Understanding Cultural Difference in Caring for Dying Patients

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Experiences of illness and death, as well as beliefs about the appropriate role of healers, are profoundly influenced by patients' cultural background. As the United States becomes increasingly diverse, cultural difference is a central feature of many clinical interactions. Knowledge about how patients experience and express pain, maintain hope in the face of a poor prognosis, and respond to grief and loss will aid health care professionals. Many patients' or families' beliefs about appropriate end-of-life care are easily accommodated in routine clinical practice. Desires about the care of the body after death, for example, generally do not threaten deeply held values of medical science. Because expected deaths are increasingly the result of explicit negotiation about limiting or discontinuing therapies, however, the likelihood of serious moral disputes and overt conflict increases. We suggest a way to assess cultural variation in end-of-life care, arguing that culture is only meaningful when interpreted in the context of a patient's unique history, family constellation, and socioeconomic status. Efforts to use racial or ethnic background as simplistic, straightforward predictors of beliefs or behavior will lead to harmful stereotyping of patients and culturally insensitive care for the dying.

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In providing care at the end of life, a salient category of difference is cultural variation, which in the United States is usually understood as reflecting differences that divide along lines of race or ethnicity and, to some extent, religion. Death is inevitably understood and experienced within a complex web of cultural meanings.[1-3] How should physicians take culture into account when providing medical care for patients nearing the end of their lives?*

We focus on two questions: How does culture shape the experience of illness and death in clinically meaningful ways, such as mediating the response to pain? and How is cultural difference relevant to implementing the new "bioethics practices" that govern end-of-life care in US health care institutions? Practices such as writing do-not-resuscitate orders have become central rituals of death in our society, replacing other markers of transition from life to death.

Central to our discussion is a strong argument about the complexity of cultural interpretation and the need to draw clear distinctions between culture, race, and eth-

nicity as categories of difference. Dangers exist—for example, creating negative stereotypes—in simply supplying clinicians with an atlas or map of "cultural traits" common among particular ethnic groups.

Two Case Vignettes

As medical anthropologists, we have done research on how culturally diverse patients with cancer, their family members, and their health care providers have approached decisions about care at the end of life.[4,5] The following case vignettes, collected through in-depth interviews in the course of longitudinal anthropologic research, reveal the complexity of cross-cultural medical care.

Patient 1

A diagnosis of pancreatic cancer led this patient's care providers to initiate discussions about her resuscitation status on five separate occasions during the last months of her life. A note written in her medical record during a hospital admission for pain control stated: "Pt urged to consider DNR/DNI [do-not-resuscitate or do-not-intubate orders] given her horrible prognosis." But the patient persistently resisted her care professionals' view of what her course of illness should look like. A 46-

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year-old African-American woman with strong religious beliefs, she rejected "meals on wheels," refused hospice, and until right before her death, wanted cardiopulmonary resuscitation in the event of cardiopulmonary arrest.

The patient described the following exchange with a physician after her diagnosis, established with great difficulty after several procedures, was finally confirmed:

But they told me—asked me did I want them to tell me how long I had to live. I told them no, because I said only God has priority over living. That's something man can't tell you—how long you got to live. I said only God can heal you. And they looked at me so funny.

The patient's physicians were compassionate, even visiting her at home during one attempt to verify her resuscitation status. But her medical management was complicated by fragmented care; her only insurance was Medi-Cal (California's Medicaid), and she had not seen a physician for more than five years before being diagnosed with cancer. In the end, frail, immobile, and full of ascites, she was cared for by a large extended family. Her efforts to manage her pain may have been complicated by her fear that medications sometimes "disappeared." Administrative hurdles set up by Medi-Cal made it difficult to get her prescriptions filled. Whereas from her physician's point of view, getting the do-not-resuscitate order was the key decision the patient faced, she was concentrating on getting well.

Patient 2

This patient was diagnosed with locally invasive nasopharyngeal cancer in China before he emigrated to the United States with his family. The oldest son, who attends college, always accompanied his monolingual father to the clinic. Despite treatment with irradiation and chemotherapy—along with traditional Chinese medicine—the cancer progressed to the point of being immediately life-threatening due to hemorrhage. Although aware of the nature and severity of the diagnosis, family members avoided the use of the word cancer, preferring the more neutral Cantonese term for tumor when discussing the patient's illness. The family's ideas about appropriate disclosure varied from the health care team's view. The patient's son complained, "For us Chinese, we are not used to telling the patient everything, and patients are not used to this either. If you tell them, they can't tolerate it and they will get sicker."

During one visit to the clinic, the physician wanted the patient's son to explain that chemotherapy had not been effective in his case and that there were no more treatments available. The son became distressed.

I did not want to translate this to my father, but the doctor insisted on telling him everything. The doctor found the Chinese-speaking nurse to translate for him and told him everything.

