Cultural Diversity in Medicine and Medical Ethics: What Are the Key Questions?

by John La Puma

Culture, cultural diversity and value choices are 1990s buzz words that are likely to have lasting meaning for American medicine. To understand cultural diversity and to help patients and institutions into the twenty-first century, bioethics should not make the same mistake as it has in medicine as a whole. It should not leave discovering the facts of a case to others. Instead, it must go to the patient's side, where death and dying, managed care, and family decision making will be key crossover areas of expertise for institutional ethics committees.

Introduction

Cabbage Patch dolls, Ninja Turtles, Power Rangers. Quality, outcomes, health reform.

Buzz words are easy to repeat. They are meaningful for a moment or for a whole meeting, but in a short time, they've been replaced. Culture, cultural diversity, and value choices, however, are 1990s buzz words that are likely to have lasting meaning for American medicine.

In this paper, I will touch upon each of these latter terms and explore their new importance in discussions of three central areas in medical ethics: death and dying, managed care, and family decision making. I will also suggest ways in which clinicians and ethics committees can help patients and institutions by addressing the dilemmas that cultural diversity raises.

Definitions

Culture, Buchwald and colleagues write (1994), is a "textured pattern of assumptions, beliefs and practices that works tacitly and unconsciously to frame or guide the outlook and decisions of its members." Culture is not a thing, but a context. Christakis (1992) notes, "It is not the existence of moral standards that varies cross-culturally—it is their form and content."

Cultural diversity, then, is the intersection and

interaction of inter and intra-group patterns, which yield complexity, depth and personalness to who we are as a society and what kind of society we wish to become.

How do patients use culture? They live within it and make value choices—i.e., what matters most, and why—about their health care, often relying on culture as a foundational framework.

Patients also use culture to understand, interpret and explain their symptoms. For some people, imbalances of body temperature, blood level, and social discretion define normal and abnormal. Disease cause, treatment, severity, and prognosis may not be explained using the scientific reasoning of modern medicine, but instead, by traditions, rituals and beliefs. It is how individuals assess their own behavioral ethnicity that determines their true ethnicity.

Cultural Diversity and the Culture of Clinical Practice

Is medicine ready for culture, cultural diversity and value choices? After all, these buzz words

John La Puma, M.D., helps doctors and hospitals improve and strengthen ethics committees and programs. He is a consultant in clinical ethics in Chicago and clinical associate professor of medicine at the University of Chicago. represent the active incorporation of personal, familia,l and spiritual aspects of care into the health care system, things for which Western medicine has little time. They do not, after all, compensate providers, are devalued as soft and ethereal, and are of minimal use in daily patient care.

Moreover, in ethnography there is a feeling of futility about its practical application. There are hundreds of cultures and thousands of cultural beliefs about medicine—how is one to keep them

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straight? The ethos of individualism and patient autonomy in Western medicine is so strong, and the variation within cultures so great, that anything learned about a patient's particular culture may not apply to the patient. For example, a trance to Native Americans is more like a blessing than a psychosis, but this does not mean that a particular individual Native American would feel that way (Buchwald 1994). If it is unfair to the individual to generalize about his or her beliefs, what is the use of studying cultural diversity?

What is culture's proper role in medical moral decision making, given the resident Western view of medicine as biomedical and technically progressive? Is culture something to be overcome, as a barrier to the patient's real feelings, for example, or can it be a therapeutic tool within the context of what matters most to the patient?

To lay the foundation for answering these questions, I will consider three key areas of medical ethics: death and dying, managed care, and family decision making.

Death and Dying

How does medicine think about death and dying? In general, medicine presents death and dying as a choice to patients (La Puma, Schiedermayer, and Siegler 1995). Medical ethics has persuaded medicine that, regardless of their culture, patients have autonomy to make health care decisions; that they should be offered real choices in care, especially at or near the end of life; and that they, in fact, want to make these choices (Orona, Koenig, and Davis 1994).

Medical ethics also assumes that patients are well educated, filled with decision-making capacity and independent (Koenig 1993); that health is more important than most other values to patients, especially those that involve money; and that ethical innovations, such as informed consent forms and written advance directives, and organ procurement, preservation and transplantation, will be well received by all.

