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Moving Beyond Paradigm Paralysis: American Indian End-of-Life Care

Introduction

Health care and social services professionals may need to re-examine their assumptions about the end-of-life beliefs of American Indian and Alaska Native (AI/AN) elders. In light of changing culture and demographics and recent successes with new end-of-life care models for AI/AN populations, long-held but increasingly unjustified assumptions may no longer apply.

Conventional wisdom has long held that Indian elders—especially those couched in traditional belief systems—will not openly discuss issues related to death and dying.

Research findings have frequently reinforced the view that “some tribes do not talk about terminal illness for fear that talking about terminal illness will cause it to happen.” (Hepburn 1995)

Struthers and Lowe proposed a nursing care model “built upon a foundation of the ancient and venerable Native American culture and [embodying] the holistic worldview, beliefs, traditions, practices, and values presently utilized by Native Americans.” (Struthers 2003)

Carrese and Rhodes observed in a 1995 study “that Western biomedical and bioethical concepts and principles often conflicted with traditional Navajo values and ways of thinking.” (Carrese 1995) Eighty-six percent of those interviewed for the study considered advance care planning a dangerous violation of traditional Navajo values. The authors reported that “discussing negative information”—such as end-of-life care—was considered culturally offensive and potentially harmful.

Assumptions about the beliefs of AI/AN elders and their caregivers have not effectively changed for many years. However, AI/AN culture is not a static set of characteristics; it reflects the changing experiences of its members.

In 2005, the Spirit of Eagles program, sponsored by the Mayo Clinic through funding from the National Cancer Institute Quality of Cancer Care Committee, sent tribal health directors a 38-item questionnaire on the availability of end-of-life and palliative care services. Seventy percent of the respondents reported pain management services as the most pressing need, followed by advance care planning (58%), hospice contracts (54%), care for dying (53%), and bereavement support (52%).

Nearly half of the Spirit of Eagles survey respondents reported that services were available only outside the local community or not at all, and that 70% of respondents reported very high levels of interest in end-of-life care among their medical teams. Sixty percent reported less-than-adequate community access to end-of-life care. In addition, the survey report observed that a literature review on palliative care had identified 31,518 articles, but only two of these substantively addressed AI/AN issues. (Michalek 2005)

Despite the clear indication of need, both professionals and the public believe that cultural barriers are difficult to surmount. As Gorospe noted, based on a nationwide study of hospital patients, “With chronic illnesses, more than half of terminally ill individuals experience unrelieved pain and prolonged suffering.” (Gorospe 2006) Due to limited health care resources, only 6.5 % of American Indian elders receive personal care (Gorospe 2006), let alone quality end-of-life care.

For the broader U.S. population, researchers estimate that only 20-30% of the population have advance directives that define preferences for end-of-life treatment, usually completed by those with terminal illness or by individuals from higher socioeconomic classes. (Kitzes 2002; Pew Research Center 2006) Even then, physician compliance with advanced directives is poor, according to Kitzes. (Kitzes 2003)

The Centers for Disease Control and Prevention (CDC) and other public health professionals seek to help older adults and their families address important end-of-life care issues, as more people are living longer with chronic illness. It may also be possible to help improve quality of care for older adults and increase adherence to end-of-life care preferences and values. CDC’s Healthy Aging program is developing a modular online course on end-of-life care planning, entitled Advance Care Planning, to help public health and aging services professionals to better serve older adults and families.

“The Healthy Aging program has long recognized the importance of promoting health and health decisions in diverse communities across the country,” said Lynda A. Anderson, Ph.D., director of the program. “We are honored to be collaborating with key partners that have guided us to examine critical areas important to American Indian elders, including family caregiving and, for the first time, end-of-life issues.”

As the following case studies show, there are successful programs providing end-of-life and palliative care in Indian Country. Their work shows that this need can be met in ways that appropriately address the wishes of the patient and family.

Ft. Defiance Home-Based Care Program

At Ft. Defiance, Arizona, the Home-Based Care Program is exceeding national rates of advance directive completion by nearly 300%. Notably, this program serves a rural, isolated reservation community, with a large cohort of traditional Navajo elders.