Because of the family's reluctance to discuss the prognosis openly, the team's well-intentioned efforts to manage the patient's death at home were thwarted.

These case presentations reveal a range of ways in which culture is relevant to terminal care. Patient 2's use of Chinese herbal medicines in combination with biomedical therapies represents a successful blending of

traditions. The two cases also show the potential for serious disputes and dissatisfaction when patients from a minority group are confronted with practices routinely accepted within US biomedicine. The patient's son did not share the high value his father's physician placed on open disclosure of a cancer diagnosis and limited prognosis. Patient 1 did not comprehend her physician's view that further treatment of her illness, including resuscitation, was futile.

Race, Culture, Class, Ethnicity— The Nature of Difference

Patient 1's race varies from that of most of the physicians who cared for her. Patient 2's ethnicity derives from his country of birth, his language, and his immigrant status. What do these categories mean, and how do they intersect with culture and with social class? One distinction—that the designation "race" reflects biologic difference whereas "ethnicity" refers to cultural variation—is outmoded. Adopting the term ethnicity was a change from 19th-century conceptions of race (or biologic variation) as the bedrock of difference. Although the word "race" remains in popular use, as a scientific classification it is based on "outmoded concepts and dubious assumptions about genetic difference."[6(p248)] Genetic variation within races is always greater than variation between races.[7] Races do not exist as natural categories; rather, they are social constructions, meaningful only within particular historical contexts, and subject to change.

In the United States, cultural and social class differences are often confused because ethnicity and class are closely correlated. Culture is not reducible to class, however. (A full discussion of the culture concept is beyond the scope of this review.) The medical anthropologist Arthur Kleinman explains how the concept has evolved and changed[8,9(pp113-114)]:

Culture is now viewed not merely as a fixed, top-down organization of experience by the symbolic apparatuses of language, aesthetic preference, and mythology; it is also "realized" from the bottom up in the everyday negotiation of the social world, including the rhythms and processes of interpersonal interactions.

We focus here on interpretive approaches, on "reading" patients, as opposed to thinking about culture as a demographic variable that predicts specific behavioral traits. Gender differences must be approached in similarly sensitive ways. Culture is constantly redefined and negotiated, meaningful only when interpreted within the context of a patient's unique history, family constellation, and socioeconomic status.

Considering culture as a predictive variable is inherently limited—that is, simply plugging race or ethnicity into a multiple-regression analysis or, in a clinical context, assuming someone's name, appearance, or national origin is a predictive factor. The image that comes to mind is of a young medical resident, recently returned from a lecture on cultural sensitivity in health care, who pulls his or her index card from a pocket when dealing with a patient like patient 2 and, assuming that there

is no need to discuss his care directly with him—because Chinese culture is family-oriented—concludes that the resident's only responsibility is to follow the son's wishes.

Changing Demographics

As the United States becomes increasingly diverse, situations often occur in which the cultural background of a physician or other health care professional differs from that of a patient and family.[6] According to the 1990 census, the percentage of foreign-born residents in the United States is 8%. In the state of California, that figure has increased to 22%, with a concentration in urban areas. A third of residents of San Francisco and Los Angeles, for example, are foreign-born. In the United States, 12% of the population identifies itself as African American. Dramatically changing demographics offer only a partial explanation of the urgency of respecting cultural differences in clinical work. Equally salient are the political forces of multiculturalism.[10] The call for the recognition of minority voices in US society will inevitably surface as a serious concern during discussions of ethical issues in end-of-life care, particularly the appropriate allocation of ever-scarcer medical resources.

Cross-cultural Variations in Death and Dying

The culturally constructed boundaries between life and death are more variable than scientific definitions, based on cellular death or organ system failure, suggest. In Vanatinai, a small island close to Papua New Guinea, those who would be considered unconscious by western-trained physicians are viewed as already dead, leading to cases where a person may "die" many times.[11]

Similarly, cultural practices at the beginning of life shape the definition of death. In some traditional Native American societies, an infant was not considered a full member of the community until a "naming ceremony" or other ritual is performed, often at 1 month of age or older.[12] If an infant dies before this important ceremony, no funeral is required because the infant is not yet a part of the social group and hence not fully alive.