These assumptions are not supportable. Other cultures think about death differently. Many cultural groups find the idea of terminating life support, for example, offensive (Klessig 1992).

Jill Klessig gives several examples of differing cultural behaviors near the end of life. In the Iranian culture and in many other Middle Eastern cultures, for example, the family can be demanding if the patient is critically ill. This behavior shows concern for the family member and is a reason for insistence on a wide range of medical care (1992).

In the Korean culture, filial piety, or loyalty to one's parents, is the greatest value. Elders are to be cared for and respected; forgoing life support may dishonor the family member in the eyes of relatives or the community. Children are responsible for their parents and must preserve their lives at all costs (Klessig 1992).

In the Philippines, the family greatly influences patients' decisions. Harmony is valued, and personal needs are subjugated to group harmony. Although the patient may want a Do Not Resuscitate order and may not want life support

measures initiated, the family's objection might be enough to change the patient's mind, if only to avoid outright disagreement (Klessig 1992).

Moreover, many Mexican Americans believe that "health is a gift from God, and ill health, including accidents, may be due to (sic) a punishment from God or the Saints." If terminal suffering is part of God's plan, perhaps family members should not try to change it. Since there is always the hope the patient may get better, stopping life support may cause the family guilt. Enduring sickness is a sign of strength, and believing the doctor to know best is still the rule (Klessig 1992).

Managed Care

The traditional population of managed care organizations has been middle class. New populations will have new expectations, especially about limitation of treatment, as noted above.

Because poverty and ill health are still strongly related to being nonwhite (Barker 1992), managed care faces enormous cultural barriers. In managed care, the incentives are to limit life-sustaining treatment, specialist referrals, and medications. Consider this paradox: Will groups traditionally disadvantaged and underserved in the American system willingly give up care when they have not received their due to begin with?

In a study published in the *Journal of Clinical Ethics* in 1993, significantly more African Americans and Hispanics than whites wanted their doctors to keep them alive regardless of how ill they were (Caralis et al. 1993).

This isn't surprising. The mortality rate for heart disease in black males is twice that for white males. Blacks tend to receive less-aggressive treatment for this condition. African Americans live five fewer years than do whites. While institutional racism, economic inequality, and attitudinal barriers to access are held responsible for these inequalities, it is a logical stretch to think that less health care, like that of managed care, will improve things (Dula 1991).

This focus on finances is particularly Ameri-

can, but other cultures also value finances. The Hmong people, for example, numbered 90,000 in the United States in 1990, a more than 2,400 percent increase in ten years. Linda Steele-Uzquiano writes "... the Hmong consider death as part of the rhythm of nature. It is therefore seen as acceptable and easier to adjust to than chronic illness or artificially extended life, especially in those cases where the illness or extreme treatment measures deplete resources that may be better used for the welfare of the whole family or community. As an example, one Hmong father, trying to understand why American physicians and nurses were so intent on saving his premature and severely brain-damaged daughter, noted that the child would be a long-term burden on the family and that the medical costs of over \$275,000 incurred in her first three months of life would have supported 255 Hmong families for an entire year. His attitude may have seemed heartless to health care providers who saw their care of his daughter in terms of the high value Western society places on the life of an individual. Yet, the value of community expressed by this man had its own elements of compassion; his caring extended to the wider community instead of focusing on one person" (Steele-Uzquiano 1994).

At its most generous, it is this same philosophy of public health that managed care embraces, and which seems so foreign to many white Americans. With much the same premise, the often maligned United Kingdom provides basic health care for all citizens, even if specialized care is not as accessible as it is in the United States.

There is another challenge to managed care decision making, still unanticipated: AIDS. A costly, deadly disease that challenges managed care to be compassionate and community oriented, AIDS occurs disproportionately in non-white communities. According to new data released last fall, fifty percent of reported AIDS cases occur in people of color: African Americans, Native Americans, Asian Pacific Islanders—yet they represent only one-fourth of the nation's population. Black women are fifteen times more likely than white women to have AIDS. More than half

of all cases reported in 1993 in children under thirteen were in African American children. AIDS is the leading cause of death for African Americans between twenty-five and forty-four years old, and the second leading cause of death for Hispanic Americans in that age group (Pinkney 1994).

