

# End-of-Life Issues for American Indians: A Commentary

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The American Indian population is growing according to the latest census; the members of over 500 nations that survived into the 20th century are thriving. This heterogeneous population has over 350 different languages and dialects. Some tribes base membership on degree of native ancestry, whereas others base it on the ability to trace native ancestry.<sup>1</sup> Some tribes are matrilineal only. The population is young, but life expectancy is increasing. There is still less than the general population of persons over 60 years of age. Median income for the American Indian population remains low, and fewer individuals have health insurance. Their overall income is only about 30% of the general population. One half of the reservation Indians have incomes below the poverty level.<sup>2</sup>

More American Indians are living longer and dying of chronic diseases such as diabetes, heart disease, and cancer. The historical background of the treatment of American Indians by the federal government was reviewed by Rhoades and Deersmith<sup>3</sup> who explained "Health services provided by the federal government for Indian people are not a gift. They are the result of business arrangements between two parties that resulted in a pre-paid health plan. The health plan was prepaid by cession of their entire lands (except for small parcels 'reserved' for Indians to live on and for other federal purposes) of the United States." The Indian Health Service (IHS) was established as a commitment on the part of the US government to guarantee health care for American Indians in exchange for their lands ceded by treaties. Congress has never appropriated sufficient funds to cover the medical costs of Indian people, especially with such expensive diseases as cancer.

In the last half of the 20th century, cancer has become the leading cause of death for Alaska Native women and the second leading cause of death for Alaska Native men. Cancer is the third leading cause of death for American Indians of all ages.<sup>4</sup> The increase in cancer mortality means that end-of-life issues have become more important for the American Indian population. D'Angelo<sup>5</sup> wrote in a monograph, "What kills Indian Elders," that their chances of dying from cancer have increased 22% since 1982. Of the IHS

service areas, the north central region has the highest cancer death rates.<sup>5</sup>

Kitzes,<sup>6</sup> writing in the *IHS Provider*, said that "the end-of-life experience for Native American elders mirrors that of the general population in that it is commonly extended, takes place away from family and the home, and is superseded by a technological, professional, and institutional process of treatment for the dying." Klitzes<sup>6</sup> stated that there is a "growing body of evidence that unrelieved pain carries with it great physiological and psychological risks including increased metabolic rate, blood clotting, water retention, impaired immune function, anxiety and depression, loss of hope and even risk of suicide ... many elders and their health care providers are fearful of the 'myth' of opioid addiction in the treatment of pain."

A hospice nurse of American Indian ancestry wrote in an article<sup>7</sup> published in the *Hospice Journal* in 1995 that a person's time leading up to death "should be a time of peace and understanding; a time to communicate ... to settle differences, to make peace with ourselves and others. Then we are prepared to take the next step through the 'Big Open Door' into the spirit world, to greet our Creator and all of our ancestors." Death is accepted as a natural part of life, and a spirit world exists after death—a world inhabited by loved ones and ancestors.<sup>7</sup> Terminal care in the last 50 years has concentrated on the palliative management of people for whom the advent of death is felt to be certain and not too far off and for whom medical effort has turned away from (active) therapy and become concentrated on the relief of symptoms and the emotional support of both the individual and his/her family.

In 1979, I had the opportunity to visit St. Christopher's Hospice 12 years after it had been opened by Dame Cicely Saunders in 1967. After 6 months of epistolary negotiations, she permitted me to visit her hospice for a day. I took the train from London to Sydenham and arrived at 9:00 AM. The session had just begun, and Dame Saunders was lecturing to the small group of visitors and her nurses. Dame Saunders said to the visitors

I want you to know that I am making special allowances today in permitting you to visit us. I think it takes six weeks of training before you can really begin to understand palliative care. For physicians it takes longer because you need to start with basic care of bathing a patient and removing their bed pans before you really begin to comprehend the compassion

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needed for end-of-life care. (Dame C. Saunders, oral communication, July 1983)

I was impressed with the dignity and love with which her staff conducted their discussion of their patients as if they were relatives and it was their privilege to make them comfortable.

Later, Dame Saunders, in an interview in New York, discussed physician assisted suicide. She was quoted in the *New York Times*<sup>8</sup> as saying "What I have learned over the years, especially of what people can do at the end of their lives if they have good care makes me very wary of a 'quick way out.' I think it denigrates people into just being an incurable illness and I think it is socially really very dangerous." With response to the question, "What about Kevorkian?," She replied, "Well I think it's bizarre, isn't it? What he has been doing is not looking at the whole patient. He's a pathologist. He's not a skillful physician who can offer alternatives."<sup>8</sup>

When I returned from England in 1979, I met with little enthusiasm on the part of physicians in my community for starting a hospice. Later, however, I learned that another Oklahoma City citizen had visited St. Christopher's Hospice that same summer—a dialysis nurse, Virginia Staples, RN—and we began to discuss developing a hospice for care of the terminally ill in their homes. At the same time, Betty R. Ferrell, RN, PhD, who lived in Oklahoma City at that time had also attracted some citizens interested in forming a hospice. The two groups merged as the Hospice of Central Oklahoma. This hospice, however, preceded the funding by Medicare of hospice care and failed in August 1989 due to the excessive burden of indigent care.