Death is socially constructed in the United States as well. The life of a bedridden, isolated, demented elderly woman could be described as a form of social death that precedes biologic death. Our familiarity with existing social definitions of life and death disguises the strangeness of a concept such as brain death. In the past three decades, the relationship between biologic and social death in the United States has been transformed by the new concept of brain death. Perhaps not surprisingly, this new construction has not been universally embraced. Empirical evidence documents a lower rate of organ donation by minority groups in the United States.[13,14]

The response to the loss of particular persons also varies considerably through time and place. In the contemporary United States, the loss of an infant or child is considered one of the most tragic experiences a family can face. By contrast, in less economically privileged societies, the loss of the family's primary worker may be much more tragic. In the northeast of Brazil where anthropologist Scheper-Hughes studied impoverished mothers, child deaths, which happened frequently, were understood to be inevitable, a function of the child's will to life; mourning lasted only a few days.[15]

Emotional expressions of grief are also highly culturally patterned. Although some form of ritual or ceremony to mark a death is universal, expressions of grief vary widely. Two societies that share the Muslim religion—Egypt and Bali—condone opposite expressions of grief. In Bali, a person in mourning must remain calm and cheerful, keeping a strict separation between inner and outer feelings. By contrast, in Egypt a woman who remains "withdrawn, mute, and inactive" for seven years while mourning the death of a child is considered sane and healthy.[16] In the dominant European-American tradition, both these patterns would be considered disorders.

A problem with blanket statements about cultural patterns is that they disguise the often important intracultural variation that exists in most societies and has always existed, even before the modern era of instant worldwide communication and massive migration. The notion that culture can be simply and easily "mapped" onto geographically isolated human groups has been abandoned by anthropologists.[17] Calls for "culturally competent care" ignore the dynamic nature of culture. It cannot be assumed that patients' origins will lead them to approach decisions about their death in a culturally specified manner.

Cultural Difference in the United States

Differences between nations are generally not ethically troubling for clinicians. That physicians in Japan or Italy choose not to reveal a diagnosis of cancer to a patient is not a problem if this is accepted and expected practice in a homogeneous society.[18,19] The situation in the United States is notably different. Maneuvering within cross-cultural encounters requires familiarity with the possible range of variation, both around the world and in the United States. Physicians need to know the possible range of variation in response to illness and death to respond to the needs of their patients.

In the care of dying patients, managing pain is often a central task. Sociologists have observed that the experience of pain and its expression varies among American immigrants.[20,21] Models have been developed that describe how cultural groups have different standards of appropriate behavior when in pain, which in turn lead to variation in how patients perceive, interpret, and respond to pain. More recent models integrate biologic, psychological, and sociocultural aspects of pain.[22] Researchers continue to demonstrate differences in how ethnic groups express and respond to pain, both acute and long-term.[23,24]

To understand the relationship between pain control and cultural difference, it is necessary to consider the historical and political context. Health care workers in urban clinics struggle with the issue of managing pain in an environment of poverty where drug abuse may be present. Social class-based divisions that separate the lives of health care professionals and patients are further accentuated by decades of overt racism and open discrimination. Pain management of Hispanic and white patients with similar trauma was compared in an emergency department.[25] Undertreatment of Hispanic patients in pain by health care professionals—perhaps because of overt discrimination—could not be ruled out, as later research showed that physicians were not simply making inaccurate evaluations of the amount and intensity of pain experienced by these patients.[26]

What constitutes a "good" death? As with the experience of pain, cultural narratives of dying vary. The ideal of hospice care, with its emphasis on a peaceful, accepted death at home in familiar surroundings with family members present, demonstrates unexamined white middle-class assumptions. African Americans have more negative attitudes toward hospice.[27] Admission to a hospice facility generally requires accepting the inevitability of death, expressed through the idea of a prognosis of less than six months to live and an agreement to forgo aggressive care and resuscitation.

Chinese immigrants may choose to avoid death at home because of traditional beliefs about ghosts inhabiting dwellings where someone has died. Indeed, a recent death may affect the market value of real estate in some Chinese neighborhoods (Evelyn Lee, EdD, oral communication, Richmond Area Multi-Services, San Francisco, California, June 1992).

Beliefs about the integrity of the body and its proper treatment after death are also areas of possible cross-cultural conflict. The idea of an autopsy may be repugnant to some groups, particularly if the request is made while the patient is still alive.[28]

New Rituals of Bioethics

*Implications for Culturally
Diverse Patients*

Understanding that the experience of pain varies across cultural groups may lead to improved clinical management. More problematic is the observation that notable differences exist among cultural groups in the United States in accepting and using the bioethics practices that regulate end-of-life care. Inevitably, each ill person reaches a point when medical interventions can do little to stave off death and may, indeed, prolong the process of dying. Because expected deaths are increasingly the result of explicit negotiation about limiting or discontinuing therapies,[29] the likelihood of serious moral disputes and overt conflict increases. Negotiated deaths lead to bioethics rituals as a new rite of passage to death. In many American hospitals, the decision not to resuscitate a patient or to limit or discontinue therapy is the pri-

mary indication that the end of life is approaching. In a sense, because of changing medical technology, death has moved from the realm of nature to that of culture in our society. The cultural values and beliefs that inform the new bioethics practices are white, middle-class, and based on western philosophical and legal traditions that emphasize the individual and individual decision making.[30] Successfully implementing "death by decision" depends on a set of cultural attributes, including the open disclosure of distressing information, the desire for control, and future orientation, described elsewhere as the "autonomy paradigm" in bioethics.[31]

