
Notes from the Field — An Adventure in Multiculturalism

by M.C. Sullivan

M.C. Sullivan was formerly the Executive Vice President of Midwest Bioethics Center. During her tenure at MBC, she was awarded a Kornfeld Foundation fellowship to pursue fieldwork in multicultural healthcare ethics. This article reports on her project, which involved travel in Europe, Asia, Central and North America, and the Caribbean, to experience indigenous culture, and to learn, in the United States, from established agencies serving immigrant populations. The research was not conducted scientifically. The methods and findings are anecdotal and attributable only to the author.

In 1998, a membership survey conducted by Midwest Bioethics Center indicated that many Center members are typical of those individuals who make up the national roster of the bioethics community in North America. They identify themselves as Caucasians, about fifty-seven-years-old and well educated; and they have, on average, high household incomes. This information, whether regional or national, has a downside: it clearly does not reflect the inclusive nature that ought to define "bioethics."

Midwest Bioethics Center self-defines as a community-based organization. Whether "community" is geographically understood (i.e., the Kansas City metroplex), or more comprehensively translated (i.e., everyone affected by, or making, healthcare decisions), we are neglecting a significant number of citizens whose interests ought to be reflected in the bioethics conversation. Midwest Bioethics Center seeks to remedy this exclusivity and the impact it has on the activities and attendance of Center programs.

Recently, the Center engaged in a multiyear initiative designed to improve care of the seriously

ill and dying in our community during which we realized that better accommodation to cultural diversity had become a strategic need in our city's care of the dying. As we struggled to create and then implement projects for that strategy, we ran into two major, perhaps predictable, and definitely interrelated, barriers.

First, knowledge of, and familiarity with, a community's cultural foundations is absolutely necessary to understand that community's behaviors and attitudes. Admittedly, we lacked that knowledge. Second, the Center's usual way of announcing programs or activities and simply expecting "everyone" to find us does not adequately invite multicultural participation. Over and over, we heard two messages: "you have to go where your audience is"; and "you have to have something relevant to offer when you get there."

In Missoula, Montana, in 1998, the Mansfield Conference on Living and Dying Well examined "The Healing Arts in American and Asian Culture." Psychologist Lobsang Rapgay, a Tibetan monk, commented that death and a fear of dying

are universal, existential human experiences. Nurse-anthropologist Marjorie Kagawa-Singer responded to Rapgay's presentation. She said that the ways in which people experience death and then construct meaning from it are culture-dependent. Many clinicians, in her opinion, work hard to determine the physiological, emotional, and social needs of their patients but do not think or learn about the significance of culture as it relates to those needs.

Such understanding is not likely to come from a staff education panel at which different cultures

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are presented in ten-minute modules. Indeed, this way of addressing cultural diversity in healthcare education is dangerous because it can lead to distortion and stereotypes.

In Kansas City, our first actions to provide and respect cultural diversity demonstrated how little we knew. We were faced with different "takes" on what we in bioethics have always regarded as fundamental, linchpin notions. For example, colleagues from our Mexican and Vietnamese communities asked us to reexamine the preeminent position we give to the principle of autonomy in healthcare decision making, especially at the end of life. We had lively discussions about how to accommodate cultural differences without falling into ethical relativism, but these discussions were eventually nonproductive. In fact, such discussions only reinforced how little we know about the cultures with which we live and work.

Bioethicists must learn first-hand about the cultural foundations of their communities and the

effects of particular cultures on the attitudes and behaviors that surround healthcare. At least three aspects of cultural information require study: developmental and historical work with primary sources; first-hand observation of different communities; and finally interaction and collaboration with other groups who work with these communities in the United States. To genuinely and authentically study these three aspects, I proposed narrowing our range of "healthcare" topics to only one, namely, to the influence of culture on the care of the dying.

The Kornfeld Fellowship

I applied for a Kornfeld Fellowship to apply my cultural study on two levels; I had two objectives. First, as a member of the executive team of a community-based bioethics center that straddles the bistate city of Kansas City, whose dominant cocultures are African-American, Asian (significantly, Vietnamese), and Hispanic (primarily, Mexican, but with a rapidly growing Cuban population), I proposed to study the cultures that contribute to the diversity in this city. My goal was to expand the Center's working agenda and to create opportunities for more collaboration and better community outreach. Second, I wanted to broaden the general bioethics conversation to make it more inclusive.

