Palliative Care: An Emerging Issue for American Indians and Alaskan Natives

Judith A. Kitzes
Timothy Domer

SUMMARY. Over 4 million American Indians and Alaskan Natives live in communities that receive health care primarily from the federal Indian Health Service or tribal health programs. Palliative care has only recently been formally addressed for these communities. An Indian Health Service program introduced the topic and several programs are ongoing. Needs for and barriers to palliative care in native peoples’ communities are discussed and several successful programs at various stages of development and implementation are described. [Article copies available for a fee from The Haworth Document Delivery Service: 1-800-HAWORTH. E-mail address: <docdelivery@haworthpress.com> Website: <http://www.HaworthPress.com> © 2003 by The Haworth Press, Inc. All rights reserved.]

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BACKGROUND

In the year 2000, there were an estimated 4.1 million American Indians and Alaskan Natives living in the United States. The age distribution of these indigenous peoples is skewed toward a younger population and the older cohorts are growing at a rapid rate with a dramatic increase in life expectancy, from 63.5 years in 1972-74 to 71.5 years in 1992-94 (Figure 1). The leading causes of death above the age of 55 are chronic diseases: heart disease, cancer, cerebrovascular events, and diabetes mellitus.

With the increase in longevity and prevalence of chronic disease, the dying process of American Indians and Alaskan Natives has changed, echoing the shift in the general American population that occurred a generation earlier. Rather than experiencing sudden unexpected death following brief acute illness, American Indians and Alaskan Natives now most often die following a prolonged extended process with gradual decline punctuated by episodes of acute distress. With this change, issues of care at end of life and decisions about location of death and intensity of intervention in the period before death have become critically important.

Until recently, issues surrounding end-of-life care in American Indian and Alaskan Native communities have not been formally discussed within their own health care systems due to concerns over cultural sensitivity regarding dying, limited resources, the orientation of the federal Indian Health Service toward disease prevention and care of the acute illnesses. Palliative care is now emerging within the American Indian and Alaskan Native health care system.

FIGURE 1. Estimated Number of Elders in the Indian Health Service Population
In 2000, of the estimated 4.1 million American Indian and Alaskan Natives in the United States, 1.6 million lived in geographic areas served by the Indian Health Service (IHS), an agency of the Department of Health and Human Services. The Indian Health Service is responsible for delivery of health services to federally-recognized American Indians and Alaskan Natives through a system of IHS, tribal, and urban operated facilities and programs based on treaties, judicial determinations, and Acts of Congress (see Table 1). The mission of the IHS, in partnership with American Indian and Alaskan Native people, is to raise their physical, mental, social, and spiritual health to the highest level. Many of the people served live in some of the most remote and poverty-stricken areas of the country and these health services represent their only source of health care. Thirty-two percent of American Indian elders live below the poverty line compared to 10 percent of Caucasian American citizens. National American Indian Housing Council published data show that thirty-three percent of reservation homes are overcrowded compared with less than 10 percent of all US homes. Census data from 2000 indicate that over 10% of American Indian homes lack plumbing, compared to 0.6% of all US homes.

The Indian Self-Determination and Education Act (United States Public Law 93-638) provides individual tribes the option of assuming the funding and administration of some or all of the local programs. In recent years tribes have increasingly exercised this option. This has resulted in greater local control over how programs are run, which programs will be funded and the form the programs take.

When planning and initiating end-of-life care, it is critical to understand that each of the hundreds of extant American Indian and Alaskan Native tribes and communities has its own rich history and its own sacred culture and traditions. Each program has unique features that reflect understanding, appreciation, and incorporation of the local culture, customs and traditions.

In Duluth, Minnesota at the Innovations in Eldercare 2000 conference, a consensus statement regarding the elements of a model eldercare program was developed. This statement applies to palliative care as well. The elements for a model programs include:

1. Tend to use existing resources to fund services.
2. Attempt to integrate and coordinate resources from state, federal and local funds.
3. Focus planning on the tribe and local community.
5. Include tribal and community values in planning.
6. Are strongly reliant on family members to provide care.

