



Palliative Practice in Indian Health

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Overview

Any discussion of palliative and end-of-life care provided to the approximately 4 million U.S. citizens who identify themselves as American Indians and Alaska Natives (AI/AN) must recognize the rich diversity of cultures, beliefs and lifestyles within this group.

In 2007 there were 560 federally recognized tribes in 35 states in the United States. The Indian Health Service (IHS) provides medical care to approximately 1.8 million AI/AN through 268 health centers, 135 health stations, 162 Alaskan village clinics and 48 hospitals. In addition, there are 34 urban centers serving AI/AN people who live

outside of Reservation lands.¹

Certain demographic differences with implications for palliative care exist between AI/AN and other white and non-white Americans. The AI/AN population is younger, with a median age of 24 years, compared to 33 for all U.S. races. Approximately 6 percent are over age 65 compared to 13 percent for all races. AI/AN are also much poorer, with a median household income 34 percent below that of the general population.²

The 10 most frequent causes of death for all U.S. races reported in 2004 by the Centers for Disease Control and

Prevention (CDC) National Center for Health Statistics are, in order: heart disease, malignancies, cerebrovascular disease, chronic pulmonary disease, unintentional injuries, diabetes, Alzheimer's disease, acute respiratory illness, renal disease and septicemia. Among the AI/AN population, the two leading causes are the same; however, unintentional injuries jumps to the third, diabetes fourth, liver disease sixth and suicide eighth. Alzheimer's disease does not appear until No. 15, though in the age group 65 and older it is the eighth leading cause of death.³

Death rates are significantly higher for: alcoholism, 638 percent greater; tuberculosis, 400 percent; diabetes mellitus, 291 percent; unintentional injuries, 215 percent; suicide, 91 percent; homicide, 81 percent; pneumonia and influenza, 67 percent; gastrointestinal diseases, 38 percent; and heart disease, 20 percent. On the other hand, malignant neoplasms overall are 1 percent lower, though some such as gastric cancer are higher. The rate of HIV disease is 43 percent less.

The result is a life expectancy nearly seven years less than U.S. Whites. The years of productive life lost (YPLL – measures the burden of premature death. It is the sum of the difference between the midpoint of the age of death in all age groups less than 65, compared to 65) is 80 percent higher than all U.S. races and 110 percent greater than U.S. Whites.²

While significant strides have been made in reducing death rates for many of the major causes of death since the 1970s, chronic illness has emerged as a major challenge and focus of attention in the IHS.⁴ Palliative care and hospice services must be a major part of any effort to improve quality of life for patients suffering from chronic illness, yet AI/AN people lag far behind the rest of the nation in access to these services.

In its report to Congress in June 2006, the Centers of Medicare and Medicaid Services (CMS) emphasized the growth and change in Medicare's hospice benefit. Since 1983 the Medicare hospice benefit has funded most formal end-of-life services. In 2004, 31 percent of Medicare beneficiary decedents opted for hospice use, up from 22 percent in 2000.⁵

In contrast, using the Dartmouth Atlas utilization data, the New Mexico Medical Review Association (NMMRA), the Medicare Quality Improvement Organization for New

Mexico, found that from 1999-2003 only 2.8 percent of Medicare patients at two IHS hospitals were enrolled in hospice when they died. This compared to a state average of 30.8 percent.^{6,7}

During a meeting with reviewers in May 2007, one explanation of this dramatic difference was that perhaps Native American beneficiaries were culturally opposed to hospice care. A better explanation, however, is a lack of hospice services. For example, the authors are unaware of any formal CMS-accredited hospice program bringing services to significant numbers of patients living on Reservation lands in the Four Corners area of the United States.

Tribal and Regional Diversity

Each tribe has unique traditions, customs and beliefs. Within each tribe, however, there are variations in how families and individuals interpret and practice tribal customs.⁸

Many individuals have joined any number of faiths or denominations. The influence of these outside faiths on traditional customs and practices may vary widely within families and from individual to individual within a tribe. Because of these variations, one cannot assume anything about an individual's beliefs regarding end-of-life or palliative care issues. The only way to find out is to ask!

Numerous studies and journal articles underscore the critical role of cultural sensitivity, understanding and consideration in the success of any palliative care program.^{9,10,11,12,13,14} Critical illness, injury and the end stages of chronic illness inevitably raise issues of mortality for patients and families. Cultural background and religious beliefs are central to how patients and families receive information, make decisions, and try to find meaning and direction in the face of potentially life-limiting or end-of-life situations.