Although the Center already had relationships with and resources allocated to the African-American community of Kansas City, including a partnership relationship between Midwest Bioethics Center and Tuskegee University's National Center for Bioethics in Research and Health, the other two cultures were not receiving the internal resources and the external attention that are minimally necessary for mutual understanding. The Center's partnership with the National Center at Tuskegee allows for faculty exchange and joint projects; we had no similar opportunities in the Hispanic and Vietnamese communities.

I identified two phases for study with individuals and resources for each of the three cultures with whom I intended to work. These phases

followed formal consultation periods in how to do multicultural healthcare with mentors such as Ralph Masi and Marilyn Lundy at the University of Toronto and St. Elizabeth Health System in Toronto, Canada, and with the multicultural program educational staff at the Mexican-American Multicultural Center in San Antonio, Texas.

Phase One of this project involved work with "primary source" resources, that is, individuals and organizations in the home country of each of the three cultures on which this project focused. They are the National University of Vietnam in Hanoi Medical faculty; palliative care physician Gustavo Montejó Rosas and his team in Guadalajara, Mexico; medical and nursing faculty at the Medical School of the Universidad de La Habana, Cuba, and the clinical staff at the Centro de la Restauración Neurológica in Havana.

I visited each site twice, for three to five days at a time. In the first round of visits, which took place during the first six months of the fellowship, I spent most of my time with a mentor who introduced me to the culture and its healthcare system, and who directed me to the materials I needed to study. Each of these mentors gave me "homework" to do as I was actually pursuing a directed, independent study model. In additional time spent in each country, while I was not being directly mentored, I had the opportunity to just chat with people, from shopkeepers to taxi drivers to journalists to people in the streets.

The second round of visits occurred after I had assimilated information from the assigned readings. I returned to each site for an opportunity to test my learning and the accuracy of the conclusions or judgments I was making. On these visits, I also learned many valuable lessons from members of nongovernment organizations (NGOs) involved in healthcare, for example, the Catholic and Mennonite Relief Services, Doctors of the World, and Physicians without Borders, about how cultural behaviors and rituals are accommodated in the delivery of healthcare at the end of life.

Phase Two of my study project commenced following my "primary source period," after I had learned about the history and culture of each of the three communities. I scheduled learning visits to American cities where these ethnic and cultural communities have been present in significant numbers for many years. In each of these cities, I had identified people, healthcare providers, social services workers, and academics, who

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had established successful outreach programs. These visits took place in the second six-month period of the fellowship. The U.S. locations included Albuquerque, New Mexico; Boston, Massachusetts; San Diego and San Francisco, California; and Miami, Florida.

Upon my return from the first round, I worked with colleagues in Kansas City to identify and establish a Cultural Diversity Work Group. Many of these new colleagues served as forerunners for a new and significant Center project on cultural diversity.

In meetings with these community groups, I began to put together and analyze the data and insights gleaned in the field and to test that knowledge against the reality of Kansas City communities. One thing that I had learned in previous multicultural work is that acculturation is affected by geographic and regional nuances of the recipient community. Nevertheless, as my fieldwork progressed, I discovered that common ground and common themes were emerging that literally spanned the globe in the way in which people make their healthcare decisions.

Findings

The countries that I visited were as culturally and ethnically different as they were geographically distant. Within weeks of my first visits, four themes began to emerge and I found them consistently repeating from one site visit to another. Ironically, the only place where these themes were not dominant in the attitudes and behaviors of healthcare decision makers was in the United States. Here, at least in places where immigrant families had been present for two generations or more, assimilation into American culture had already occurred.

Importance of Family Roles and Relationships

The first common theme I saw recurring in each culture was the role of the family in healthcare decision making. Contrary, one might say, to the

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preeminence of patient autonomy that is found in twenty-first century America, family input and counsel, and the patient's role in the family story, are major drivers of healthcare decisions made in other cultures. Reliance on, and support from, family members provides the framework within which decisions are considered.

I found it interesting that while many cultures assign dominant voices in the decision-making process to male members of the family, in each of the three countries I visited, the women of the family almost always served as discussion leaders, sometimes as mediators, and often as final arbiters of the decision. Given that in each of the countries I visited, an extended family structure

served as the bulwark of society, the importance of the family in determining healthcare decisions is easily understood.

Awareness of the Sacred

The next prominent theme to emerge was an awareness of the sacred that is integrated into everyday life. This theme was articulated by virtually every person I interviewed or observed. Though not necessarily always a religious belief, persons of other cultures often make explicit reference to, or acknowledge, a greater plan, a superior being, karma, *el destino*, or God's will.