“We’ve completed more than 800 comprehensive elder evaluations (CEAs) over the past five years,” Tim Domer, M.D., said of the 11-year-old elder care program. “When we began, 4% of our patients agreed to complete durable medical powers of attorney, 1% agreed to other advance directives. By 2008-09, 73% of patients seen through the Comprehensive Elder Assessment Clinic completed durable medical powers of attorney and 60% established advance directives. In 2009-10 that number was 89% and 85%, respectively. We’re aiming for 100% for durable medical powers of attorney, but don’t know if we’ll actually get there. Advance directive [completion] will never be 100% because of cultural reasons. Some patients and families simply do not want to sign these documents, even if they tell us their wishes. In those cases we carefully note what they said.”

A physician with 28 years of experience on the Navajo Reservation, including 19 years at the IHS Ft. Defiance Indian Hospital (now tribally operated by the Fort Defiance Indian Health Board), Dr. Domer admits that the path hasn’t been an easy one. “Nine years ago we weren’t having much success. We came out of end-of-life conversations feeling drained and frustrated, and our staff wasn’t comfortable. So I asked our Navajo social workers to come up with a plan that would use words and images that were culturally acceptable for end-of-life discussions—and they did. [Then] we brought in everybody involved in elder care—including medical and social work teams, even the BIA [Bureau of Indian Affairs] and law enforcement.

“The elder care program started in 1999, when a small interdisciplinary team sat down at lunch one day to work on difficult cases involving a couple of elders. The discussions grew rapidly, bringing in more groups and agencies involved with elder services.”

The Ft. Defiance team has based its approach on two models—PACE (Program for All-Inclusive Care of the Elderly) and the Medicare hospice benefit—both of which feature the use of interdisciplinary teams. “We mixed and matched the two to get a care continuum,” Dr. Domer said. The program avoids PACE reimbursement issues because much of the care is provided by IHS providers and volunteers. [PACE requires a capitated risk pool to help ensure economic viability, but in this case the IHS pays for the care.] “For the Medicare hospice benefit model, interdisciplinary care is focused primarily in the home, for patients with a six-month life expectancy. The six-month time frame is too short for us, so we have not pursued becoming an accredited hospice program. We need to enroll our patients well before this, to build trust and to address their often-difficult social issues and situations.”

Ft. Defiance also draws on the “Care Transitions” model developed by Eric Coleman, M.D., providing post-hospitalization home visits by nurses and social workers to reduce hospital readmissions. The program aggressively pursues cooperation with private home care agencies. (Coleman 2010) According to Domer, the success of the elder care program has contributed to the expanded use of these agencies, from three on the Navajo Reservation in 1999 to 23 today, funded through Medicaid waivers.

“Our focus is to look down the road with each patient to see what problems are coming our way,” Dr. Domer explained. “Avoiding or anticipating problems is the way to keep our elders healthy. The system often makes things so complicated. Our elders just don’t have that kind of time. Visiting the hospital takes up less than 1% of their time. One can only get a snapshot of what is actually going on. We go out into the community to their homes, to connect with them where they live their daily lives.”

The Ft. Defiance team has taken measures to assure that the daily connections are especially meaningful. The team’s home care staff, almost all of whom speak Navajo fluently, are now well trained in framing and responding to difficult questions in culturally acceptable ways. The communication process has become an integral part of the continuum of care, especially with respect to end-of-life care.

“Fort Defiance continues to prove that it is very possible to address and establish advance directives and the assignment of durable powers of attorney in what has widely been described as a population and culture that is resistant to having these discussions,” Dr. Domer explained. “It is all about language and timing – and talking with people in a way that gains trust and understanding. Unless one asks a person what they think or would want, one will never know. The biggest problem that we have overcome is the reluctance of the staff to bring up the issues with the patients. Once the staff is comfortable with the subject and knows the right words to use, the patients are most often quite willing and often eager to have these discussions and formally establish their advance directives and durable medical powers of attorney.”

The Ft. Defiance Elder Care Task Force attributes its growing rate of success to several factors: First, *they are proactive*. “We put in 150% of our time to make it work!” said Lucinda Martin, M.S.W., A.C.S.W., and director of Medical Social Services.

