
Learning from Different Cultures — A Cultural Diversity Project in End-of-Life Care

by Myra Christopher and Helen Emmott

In January 1997, Midwest Bioethics Center (MBC) launched PATHWAYS to Improve End-of-life Care, a three-year multifaceted community initiative to improve care of the dying in the Kansas City metropolitan area. Pathways focused on professional education and development, institutional reform, and public engagement, using thirteen different strategies to accomplish dozens of projects. Ultimately, more than 2,000 professionals and other community leaders were involved and more than 600 organizations participated. This article describes a cultural diversity project on end-of-life care that developed from this program.

Greater Kansas City is a metropolitan area of diverse racial and ethnic groups, and although “cultural diversity” has been one of the Midwest Bioethics Center’s organizational goals for many years, we had no formal cultural diversity projects until we focused on this issue as part of PATHWAYS, a three-year initiative to Improve End-of-Life Care in our communities. Our first strategic action was to undertake an active listening project with the help of the Ethics Committee Consortium, one of the Center’s oldest and most important programs. We engaged Consortium members and a communications consultant with special expertise in cultural diversity to mount this project.

Program Design and Objectives

Our goal was to provide a forum in which to “confront the dilemma of difference,” and our hope was to “transcend the difficulties difference implies.” We wanted to persuade clinical leaders “to listen actively and ask questions that would help them learn about cultural diversity.” To

better employ the active listening model, we hosted a series of panel presentations over several months with participants from diverse ethnic, racial, and socioeconomic backgrounds. Each panelist was asked to tell one or more personal or professional stories about end-of-life care and to dialogue with consortium members about their experience. The idea was to provide a forum, literally a “safe place,” where local ethics committee leaders could engage in open, honest dialogue about issues that make them feel, inept, uncomfortable, or awkward when treating patients from different cultural perspectives.

Flaws in the plan were apparent almost immediately, and significant modification was necessary. Consortium members were extremely uncomfortable because it “felt like our visitors were being objectified.” The conversations did not distinguish cultural relativism from ethical relativism, and although some wanted to have an intellectual/analytical discussion about these theories, others thought the discussion appeared confrontational and hostile toward our guest panelists.

Imagine the Center's distress: some participants believed that the process was damaging the personal or professional relationships they already had with panelists and organizations. In hindsight, providing a clearer rationale for participation could have mitigated these tensions but no such plan had been established. For nearly six months Consortium members and Center staff struggled with the plan. As the divisiveness of the project increased among Consortium members, we realized that another strategy was needed. Nevertheless, the experience actually strengthened the Center's resolve to address cultural diversity in the context of the PATHWAYS project.

Project Redesign

"If at first you don't succeed, try again." This adage, often taught to small children, became the mantra of staff working on cultural diversity; and, in 1999, we began the project anew, retaining the "active listening/learning" model, but with a smaller task force (members of the Consortium, rather than the entire group), and with clarified goals and objectives.

Our immediate goal was to "seek to understand differences in knowledge, ideas, and attitudes among persons of diverse cultural backgrounds [and] improve communication regarding health-care decision making at the end of life." Our long-range goal was to elevate the importance of learning about diverse cultures in programs for improving end-of-life care by building and enhancing relationships with leaders from diverse communities in the Kansas City area. We also wanted to develop and test the effectiveness of a cultural diversity intervention targeted at ethics committee members.

The methodology was also refined to take us outside the confines of the Center to where diverse groups live and work. We planned to ask volunteers from local social service organizations to develop a set of diverse end-of-life narratives and tools to facilitate active listening and ethical discourse. The narratives would then be used to develop a set of recommendations for how

ethics committees can address cultural issues as a way to improve the care of seriously ill and dying people.

In the process, we hoped to learn how individuals from various cultures define "dying well" and about institutional or systems barriers that they think makes dying well either difficult or impossible to achieve. We hoped to learn how they derive their knowledge and the sources they turn to for advice and support. We also wanted to learn about variations in orientations to the self and family and willingness to talk about dying and death.

Funding

Obtaining funding for this project was exceedingly difficult and time consuming. The W.K. Kellogg Foundation made the first grant to this project but enjoined us to apply for a matching grant from the Kansas City community. It took us nearly a year to find a matching grant so the project was significantly delayed. Eventually, the Wyandotte Health Foundation, a relatively new "conversion foundation" made the matching grant. The Wyandotte Health Foundation's giving guidelines narrowed the geographic scope of our work to one county among the five urban counties in the Kansas City metropolitan area. However, this restriction proved fortuitous, since Wyandotte County is one of the most culturally diverse counties in our community.

Leadership

Assembling the task force also took tenacity and salesmanship. Membership recruitment was much more difficult for this task force than for many others that MBC has established over the years. Many potential members said the project was too time consuming or that they did not have the "expertise" necessary to participate. We also came to realize that many long-time Center volunteers were not comfortable in the role we were asking them to assume. These difficulties notwithstanding, we eventually assembled a task force of eleven highly motivated volunteers, including three physicians, four nurses,

a chaplain, and two social workers. Ultimately, nine people participated in the interviews. Ten Center staff members including, among others, a physician/ethicist who had practiced medicine in the county, an attorney, and a social worker, participated in the program.

In the meantime, my coauthor, Helen Emmott, a nurse with formal training in ethics, had agreed to manage the project. Her interpersonal and communication skills are outstanding and she is excellent at building relationships and doing effective community outreach. Perhaps, most important, she is a good listener and was willing to take on a difficult project. We knew that we needed a project manager who would be morally courageous and willing to work with many people to accomplish the goal. From the outset, we knew that we were on "terra incognita." We were, in effect, following maps like those that guided the ancient mariners to lands unknown. As the early sailors were warned, so also were we: you are now entering uncharted areas; look out, "there might be dragons here."