On February 6, 1990, at an Oklahoma County Medical Society (OCMS) board meeting, I stressed the importance of reestablishing a local hospice and recommended that plans be made to carry out that mission. The invaluable leadership of Doris Clark, the Executive Director of the OCMS, in planning a forum on hospice made it possible. In June 1990, members of the OCMS and the community combined efforts to establish a nonprofit hospice supported uniquely by the organized medical group (OCMS). Thus, Hospice of Oklahoma County came to be. The Society's member physicians were the first practicing doctors in a medical community to recognize the need for care of the dying. They are recognized as "pioneers" in the community institution of palliative care.

Under the leadership of William Coleman, MD, President; Robert McCaffree, MD, Chair of the Public Relations Committee; Richard Trautman, MD, Chair of the Community and Mental Health Committee; and myself as Editor of *The Bulletin*, an impressive 50 member advisory board was assembled. Seated were representatives of local hospitals and funeral homes, health care providers, doctors, lawyers, social workers, clergy, bankers, volunteers, and representatives of the media. All committed their expertise and guidance to make Hospice of Oklahoma County a success. They kept their promise.

With the board in place, OCMS physicians pledged \$120,000 for the new venture. Local hospitals and health foundations made significant monthly contributions for the establishment of the hospice. Hospice of Oklahoma County opened its doors with an executive director, 2 nurses, funding from the doctors and the community hospitals, and telephones and desks donated by Khader Hussein, MD who was my second fellow in Hematology and Medical Oncology at the University of Oklahoma Health Sciences Center. He would play a key role in securing the hospice's future through his leadership as medical director for its first 5 years.

Last year, volunteers spent more than 3600 hours helping Hospice of Oklahoma County. Volunteers helped bring in \$34,000 in contributions and sponsorships during the seventh annual community wide Tree of Life fund-raising effort in the 2003 holiday season. Their hours included numerous fund-raising events, hours spent doing dozens of office tasks, and countless hours in patient care.

Those volunteer hours permitted Hospice of Oklahoma County to look beyond its own territorial boundaries and work to bring its message and mission to all races and ethnic groups in the community. Through interactive partnerships, Hospice of Oklahoma County was the local host for the national Living With Grief Teleconference held at Rose State College. The theme was titled "Caregiving and Loss: Family Needs, Professional Responses" and focused on the insight and practical suggestions professionals can give to family caregivers in times of critical decisions. More than 2000 organizations across the United States and Canada took part in the live-via-satellite event on April 19, 2001. A distinguished panel of experts was featured.

In addition to its national partnerships, Hospice of Oklahoma County works with local partners such as the Oklahoma Alliance for Better Care of the Dying and took part in Oklahoma's Palliative Care Week proclaimed by Oklahoma Governor Frank Keating as April 15 to 21, 2001.

Now as an affiliate of INTEGRIS Health, Hospice of Oklahoma County continues its mission of enhancing the quality and dignity of life and death for the terminally ill and their families through its outreach and patient care. The Hospice of Oklahoma County's future is secure thanks to the support of doctors, nurses, administrators, and the community as a whole. Hospice of Oklahoma County now enjoys the position of being able to look back over the past successful years of service to the Oklahoma City community.

This unique hospice was guaranteed funding and support by the concerned physicians and hospitals of the community. The President of the Oklahoma County Medical Society sits on the board of directors and contributes to its future direction. An inpatient respite facility is planned by Integris with encouragement from the city and civic leaders.

Oklahoma, the state with the most American Indians, is named for two Choctaw words: *Okla*, which means the people, and *homa*, which is red. The Hospice of Oklahoma County has provided care for many American Indian patients. The nurses have accommodated their cultural differences and sought to be more sensitive to their pain so that

fewer will suffer during the terminal illness. Many of the people have very different cultural beliefs about death and the afterlife, and there has been a conscious effort by the hospice providers to include them in their care.

In a publication of the Institute of Medicine, the low priority that the National Cancer Institute (NCI) had placed on research on palliative care was identified, and the need for NCI to collaborate with other federal agencies to correct this deficiency was mandated.<sup>9</sup> The disparities in end-of-life care for ethnic minorities and socioeconomic disadvantaged (including American Indians) was listed as a barrier to optimal palliative care. Billings<sup>10</sup> quoted Rowe in his opening paragraph of an article titled "Palliative Care: Definition and Controversy" as declaring that education of students on the management of the dying patient is a "vast wasteland in American Medicine and nowhere is it less well understood or more neglected than in the academic health science centers."

Van Winkler,<sup>11</sup> in her chapter on "End of Life Decision Making in American Indian and Alaska Native Cultures," reinforced the statement that the regional and tribal differences in beliefs, customs, and lifestyle affects the mortality rates due to cancer. Cultural differences between tribes exist in beliefs about death and expectations of how the survivors should behave. The influence of Christianity on American Indian beliefs is an important factor in attitudes about death. Tribal tradition, the degree of adherence to the beliefs of the Native American church, and the degree of acculturation of the family to the influence of the dominant culture may be significant. The disclosure of "dangerous or potentially lethal" side effects by the protocol nurse who is attempting to interpret the consent form for a clinical trial may be viewed by potential American Indian subjects as "negative" and arouse their concern that the research drug may be more harmful to them, and they become suspicious and fearful and decline the offer.