Second, *the team’s members are invested in the community*. They express their commitment to patients through the many ongoing aspects of long-term care, not just in relation to end-of-life care issues.

Third, *the team puts the pieces together*. “We didn’t have to invent much of anything. A lot of services are out there, they’re just not coordinated. I think that’s probably true everywhere,” Dr. Domer said.

Finally, the team is personally invested in the well-being of end-of-life patients and their families. Most team members have lived in the communities and served in the area for years. They personally know the patients or members of their extended families.

Ft. Defiance has expanded the concept of cultural sensitivity to include personal relationships, trust, and cultural acceptability, and continues to expand its end-of-life care outreach into its high-risk, frail patient population.

Cherokee Nation Home Health Program

Serving an estimated 295,000 tribal residents and 160,000 families over 7,000 square miles in 14 northeast Oklahoma counties, Cherokee Nation Home Health Services (CNHHS) has emerged as a premier large tribal program. Initially established by the Cherokee Nation in 1981, CNHHS now employs approximately 220 staff members, including 140 home health aides and personal care attendants.

Cherokee Nation Home Health Services houses three departments: Cherokee Nation Outreach is a state Medicaid Advantage program; Cherokee Nation Home Health is a Medicare- and Medicaid-certified home health program; and Hospice of the Cherokee is a Medicare and Medicaid certified in-home hospice service and the only hospice program in eastern Oklahoma that provides respite care as a “core” service. CNHHS is also contracted to serve the patients enrolled in Cherokee Elder Care, the Cherokee Nation’s PACE program.

“Like many tribes, we initially set up our hospice program according to a consultant’s advice,” said Rick Richards, CEO of CNHHS. “But then we had an ‘aha moment’ and threw all the models out the window. Instead of overwhelming patients and their families with a detailed list of available services, we started approaching them with a single question: ‘What do you need?’ What we discovered was caregivers becoming increasingly stressed from taking care of their family member, so we began to focus more on personal care, homemaker chore services, and extended respite care,” Richards said.

Richards agreed with the staff at Fort Defiance that, in addition to pain management, working with families to get legal paperwork signed is among the most important services a hospice can provide. “Including Social Security Administration and Veterans Affairs, there can be up to a dozen forms,” Richards said. “We try really hard to get the advanced directive,” he added. “If patients are not ready for that discussion, we may delay admission to hospice and refer them to one of our other departments.”

The Cherokee Nation program reports that about half of its referrals come from the community, and half from home health care agencies, hospitals, and clinics. “We’re on call 24/7 for admissions to the program,” Richards said.

If a patient or his or her caregiver is considering hospice care, the staff visits them to discuss the hospice program. During the admission process, hospice nurses meet with the patient and family at their home and conduct a nursing assessment and home safety check. Staff may meet with the family separately to discuss bereavement issues and spiritual needs. Western medical concepts do not always conflict with traditional cultural beliefs — in this case, up to 85% of tribal members belong to or attend one of the tribe’s Southern Baptist churches, according to Cherokee Indian Baptist Association mission director Jim Foreman.

If necessary, nurses visit daily and home health aides are trained to recognize potential problems with cognition or medications. Transportation arrangements and assistance with medical and social support appointments are also provided to patients and their caregivers.

Richards believes that his staff's personal commitment is the program's major strength. "We see high levels of anxiety and fear in households. Working closely with families is so vital."

"That is why we try to hire people who project a calming spirit, who are self-sufficient and can interpret situations 'outside the box'," he said. "It's important for them to avoid lapsing into Medicare regulatory compliance mode and to remain family-service oriented." Richards feels the CNHHS program is replicable by other tribes, but they should be aware of the complexities of Medicare requirements. "Follow Medicare requirements, but in the end you've got to do it your own way."

Zuni Home Health Care Agency

Since 1980, the Zuni Home Health Care Agency (ZHHCA) has operated as a non-profit Medicare-certified skilled nursing provider of home health services and Medicaid home health care. Serving an elder population—estimated by the tribal senior center director at about 1,350 people—the tribally operated ZHHCA has developed one of Indian Country's best examples of an end-of-life care-focused Tribal-IHS Partnership model. Under the leadership of ZHHCA Administrator Theresa Bowannie, the agency developed the program together with its primary partner—the IHS Zuni Comprehensive Health Center (local IHS hospital). The agency now provides "enhanced" home health care for eligible end-of-life patients.