Surveys have documented the lack of fit between bioethics innovations and minority populations in the United States. Substantially fewer minorities make use of advance directives to guide their care at life's close. African Americans differ notably from European Americans both in their unwillingness to complete advance directives and in the desires about life-sustaining treatment expressed.[32] Substantially more African Americans and Hispanics "wanted their doctors to keep them alive regardless of how ill they were, while more . . . whites agreed to stop life-prolonging treatment under some circumstances."[33(pp157-158)]

A study comparing elderly persons from four cultural groups in Los Angeles found that 80% of Hispanics and Korean Americans endorsed the statement, "Life-sustaining machines should never be stopped because even if the patient appears to be dying, there is always the chance of a miracle." Fewer than a third of the European Americans agreed. The research demonstrated equally striking ethnic differences in beliefs about discussing death openly with patients; most Koreans and Hispanics believed that this was harmful to dying patients.[34]

An Individual Approach Versus Cultural 'Traits'

The challenge of respecting diversity is great. Because culture is fluid and dynamic, how can we respect differences while avoiding stereotyping of patients? The answer is clear. Patients should never be approached as empty vessels, as the bearers of particular cultures. Rather, it is essential to approach patients first as unique persons, assessing them within the context of their family or other key social support system. General knowledge about theoretical differences among groups is helpful. For example, it is useful to bear in mind that in many Asian societies, ideas about "selfhood" vary from the western ideal of an autonomous individual. A sociocentric or relational sense of self often leads to decision-making styles at odds with western bioethics ideals. Likewise, it is helpful to keep in mind that African Americans, with a complex history of limited access to services, may not trust physicians to act in a patient's best interest.[35] Nonetheless, clinical inferences about cultural difference must be evaluated for relevance to a particular patient or family.

We propose an approach with patients and families nearing the end of life. Rather than memorizing the traits

associated with different groups, we suggest evaluating each patient and family using the following guidelines:

• Assess the language used to discuss this patient's illness and disease, including the degree of openness in discussing the diagnosis, prognosis, and death itself;

• Determine whether decisions are made by the patient or a larger social unit, such as the family;

• Consider the relevance of religious beliefs, particularly about the meaning of death, the existence of an afterlife, and belief in miracles;

• Determine who controls access to the body and how the body should be approached after death;

• Assess how hope for a recovery is negotiated within the family and with health care professionals;

• Assess the patient's degree of fatalism versus an active desire for the control of events into the future;

• Consider issues of generation or age, gender and power relationships, both within the patient's family and in interactions with the health care team;

• Take into account the political and historical context, particularly poverty, refugee status, past discrimination, and lack of access to care;

• To aid the complex effort of interpreting the relevance of cultural dimensions of a particular case, make use of available resources, including community or religious leaders, family members, and language translators.

Politics of Multicultural Care

Assessing patients and families against the dimensions of cultural variation is an important first step. But in the complex setting of managed death, health care professionals have no guarantee that even the most skillful assessment will avoid or resolve conflicts, improve care, or eliminate dilemmas. Some adjustments to clinical management are relatively simple and straightforward. For example, it is relatively easy to respect the wishes of an Islamic patient and family who request that the patient's body be turned to face the east after death. This act does not interfere with clinical management before death, it is not offensive to medically trained staff, and it does not raise costs. Only a small adjustment in the routine of managing the body after death is required; respecting difference is easy because it does not challenge the physician's own values.

In direct contrast are those differences that create serious disputes and the potential for conflict. Like their patients, physicians act in accord with deeply held values; scientific biomedicine has its own set of "cultural" practices surrounding death and dying.

What of a family who requests indefinite life support for a brain-dead patient in an intensive care unit? Situations like this occur, demanding skillful clinical interventions while presenting complex policy dilemmas. The state of New Jersey has enacted revised brain death legislation that allows for an exemption based on religious beliefs.[36]

The ideal of respecting diverse cultural perspectives is based on deeply held American beliefs in the value of

tolerance. This does not mean, however, that patients may demand unlimited treatment based on their beliefs or cultural identity. The challenge for clinical practice is to allow ethical pluralism—a true engagement with and respect for diverse perspectives—without falling into the trap of absolute ethical relativism.

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Talking to the Family

My white coat waits in the corner
like a father.
I will wear it to meet the sister
in her white shoes and organza dress
in the live of winter,

the milkless husband
holding the baby.

I will tell them.

They will put it together
and take it apart.
Their voices will buzz.
The cut ends of their nerves
will curl.

I will take off the coat,
drive home,
and replace the light bulb in the hall.

JOHN STONE, MD[c]
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From The Smell of Matches by John Stone
Louisiana State University Press, 1972