Very little has been written about end-of-life decision making for American Indians, and few studies have been conducted. Although family discussions may be helpful with informed consent or living will decisions, the individual may refuse to sign documents out of fear. American Indians may react negatively to professionals representing a federal government sponsored health care system and its policies. The

American Indian patient may look on the IHS provider with suspicion and refuse to sign a "Do Not Resuscitate" document because this may be viewed as genocide. Individual autonomy is upheld by most Indian communities. Tribal leaders may be consulted, but they do not always make the "right" decisions for the individual if they do not have sufficient information.

Medical symptoms such as shortness of breath and vomiting may not be reported to the physician by the American Indian patient for fear that the disease is worsening. Pain is frequently undertreated due to its being underreported or to the professionals erroneous concept that all Indians are stoic and insensitive to pain. Complaints of pain may be reported to a relative rather than to the nurse or physician. Medicine bundles, feathers, and amulets are considered sacred by some Indian cultures and a part of the healing process. Their presence in the hospital room must be respected by the hospital personnel. Cultural differences may vary for tribal nations, regions, and even within families. A compassionate approach to these differences is needed by the health care provider. A flexible attitude for the team managing the palliative care of an American Indian must be maintained. Wrede-Seaman<sup>12</sup> provided a symptom management handbook on palliative care. Table 1 lists some of their statements for emphasis.<sup>12</sup> The handbook provides a more complete listing of management details and should be consulted when a palliative care team is caring for American Indian patients.

More research needs to be done in end-of-life care for American Indians. The communities should be involved in this research so that they may mutually profit by the outcomes. Researchers should work closely with cancer survivors and tribal medical leaders to obtain culturally sensitive documents specific for the beliefs about death for the individual tribes. The religions of the tribes, their values, beliefs, and behaviors may vary from region to region and even within the families. Trained community health representatives who know the family and their culture are ideal for interpreting those end-of-life issues. Cultural conflicts between American Indian patients and their families with the hospital staff may occur. The tribal member may want a healing ceremony performed by a traditional medicine man before consenting to treatment with western medicine. A community hospital must have a flexible policy when dealing

TABLE 1. An Algorithm for Palliative Care for American Indians

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- Determine tribal affiliation of the dying individual and his/her family and their degree of acculturation.
  - Primary and secondary languages should be determined as well as the level of education.
  - Soft tones and polite speech are appreciated by most individuals.
  - Do not interrupt the patient as he/she speaks as long pauses may be a part of communication.
  - Consents and decision making should include asking the individual if others need to be consulted.
  - Value is placed on personal autonomy but often the family will need to be included, written consents may be viewed with distrust.
  - Discussion of terminal illness with the individual and the family should be approached with compassion and respect for their culture and beliefs.
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with American Indian patients to provide truly compassionate care.

In a book titled *Native Heritage: Personal Accounts by American Indians 1790 to the Present*,<sup>13</sup> Lorraine Titus, an Athabascan woman, interviewed her grandfather about "potlatches." A potlatch is a ceremony with a "giveaway." "A potlatch was held in honor of something or to give thanks for something," he stated. A memorial potlatch was held in memory of someone at the time of their funeral. Two years later, another potlatch is held in their memory and to "put the dead person away." Her grandfather said, "when you do it from down deep in your heart, it takes all that sad feeling out of you." With a death, "it makes you feel good to give away gifts to the people that (you love) who are with you." A second potlatch to "bring back the dead and completely put the person away" is performed. He said, "I mean you'll still remember the person but the potlatch helps to get rid of (the grief) the rest of the feeling." Mark Tucker, a Yupic Eskimo, also wrote on "Contemporary Potlatches" or giveaways in the same volume. He said the word *potlatch* comes from the words *pat shotl*, which means give away. He said that "during the potlatch the people believe that the spirit of the dead float around the room where the guests come and gather. The guests consume the food and drink presented to them. This way the spirits of the dead are relieved from thirst and hunger." Customs and beliefs vary from the Pacific Northwest and Alaska to the southeastern American Indian cultures, but there are some common beliefs as well.

## SUMMARY

The indigenous people of the North American continent are known today as American Indians. The cultures of those people who have survived the 500 years vary remarkably from one region to another. They represent more than 500 nations with almost as many languages. Their cancer mortality rate has dramatically increased in the 20th century. Income for most American Indians is low, and many are uninsured for health care. The IHS with its past and current federal funding cannot provide total health care, especially state of the art cancer care for American Indians. When dis-

cussing end-of-life issues with these indigenous people, an understanding of their degree of acculturation to the dominant culture is necessary. To assure successful outcome of their palliative care, more research is needed on their beliefs and attitudes about death since they may differ drastically from one culture to another.

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