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.

(Koenig BA, Gates-Williams J: Understanding cultural difference in caring for dying patients, In Caring for Patients at the End of Life [Special Issue]. West J Med 1995; 163:244-249)

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. 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 ethnicity 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. 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-
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 biological difference whereas “ethnicity” refers to cultural variation—is outdated. Adopting the term ethnicity was a change from 19th-century conceptions of race (or biological 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.”

Genetic variation within races is always greater than variation between races. 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:

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 resi-
dents 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 identi-
fies 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 multi-
culturalism.9 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 biologi-
cal and social death in the United States has been trans-
formed by the new concept of brain death. Perhaps
not surprisingly, this new construction has not been uni-
versally 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 con-
temporary 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 Schepet-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 cul-
turally patterned. Although some form of ritual or cere-
mony to mark a death is universal, expressions of grief
vary widely. Two societies that share the Muslim reli-
gion—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 tradi-
tion, both these patterns would be considered disorders.

A problem with blanket statements about cultural
patterns is that they disguise the often important intra-
cultural 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.7 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 ethi-
cally 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.17,18 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 expe-
rience of pain and its expression varies among American
immigrants.19,21 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.29 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 patient is a unique person, assessing them within the context of their sociocentric or relational sense of self often leads to decision-making styles at odds with western bioethics ideals. 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.30 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 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.

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.

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.

**REFERENCES**


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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
Atlanta, Georgia

From The Smell of Matches by John Stone
Louisiana State University Press, 1972