EDUCATIONAL EFFORTS

In 2000, the Director of the IHS committed to providing palliative care to American Indian and Alaskan Native patients by providing $50,000 to fund the first national IHS conference on end-of-life care. In March 2001, the conference entitled “Talking Circle: Palliative and End-of-Life Care for American Indian Communities” was held in Albuquerque, New Mexico. Each of the 12

<table>
<thead>
<tr>
<th>TABLE 1. American Indian and Alaskan Native Health Care System</th>
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<tr>
<td>• <strong>Indian Health Service (IHS) direct health care services</strong></td>
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<td>IHS services are administered through a decentralized system of 12 area offices and 84 service units.</td>
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<tr>
<td>• <strong>Tribally operated health care services</strong></td>
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<td>Tribal facilities are operated under the authority of the Indian Self-Determination and Education Assistance Act (Public Law 93-638, as amended), Titles I and III.</td>
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<td>• <strong>Urban health care services and resource centers</strong></td>
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<td>The 34 urban projects range from community health to comprehensive primary health care services.</td>
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<tr>
<td><strong>Population served</strong></td>
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<tr>
<td>• 557 federally recognized tribes in 35 States</td>
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<tr>
<td>• 1.46 million American Indians and Alaskan Natives residing on or near reservations</td>
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<td>• 400,000 American Indians in urban areas.</td>
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<td><strong>Patient services (tribal and IHS facilities):</strong></td>
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<tr>
<td>• inpatient and ambulatory care</td>
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<td>• health promotion/disease prevention activities</td>
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<td>• environmental health</td>
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IHS area offices was asked to send a small group of interested clinicians, nurses, social workers, and councilors. Groups from eighteen states attended. Speakers included tribal elders, spiritual teachers and a few individuals already involved in providing palliative care in the IHS. The basic questions discussed were:

1. Is there a need for palliative and end-of-life services in American Indian and Alaskan Native communities?
2. What services are needed?
3. Is the time appropriate for bringing up these concerns in American Indian and Alaskan Native communities?
4. What are the recommendations for proceeding with this initiative?

During the national Talking Circle, several common threads were woven into one consensus statement entitled “National American Indian/Alaska Native leadership action is needed to promote implementation of palliative and end-of-life care services.” Palliative care education was a key recommendation.10

The training recommendation became a reality in May 2002, when the first IHS National Palliative Care Training conference took place in Albuquerque, New Mexico. Fifty participants from 22 IHS and tribal Service Units and programs met for a five-day conference geared toward technical and spiritual training in end-of-life care. Participants included physicians, nurses, pharmacists, social workers, psychologists, and administrators. Dr. Robert Twycross and a team of clinical educators in palliative care from Oxford, England were principal presenters. Subjects ranged from pain and symptom management to breaking bad news, and providing spiritual and emotional support for the patient, family and community. Small group discussions centered on identification of obstacles and potential problems to be overcome.

**PALLIATIVE CARE PROGRAMS**

The number of palliative care programs in place or being planned in tribal and IHS sites is not known because there is no central reporting for these programs. Information on programs already functioning and those that are planned is shared largely informally, although formal presentations and meetings of like-minded individuals often occur at various IHS or tribally sponsored conferences. It is clear to those who have attended these conferences over a number of years is that the issue of end-of-life and palliative has steadily risen as a topic of great importance.
Following is a brief overview of several palliative care programs already functioning or in advanced planning stages within the tribal and federal Indian health system.

**The Alaska Native Tribal Health Consortium, Anchorage, Alaska**

A tribally operated consortium in Anchorage provides palliative care services through a Medicare/Medicaid pre-established certified Home Health Agency (HHA) within its Home Health Department. In August 2002 the HHA began to take on end-of-life patients. The program does not yet have Medicare certification as a hospice provider. However, patients who do not meet eligibility for Medicare home-care services are funded by a tribal foundation. Currently cross-trained HHA employees, rather than a separate hospice staff, provide end-of-life services. A medical oncologist provides physician support and there is excellent support from the medical staff and Clinical Director of the Alaskan Native Medical Center. Since June 2001, there has seen a 500% growth in chronic care patients and a 350% growth in the HHA patients.

