

Online Interpreters
http://www.onlineinterpreters.com (888/922-3582)