Cultural barriers seem to prevent us from helping more in AIDS. Deborah Pinkney of the *American Medical News* recently reported that many Native Americans are offended when providers try to make direct eye contact or are aggressive in their questioning. Hispanics of Mexican descent may be insulted by or even unable to read the Spanish of Puerto Rico or Cuba. Hostility towards gay men and women still pervades many minority communities, even more than in white communities (Pinkney 1994).

The link between AIDS, cultural barriers and managed care is this: AIDS patients who also happen to be African American, Latino or Asian, for example, will pose new and unprecedented financial and educational burdens on MCOs. Yet such organizations have not had a tradition of training and education, or altruistic missions. America is the only Western country that can claim to have "new traditions," and a new tradition of concern about the population's health will be needed to pay the social and financial costs of AIDS care.

Family Decision Making

What does nearly every culture have in common that is now beginning to be missed in the culture of the United States? I believe it is an emphasis on family.

Family comes up repeatedly, and the culture of patient autonomy affords family very little space. There is a distrust of family as clannish inAmerica. "The family's agenda is different from that of the patient's" is oft-repeated and often true. In Western culture, especially middle-class and upper middle-class urban, industrial America, family is something people are born with and into, not of and for. Children are brought up to be individualistic and autonomous.

Even a definition of family defies generaliza-

tions. Is family a blood relative? Do third cousins from California count? Cousins characteristically "count" in parts of the country that are poor and agricultural in background, in which extended family is as important as immediate family, but in general, they are maligned as distant both in geography and feeling.

So, it is not just the ethnicity, but the experience of families, and their interconnections about which health care providers must be interested (Klessig 1992). Families should be understood in their diversity. Combating defamation and generalization, and including scholarly knowledge about each of the new countries and new immigrant peoples in school curricula and textbooks, and perhaps in hospital and health plan employee orientation and continuing education, will help this inquiry about experience mainstream acceptance as an accurate portrayal of what our nation can be (Gambino 1994).

Suggestions

To help health care institutions meet rigorous 1995 Joint Commission on the Accreditation of Healthcare Organizations (JCAHO) criteria for accreditation, and the hoped for National Committee on Quality Assurance (NCQA) ethics criteria, institutional ethics committees must identify and understand the ethical issues raised by cultural diversity. JCAHO and NCQA accreditation are important, not just for federal and state institutional reimbursement, but also for assuring a minimal level of quality. Although ethics and quality improvement committees do not yet see cultural diversity as an item on their agendas, death and dying, managed care, and family decision making will be key crossover areas which will demand synergy with every local community in the early twenty-first century.

In cultural diversity, there is real opportunity for understanding and helping patients and families. To do so, however, ethics committees will have to take a hands-on approach (La Puma and Schiedermayer 1994). Hoffmaster has written that the aim is to search for understandings that "locate theories in our practices rather than under-

lying them" (Hoffmaster 1992). The key question is not *how* but *why*—not just what happened and what the patient wants, but why she wants what she does. This can only be discovered in exploring individual cases, and doing it thoroughly and carefully.

Bioethicists should not make the same mistake here as they have made in medicine as a whole—leaving the facts of the case to doctors to discover and relate, and applying ethical principles to those facts, instead of going to the patient's side and learning them and their nuances in person.

Buchwald, Koenig and Klessig recommend ways to approach the patient. These include

- "listening with interest and without judgmental strictures" (Buchwald et al. 1994).
- •showing a willingness to negotiate" (Buchwald et al. 1994)

Indeed, beginning by addressing a single patient's own cultural attitudes and traditions can bring us closer to a therapeutic relationship with all patients.

- being persistent, even if the patient wishes not to share information
- phrasing and structuring questions in several different ways
- reassuring patients of your purpose in eliciting their feelings or opinions
- using the patient's explanatory model as the point of departure and compromise

Conclusion

With a major demographic shift in our patient and provider populations now in evidence, new immigrants mean even more cultural diversity in medicine. This can be a sustaining, fascinating shift for medicine if providers are given sufficient time to pay attention to a patient's social and family history. Indeed, beginning by addressing a single patient's own cultural attitudes and traditions can bring us closer to a therapeutic relationship with all patients.

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