I heard from many people, from ICU nurses in Vietnam to dying patients and their families in Mexico, to neurological researchers doing tremendous restorative research in Cuba, that death is natural. A spirituality that neither fears death nor seeks ways to avoid it is common among the three cultures.

The individuals I met also espoused the use of biomedical technology when appropriate; however, few, perhaps no one, understood how the termination of futile treatment could cause such consternation as it does in the United States.

This dependence on the sacred, in conjunction with the steadfast and comforting presence of family, also helps explain another theme that is at odds with U.S. practice.

Dependence on Oral Tradition

When I asked a woman at the Mexican American Cultural Center about a living will or healthcare proxy documents, she laughed at me, though gently. She explained to me that I would find, or perhaps had already heard about, resistance to such forms. She also told me that our presumptions about why immigrants are reluctant to fill out these forms often leads to inaccurate or inadequate explanations. Literacy may be a problem at times, but fear of police agencies is not a common reason. Instead, as I later heard from many immigrants and the social services

staff who work with them, their most important relationships and decisions are maintained and enhanced by a long-standing dependence on a rich oral tradition. Oral traditions are strengthened through continuous story telling. Family and friends in the community talk and sometimes sing about what is going on. They tell stories about how the illness came about, what treatments are being done, and what the possible outcomes are, and interwoven in the tales are related stories about familial relationships. Family members are present during moments of serious decision making, and their stories and presence eliminate the need for documents. Indeed, written documents are sometimes seen as undermining these relationships by implying a lack of trust. In the cultures that I visited, one expects that the family will know and decide what is best.

Resistance to formal, written, end-of-life decision-making documents is frequently attributed to derivatives of this reasoning ("My family will take care of me."). In Vietnam, Mexico, and Cuba, the oral tradition that informs familial and community life has a magnitude that dramatically underscores the rationale for this resistance.

Civility in the Physician-Patient Relationship

Finally, I was struck again by the difference among the cultural behaviors that I saw on my site visits and the ones I had seen growing up in the United States when I considered a fourth theme: the presence of civility in the provider-patient relationship. In the States, when we teach patients to advocate for themselves, we often seem to be cultivating a culture of confrontation. Patients in the countries I visited do have opinions about the care they are getting. But they also have a deference for the dignity of the clinical provider, for the service that he or she means to deliver, combined with a kind of face-saving gentility that is different from the abrasive assertiveness that sometimes results when patients have been educated to watch out or stand up for themselves.

It is clear that patients in the countries I visited did not remain in unsatisfactory provider-patient

relationships if they have other alternatives. But they let their feet do their talking; they move on to other clinics, practices, or dispensaries, rather than engage in confrontational conversation or behavior. Such behavior, they repeatedly described, is demeaning to all parties.

Discussion

As my study evolved, its most surprising aspect was the presence of these four common themes as they played across geography, culture, and ethnography. Interestingly, when I mentioned this outcome to friends who had lived and worked

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in African and South American countries, they looked at me with "ho-hum" expressions, having discovered similar themes and behaviors in still other cultures. While those of us who live and work in the North American healthcare community know that no simple American mindset regarding healthcare decision making exists, it seems empirically obvious that the behaviors of patients whose families have been in the United States for more than three generations do not explicitly reflect these themes that appear to be so fundamental, so present, so commonly experienced, and so influential in other communities around the world. Why is that?

The question merits a great deal more reflection than I have presented in this paper. However, the consistent appearance in these multicultural settings of the importance of family, the appearance of the sacred, appeal to the oral tradition, and civility in provider/patient relationships impels me to imagine a different model for teaching medical and nursing students how to deal with diverse cultures. For example, clinical providers need to work within a framework that includes

the gathering of more medical history and a better review of systems and symptoms. We must place renewed emphasis on our patients' families and social history and their implications for the way patients think about, and report, symptoms, and whether they will comply with treatment. We must also underscore the helping nature of patient-provider relationships, and base them on mutual respect.

Areas that have long been regarded as "soft" by healthcare professionals who see themselves primarily as scientists should be reconsidered for their influence on the way patients respond to treatment. Patients are unlikely to view science and technology as the sole, or even the primary, reason they see physicians and nurses. The rigor we have brought to bear in developing the scientific curricula for healthcare professionals may, and should be, used to strengthen their abilities in another area: providers ought to be adept at eliciting other, equally important data from patients.

Acknowledgement

The author expresses her profound gratitude to the Emily Davie and Joseph S. Kornfeld Foundation for the opportunity to pursue this study.