**Bristol Bay, Alaska**

The palliative care *Helping Hands Program* is a tribally operated program that started as a demonstration project funded by a Robert Wood Johnson Foundation grant in 1999. It is now funded through a certified Home Health Agency. It was designed as a “high touch, low tech” program so that the Native villages could provide most of the services. Before starting the formal program, great effort was made to ensure that the program would be culturally sensitive and appropriate. A medical anthropologist worked with the development team. Three focus-group sessions were held with elders and members in the villages to gain an understanding of traditions, ceremonies and beliefs pertaining to death and dying. Most Alaskan Natives have a strong desire to die at home, among loved ones.

The palliative care program is home-based and staffed primarily by family and village members. A registered nurse is regularly available in person or by telephone on a weekly basis, depending on the weather and census. The nurse is available on an “on-call” basis should the need arise. Each village has a health clinic run by a health aide under the direction of a physician. Opioids are kept in a locked box in the clinic and are administered under the direction of a physician, with assistance of the nurse when present. Durable medical equipment and supplies are flown into the villages. These types of services are coordinated through the Tribal Social Services agency. Since the program’s inception in 1999, the percentage of home deaths for selected causes has increased from 37% percent in 1997 to 77% percent in 2001.11
Indian Health Service Area Office in Aberdeen, South Dakota

A centralized area office palliative team has been formed to implement palliative care within the Aberdeen area. The team has met three times with area tribal and IHS staff, and partnered with faculty at the University of South Dakota. “Talking Circles” have been held in order to learn customs, beliefs, and desires from tribal elders. The area palliative care team has supported the development of local IHS hospital palliative care teams. Presently, Aberdeen area IHS is seeking funding to implement the local palliative care teams and the Aberdeen area tribes are pursuing funding for construction of a hospice facility.

Cherokee, North Carolina

The IHS program at Cherokee, North Carolina has developed a contractual relationship with the two hospice programs in the area. A dedicated inpatient hospice room that will provide a home-like atmosphere for terminal patients who cannot or prefer not to be cared for at home is being developed. A series of certified continuing medical education programs about practical issues in palliative care for the medical staff is being planned.

Navajo Reservation: Fort Defiance, Arizona

An Elder Care Task Group was formed three years ago. The group is made up of members of several departments in the IHS, the Navajo Tribe, Bureau of Indian Affairs, and Arizona long term care that provide services to elders. The group meets twice monthly to provide case management for high-risk elders. Because the full team meets together in one room, many bureaucratic, procedural, and communication barriers have been eliminated.

In this spirit of cooperation, palliative care and end-of-life care issues are being addressed. The Fort Defiance Chief Executive Officer has shown a commitment to developing a comprehensive elder care program that will include hospice care by funding a long-term training of a senior physician to complete a formal Geriatric and Palliative Care Fellowship. On returning from the fellowship, the IHS physician will lead the development and implementation of a Medicare-certified hospice program that will provide both inpatient and outpatient services.

In May 1999, in anticipation of developing a hospice program at Fort Defiance, a meeting was held with the Dine’ (Navajo people) Medicine Man’s Association, the official association of practicing medicine men and women. Traditional beliefs and practices relating to death and dying were discussed. Many native practitioners expressed support for bringing end-of-life care and services to the Navajo Reservation and a resolution of support was passed.
Zuni Tribe and Albuquerque Area Indian Health Service, Zuni, New Mexico

Since 1980, the Zuni Home Health Care Agency has operated as a New Mexico state licensed, Medicaid/Medicare certified, not-for-profit tribal enterprise. At the inception of the end-of-life care program, the tribe and area provided only home health care. Included in this was a small amount of home health care for dying patients. The Zuni Public Health Service Hospital, a part of the Albuquerque Area IHS, provides inpatient/outpatient primary care services to the Pueblo of Zuni, the nearby Ramah Navajo reservation and surrounding Navajo communities.