A common theme in studies focusing on providing palliative and end-of-life care to ethnic or racial groups is the importance of first developing trust. A major part in developing trust is taking the time and making the effort to learn the unique customs and practices of the people to whom these services will be provided.

Under the authority of the Indian Self-Determination and Education Assistance Act¹⁵ many tribes have exercised the option of assuming the administration and operation of clinical and health-related services and programs in their communities, rather than receiving direct services from

IHS. Cultural considerations and traditions may be more easily incorporated into programs under tribal control.

One such program is the Helping Hands palliative care program in the Bristol Bay area of southwest Alaska, an area of 46,000 square miles with 34 native villages.⁹ During the early planning stages of the program, a series of focus-group discussions was held with elders and younger members of native villages. A trusted medical anthropologist facilitated the meetings.

Cultural beliefs and traditions influenced the final product at every level. One example was a concern expressed by some elders that family members who obtained training as personal care attendants would be paid for the care provided. Later, a pamphlet, in the form of a short, culturally oriented story, was prepared to introduce the Helping Hands program. Incorporated into the story was a brief discussion of why it was necessary to pay the personal care attendants and professionals who provided direct care to enrolled patients.

A similar approach was taken during the development of the palliative care program in the Pueblo of Zuni in New Mexico. Members of the planning team were not certain how to discuss dying and death in a culturally appropriate way. A Cultural Advisory Committee was therefore established. Members of the committee were authoritative members of the Zuni Tribe who gave planners guidance on cultural practices surrounding the end of life.¹²

The Tohono O'odham Hospice is a new program being developed through the Tohono O'odham Nursing Care Authority in southern Arizona. The tribe oversees a skilled nursing facility and originally worked with a local accredited hospice agency. Because cultural issues were inadequately addressed, the tribe has now started its own hospice program. Areas of cultural concern included the need for extended family involvement in decision-making, specific language and words used around end-of-life issues and death, the traditional concepts of time, and the role of silence. The CMS accreditation process for the tribal hospice program is underway.

In Cherokee, North Carolina, palliative care is provided by local hospice agencies that come onto the Reservation. Within Cherokee Indian Hospital two rooms were renovated to better provide hospice care. The project grew out of the desire expressed by many patients who wanted to pass in the

hospital, rather than at home, but also wanted to remain on their own land. Similar to the experiences described previously, a committee, which included authoritative tribal members, was formed to guide the culturally appropriate development of the program and rooms. Money for the renovations came from several sources, including sales of baskets, carvings and other artwork by local community artists. In addition, the family of a patient who received hospice services donated money toward the rooms. On December 19, 2006, the first room was opened. The room is called *Ne gi I yv*, translated as: "Over there," a phrase chosen by native members.

In summer 2005 the Fort Defiance Home Based Care (HBC) program at the Fort Defiance Indian Hospital on the Navajo Nation in Fort Defiance, Arizona, admitted its first patient. The HBC program grew out of the need to provide post-acute hospital care, sub-acute and chronic care of certain high-risk outpatients, and to provide hospice and palliative care in the home. There are no other formal home care or hospice programs near Fort Defiance. Prior to the start of the program, patients requiring these services were either kept in the hospital for long periods, were transferred far from home or simply did not receive these necessary services.

The program is patterned on the Medicare Hospice Benefit interdisciplinary team approach, with some features of the Medicare Program for All-inclusive Care for the Elderly (PACE).^{16,17} Several years before the program was initiated, a presentation was given to the Dine' Medicineman's Association to seek their guidance on traditional considerations and practices. This distinguished group of native healers voted unanimously to support the program, stating that the Navajo people needed these end-of-life services.

The HBC program includes full-time social workers (all of whom are Navajo), nurses, physicians and a cultural liaison. One cultural issue that had to be addressed was how to discuss "code status" with some of our patients. Talking directly about dying and death, particularly about CPR, is a taboo for many.¹⁴ The social workers developed a gentle, indirect statement which patients and families can read and sign: "The Fort Defiance Indian Hospital Home Based Care Program would like to help you make a choice regarding your wish to die naturally with dignity and respect. In signing below, I acknowledge that when that time comes, when my last breath leaves me, I choose to die in peace to meet

shi'dyin (deity).” This approach has been well accepted. In the hospice portion of the program there have been 30 deaths. Because of cultural reasons many patients and families do not want death to occur in the home, yet eight (27 percent) of these deaths have occurred in the home at patient and family request.