An advisory committee was assembled that included both local and national experts in cultural diversity. The advisory committee met once as a whole, but members of the committee have consulted with staff and several have contributed to publications about the project. Advisory committee members were multidisciplinary, highly skilled, and professional. Its members included a physician, professors of nursing, sociology, and ethics, a Holocaust educator, and a civic leader.

Methodology

The initial assignment for task force members and Center staff was to identify four diverse communities on which to focus and to find partnering agencies in those communities. By size, African-American and Latino communities were at the forefront of our project; our other two choices were less obvious. After much discussion, we agreed that demographically the Vietnamese, Hmong, and Lau communities were significant and we agreed on the Hmong. We also decided

after much debate to focus on Caucasians of low social and economic status as the fourth group. We wanted to interview people who might be especially vulnerable for reasons of their culture, ethnicity, race, or class.

We divided into four work groups, each group focusing on one community. The initial responsibility of each group was to secure a partnering agency. We began by calling on social service agencies that serve individuals in the designated communities. At a snail's pace, agreements were

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made, participants were identified, and a series of panels or interviews were scheduled.

Our first agency partner was El Centro, Inc. Connie Flores, the director of human services introduced Emmott to Sister Alicia Macias, a social worker who serves the Latino community by providing various kinds of emergency assistance. For example, she helps families find resources to bury their dead and helps young mothers who do not speak English find food, work, and other resources for their families.

Sister Alicia also provides translation for hospitalized Spanish-speaking patients, and helps them make treatment decisions and payment agreements with hospitals. She suggested that we hold one-on-one interviews rather than ask these families to share their beliefs in a group setting. She also offered to provide a translator whom the families already knew and trusted. We interviewed the members of four Latino families

at the agency on four different evenings. Sister Alicia, the El Centro translator, various family members, and two or three members of the task force accompanied the project director on these interviews.

After several unsuccessful attempts to secure a partnering agency in the Hmong community, a resettlement program for Laotians based in a Catholic Charities office agreed to help us interview four Laotian families in their homes. A Laotian social worker accompanied us to each home to provide translation.

It took some time to identify an African-American partner for this project. Even though the Center has a good relationship with Kansas City's Black Healthcare Coalition, its primary office is not in the county of our project. Fortunately, an African-American nurse on the task force made contact with a long-time nursing colleague who works for the Coalition and has a screening site in a Wyandotte county church. Not only did six individuals agree to be interviewed, they also preferred to share their stories together as a panel, since they were all members of the same church.

Emmott enlisted the aid of Kristi Bade, a medical anthropologist, to transcribe audiotapes of the interviews and panel discussions. Bade also provided technical assistance and advice to the task force through calls, emails, and written recommendations. The task force met frequently to receive reports from the small groups and to share their experiences. We also read and discussed the literature related to cultural diversity and supported one another emotionally.

Lessons Learned

Along the way, it became clear that we needed to modify the subject matter we were asking about. We were asking about cultural or anthropological ideas regarding death and dying, but those we interviewed were more interested in describing their recent collisions with healthcare entities. For example, during an interview in which we asked

a Latino family to talk about its cultural values, family members talked instead about the recent death of their little girl. The story was fraught with unresolved ethical tensions that the family wanted to express.

In another case, a Laotian man who was slowly recovering from open-heart surgery was actually waiting in his underclothes for members of the task force to assemble. He wanted to tell us about his surgery and its complications, and he wanted us to examine him and give him advice about his

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slow recovery. Everyone we talked to had a story about the difficulties he or she had experienced with healthcare delivery — and very few, if any, of these difficulties involved straightforward cultural practices. What started out to be a search for cultural preferences at end-of-life evolved into a collection of personal stories that revealed the ineptness of providers and organizations to communicate with, and to care for, individuals who are different from themselves.

The task force felt tremendous angst. We had not expected this turn of events. Therefore, the struggle to provide a framework for these findings presented a new and more challenging task. The project director asked the program team and the task force to meet together to probe the issue face

to face. In that meeting, each person was asked to recommend how we could best use the narratives we had gathered. Their suggestions varied from passionate comments like, "I just want to tell the truth" to compiling a list of recommendations for all ethics committees regarding vulnerable and diverse patients. Our hearts were lighter after that meeting, but we still had no clear plan of how to frame our work.

A Transforming Moment

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to cultural, ethnic, and class issues. The act of listening had been a transforming experience for the task force members and ripples of that transformation were still being felt. Out of the ferment, a solution began to take shape. Why, we asked, couldn't we develop a tool that would help others have a similar experience?

We chose a dozen excerpts from the narratives that seemed to have a potential for prompting self-reflection. The task force and staff reflected on these excerpts and took them to the larger group, the Ethics Committee Consortium. Finally, eight excerpts were chosen as the basis for a cultural diversity tool.

The task force and program staff met again. Working in small groups, they asked introspective questions based on their reading of the narratives. These questions were subsequently revised and edited many times by Center staff with input from the participating agencies and expert advice from the advisory council. Additionally, program staff completed a list of recommendations for ethics committee members whose responsibilities include helping organizations do ethics in culturally diverse situations. These recommendations and the cultural diversity tool appear as special supplements in this issue of *Bioethics Forum*.

As a finale to this project, Midwest Bioethics Center will hold a summit in February 2002 to discuss cultural diversity — the discoveries that were made and their implications for our community. The Center and its community partners remain committed to searching for new ways to hear and see who we are, collectively and individually, and how we can ease the ethical tensions in the healthcare experience of persons who are especially vulnerable because of cultural, ethnic, or class distinctions. ■