The ZHHCA provides home health, personal care, and durable medical equipment for the Pueblo of Zuni and several surrounding Navajo communities, including the Ramah-Navajo reservation. The Zuni Comprehensive Health Center is an IHS-operated, 37-bed hospital with a full range of primary care inpatient and outpatient services, including a 24-hour emergency room and emergency home visits.

The program's startup was entirely local and grew out of a recognition that there were unmet needs for palliative and end-of-life care. Bowannie and the ZHHCA led a series of formal and informal conversations, including some family focus group discussions to understand the need for services and the acceptability of hospice and palliative care services. These

conversations helped ZHHCA and the IHS hospital to understand how well community members understood the need for services and how best to talk about this care in a culturally appropriate way.

Although both hospital and ZHHCA staff provided end-of-life care, there were no formal programs or processes for the delivery of this care. In the initial planning, the staff outlined three goals: 1) to maintain respect and consistency with cultural beliefs; 2) to assure sustainability through Medicare and Medicaid certifications; and 3) to incorporate end-of-life care into a continuum of long-term care. Over time, ZHHCA made the decision not to seek CMS certification as a hospice. ZHCCA saw the administrative cost and burden as too high for its small agency and found culturally troublesome the CMS hospice requirement that death be expected within six months of enrollment.

At the same time, ZHHCA and the IHS hospital made a commitment to the core philosophy and practice of hospice and palliative care, including physical, spiritual, emotional, and family-centered care provided by an interdisciplinary team. The IHS hospital contributed a physician to the team and the ZHHCA was able to provide nurses as part of its home health and personal care services. The hospital put into place a policy recognizing palliative and symptom-focused care as equal in priority to all other acute care needs. The interdisciplinary team met regularly to assess client needs and coordinate resources to meet those needs.

A third partner, the University of New Mexico Medical School, provided training for hospital and nursing staff in hospice and palliative care, as well as significant technical assistance to the ZHHCA staff.

New policies were required as well. The home care program developed both administrative and staff capacities, sought extensive staff training in palliative care, and developed appropriate forms and tools.

The hospital provided staff education in hospice and palliative care, developed palliative care formularies, and made two beds available for the program's use.

Over the past nine years, the Zuni program has served 76 end-of-life patients. According to Bowannie, "about 90% of our clients now complete advance directives." This has not always been easy to achieve. "We often begin by asking, 'if this happened to someone, how do you think it should be handled?' Most of our patients understand what we're saying."

Another sign of the program's success may be the patient population's acceptance of end-of-life medical care provided by the hospital staff. "We understand that many Zuni and Navajo

patients do not want to die at home,” according to Eric Peterson, M.D. “We see that many family members are also relieved that end-stage palliative caregiving will be provided by our staff, whom they’ve come to know and trust.”

Serving a relatively stable elder population, the program’s successes include ever-growing levels of tribal and community acceptance. “We go to the families respectfully, helping them to discuss and make decisions,” Dr. Peterson said.

“Our coordination of resources that are available in the community is what makes it work,” Bowannie added.

University of New Mexico Palliative Care Program

The Palliative Care Program at the University of New Mexico Hospital (UNMH) in Albuquerque operates in a dramatically different setting than most AI/AN programs. Located in the state’s largest city (population 650,000), the 470-bed hospital serves as a state-funded “safety net” hospital and is the only Level 1 Trauma Center in the state. The palliative care program at UNMH conducts consultations for Hispanic (44%) and white (39%) patients more frequently than AI/ANs (13%).

Nevertheless, the hospital sees the highest percentage (10.3%) of AI/AN patients among total admissions of any academic hospital in the country. It serves New Mexico’s 19 Pueblo, Apache and Navajo communities, and urban Indians from tribes throughout the nation (UNM Health Sciences Center, undated).