In 1997, the Zuni Tribal Home Health Care Agency and the Zuni Public Health Service Hospital responded to the Robert Wood Johnson Foundation call for proposals for “Promoting Excellence in End of Life Care” with a proposal to develop a federally certified hospice program at the Zuni Home Health Care Agency which would both be culturally valid and would meet the needs of terminally ill Zuni and Navajo clients. This proposal was subsequently incorporated into the Robert Wood Johnson Foundation supported Promoting Excellence in End-of-Life Care grant at the University of New Mexico Health Science Center. That project is entitled, “When Cure Is No Longer Possible.”

By 2003, many but not all of the elements of a high-quality, culturally valid palliative care program were in place in Zuni. For home health clients identified as hospice patients through referral by the primary care physician, client, or family, a distinct palliative care home health chart is used. This chart includes documentation of pain management, medications, social supports, and advance directives in a format required of a Medicare (federally) certified hospice. Interdisciplinary team discussions have been held for these clients, although not yet on a regular basis. All members of the home care team, including nurses, nurses’ aids, and family members are aware of the patients’ and families’ desire for palliative care and the focus on comfort and dignity rather than life prolongation or cure. Coordination with Zuni Emergency Medical Services ensures respectful and appropriate care after death, e.g., no attempts at resuscitation, no lights or sirens. Clients with New Mexico state Medicaid coverage can receive enhanced personal care services in addition to home care services provided through federal program support. Skilled nursing care is not yet available on a 24 hour basis, but it is available on an as needed basis. Physicians from the Zuni Public Health Service Hospital have been willing to provide extensive telephone consultation to support the home health nurse, and on a number of occasions have done home visits. These services have been accepted and greatly appreciated in the community.

Concurrent with the efforts of the Zuni Home Health Care Agency in providing home-based hospice care, significant developments in palliative care have occurred at the Zuni Public Health Service Hospital. A team has met on a
regular basis over the past two years to develop initiatives for improving pain management and palliative care services. The administrator of the ZHHCA has been an active member of this team. A formal pain and palliative care policy was developed which ensures equal priority of palliative and end-of-life care with acute care for admission to hospital and an adequate hospital formulary to meet palliative care needs. The policy also establishes the use of pain as the fifth vital sign. A visual analogue pain scale was adapted to the Zuni and Navajo languages and is in use in all clinical settings.\textsuperscript{12}

**Future Palliative Care Training**

In 2003, the IHS issued a contract to the Alaskan Native Tribal Health Consortium to provide national palliative care training, annually for three years, to federal/tribal/urban interdisciplinary teams. The annual educational opportunities will be modeled after the successful training provided in 2002 that is described above. The goal is to build sustainable palliative care capacity within the American Indian and Alaska Native health care system.

**CONCLUSION**

Since 1999, efforts at addressing the growing palliative care needs of American Indian and Alaskan Native communities have emerged. Palliative care programs that serve American Indian and Alaskan Native patients must include careful and thoughtful attention to the cultural traditions, beliefs, and rituals of the people being served. In all of the programs described above, the persons developing the programs met with tribal elders and members at the outset to foster and gain mutual understanding. There is a great richness of diversity both among and within the tribes and communities of American Indians and Alaskan natives producing a wonderful blending of beliefs and practices from many traditions and religions. What is referred to as “traditional” may vary from place to place and even family to family within the same reservation. Many tribal members who belong to Christian denominations may not believe in “traditional” ways. One cannot assume that any individual subscribes to a certain set of beliefs. Each patient must therefore be approached as an individual and asked about his or her beliefs, wants, fears, desires and expectations.

**REFERENCES**


11. DeCoutrnnay C, Jones K, Merriman M, Heavener, Branch PK. Establishing a Culturally Sensitive Palliative Care Program in Rural Alaska Native American Communities, pending publication, J Palliat Med.