Formalizing Palliative Care

An organized process to advance palliative care services on a wider basis within the IHS started in 2001 and is detailed elsewhere.¹⁸

A national conference funded by the IHS, “Talking Circle: Palliative and End-of-life Care for American Indian Communities,” was held in Albuquerque, New Mexico, in March 2001. Participants of the conference strongly agreed that there was a desperate need for these services throughout IHS. The recommendation was made for formal training in palliative care to be made available to IHS staff.

The first training session was held the following year, attended by 50 participants from 22 IHS sites. Since that time, formal training conferences have been held annually. For the past three years the conferences have been hosted by the Alaska Native Tribal Health Consortium in Anchorage, Alaska. From 2005 through 2007, a total of 527 individuals have participated from across IHS. Disciplines represented include physicians, nurses, social workers, midlevel providers, administrators, spiritual counselors and pharmacists.

In 2004, at the national conference supported by the Spirit of EAGLES, Special Populations Network, breakout sessions on palliative care and hospice were attended by about 75 individuals. A smaller group of leaders met to discuss the strongly voiced need for improving palliative care in native communities. A white paper was produced for the IHS following the conference. Dr. Bruce Finke, Indian Health Service Elder Care Director, was able to identify a young Native American physician to spearhead the writing of guidelines. The publication of *Guidelines for Palliative Care Services in the Indian Health System* occurred in December 2006.¹⁹

These guidelines cover structure, process, physical, psychiatric, psychological, social and spiritual aspects of palliative care. Care of imminently dying patients and ethical/legal issues are also covered. The guidelines were based in large part on the Clinical Practice Guidelines for

Quality Palliative Care from the National Consensus Project for Quality Palliative Care.²⁰ Experts within and outside the IHS contributed to the final product. The strong hope is that service areas and programs within and outside the IHS will use these guidelines to help develop culturally sensitive palliative care services.

The most current effort to further quality end-of-life care for IHS beneficiaries is a collaborative project between the National Cancer Institute (NCI) and IHS to use the Education in Palliative and End-of-Life Care™-Oncology (EPEC-O) curriculum to train IHS staff in palliative care skills. The EPEC™ curriculum was produced by the American Medical Association and The Robert Wood Johnson Foundation with support of the National Institutes of Health and published in 1999. It teaches the fundamental skills and philosophies of end-of-life care, centering on communication skills, interdisciplinary patient-centered team care, ethical decision-making and symptom management.

EPEC-O was adapted from the original curriculum by the National Cancer Institute (NCI), with supplemental funding from the Lance Armstrong Foundation, through the EPEC™ Project Team at the Northwestern University Feinberg School of Medicine. The orientation and intent was to improve palliative care in clinical oncology. The curriculum consists of highly adaptable training modules and is primarily a train-the-trainer seminar-based format. The EPEC™-O CD-ROM/DVD is available free from the NCI site²¹ and curriculum modules are posted on the EPEC™ Web site.²² The first EPEC™-O training conference was held in June 2005. One of the invited attendees was an IHS representative.

In October 2005 an interagency agreement was signed between the IHS and NCI to repurpose the EPEC™-O curriculum for use by the IHS. This came to fruition in January 2007 when the NCI and IHS jointly sponsored the first EPEC™-O /IHS training conference, held on the Navajo Reservation in Window Rock, Arizona. In preparation for that conference a new module entitled “Cultural Considerations in End-of-Life Care of American Indians/Alaska Natives” was developed.

Representative three-member teams from nearly all IHS areas attended. Twenty-nine pre-and post-conference questionnaires were completed. Knowledge of palliative and end-of-life care among attendees improved from 55 percent

rating their knowledge as fair or poor before the conference, to 100 percent rating good (35 percent), very good (55 percent) and excellent (10 percent) after the conference.

Because of the success of the conference and the strong recommendation from attendees that training be provided to a wider audience, the NCI has provided funding for two more train-the-trainer conferences.

Summary

Palliative care and end-of-life services are poorly available yet critically needed among AI/AN people. A number of formal programs are in place that can serve as models for future programs. Formal training in palliative care for IHS providers was started in 2001 and continues on an annual basis. The involvement of groups such as the NCI should help propel these efforts forward more quickly. It is essential that all of these efforts bring services that are both culturally relevant and sensitive to people who often face desperate situations with limited resources, options and hope.

To paraphrase Robert Frost, the journey has started but we have miles to go before we sleep.

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