The UNMH palliative care program, as one of the nation’s foremost urban institutional models, provides consultative services only. Less than two years old, the program “has advocated for the institution to recognize the need for palliative care,” according to Lisa Marr, M.D., the director of the Patient Care Section. Those efforts were enhanced when the Accreditation Council for Graduate Medical Education (ACGME) recognized compassionate, appropriate, and effective patient care as part of its a new medical specialty on Hospice and Palliative Medicine in 2009. (ACGME 2009)

Operating without prior relationships with their patients, no affiliation with long-term care programs, no opportunity to provide home-based services, and no opportunity for long-term end-of-life care planning, the UNMH program would seem to face insurmountable barriers for the provision of end-of-life care. It has a lot to do and little time in which to do it.

The program engages patients with a small team, including two medical doctors, a nurse practitioner, a part-time chaplain (if requested), an interpreter, an Arts-in-Medicine team, and an occasional fellow in gerontology or oncology. Their levels of expertise are high.

“All our patients come to us in crisis, with urgent needs,” explained Judith Kitzes, M.D., who initiated the program. “We don’t worry about advance directives or paperwork. The trick is to set some goals of care, then get them translated into actual care.”

When a patient is referred—more than 60% of referrals are from the hospital’s medical and ICU services—team members meet immediately with the patient and, if possible, with the family in the patient’s hospital room. “Often the person in bed can’t talk. We try to have whatever family we can get there, to see who is the chosen authority—who will have power of attorney.

“We first try to negotiate the goals of care. What does the patient want? To be cured? To go home? Whether it’s DNR or attempt to resuscitate at all costs, it’s decided in a family meeting. A gentle, honest conversation still leaves people with an element of control and with patient autonomy. It allows us to talk about prognosis.”

For the program’s Native patients and families, goal setting has become the main reason for consultations (65%), followed by pain management (19%). Apparently, patient and family needs for structured end-of-life care planning and direction is great.

Following consultation with the program, Native patients’ preference for putting a DNR order in place increased from 22% to 62%, and family end-of-life meetings increased by an even greater rate, from 30% to 76%. Clearly, the program is having a significant effect.

The team attributes much of its success to communication skills and the development of relationships with patients and families. “We enter into all our conversations respectfully, bringing no agenda of our own. We don’t make any assumptions about them or their needs. We just try to find out what they need, and then help create a helpful plan of care,” Dr. Kitzes said. “We’ve learned, if anything, that almost everyone needs help in time of end-of-life crisis. We try to create a safe environment.”

“People tend to be very grateful for anyone who approaches them empathetically,” added Dr. Marr. “This is a multicultural model.”

Discussion

The provision of end-of-life care for AI/AN elders does not appear to be as insurmountable a barrier as has often been presumed. At least four end-of-life programs—two

serving large tribes, one at a small tribe, and one serving patients from multiple tribes in a metropolitan area—are demonstrating that success is possible.

Evolving demographic patterns continue to alter the landscape of traditional cultural values in Indian Country, sometimes dramatically. However, the end-of-life care programs discussed here serve traditional elders, sometimes as their primary cohort.

It appears that traditional vs. nontraditional issues do not override other considerations. Nor, for the UNMH Hospice Program, do cultural issues, beyond the basic need for cultural awareness of and respect for potential patient and family beliefs and views.

As Van Winkle observed a decade ago, there is “a wide range of values, beliefs, and behaviors within tribes due to factors such as acculturation and religious affiliation... Remember that the patient is an individual who might subscribe to some, none, or all of [these].” (Van Winkle 2000)

These programs exhibit several commonalities. Each observed above all that the provision of end-of-life care is always an individual process and that providers should bring no assumptions whatsoever to end-of-life discussions. Patients and their families should make all the decisions and lead the discussions if possible.

Empathy emerges as the single most important quality to bring to end-of-life care. As stated by UNMH’s Dr. Kitzes, “Not-nice people don’t get good results. Empathy cannot be taught,” Kitzes stated. “It involves inherent respect, but is not the same thing as cultural sensitivity.”

Others have found that “Compassion, caring, kindness, and respect are especially important when discussing negative information.” (Carrese 2000)

Dr. Kitzes and colleagues observed that “Families moving through the transition of death do not need to choose between traditional, complimentary, alternative and Western allopathic therapies. AI/AN communities can develop services based on historic and contemporary local values and beliefs.” (Kitzes 2004)

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