

Lifelines

from the National Cancer Institute



A Look at End-of-Life Care Issues for Native Americans

By the National Cancer Institute

More than 4 million people in the United States identify themselves as either American Indian or Alaska Native (AI/AN), a diverse group of people who come from more than 500 tribes. Access to quality health care by Native Americans is often compromised by poverty, lack of health insurance, and the fact that many Native Americans live in isolated regions. Although as a group, AI/AN have a lower incidence of most types of cancer than non-Hispanic white Americans, they are more likely to be diagnosed with late-stage disease, and their cancer survival is generally poorer than that of other groups. Yet despite this burden, their access to palliative care, hospice, and end-of-life services lags behind the rest of the nation.

The AI/AN populations need these services not only for cancer patients, but also for patients with other diseases that are more common in the AI/AN population than the white population—diseases such as diabetes, tuberculosis, pneumonia and influenza, and gastrointestinal and heart conditions.

“Palliative care and end-of-life services are poorly available yet critically needed,” said Dr. Judith Salmon Kaur, a Choctaw/Cherokee American Indian who is the Medical Director for the Mayo Clinic Hospice and for the Native American Programs of the Mayo Comprehensive Cancer Center. For a dozen years, a number of partners and collaborators have been working on an educational approach designed, Dr. Kaur said, “to bring these services to people who often face desperate situations with limited resources, options, and hope.”

Developing Trust, Awareness, and Respect

“Each tribe has unique traditions, customs, and beliefs,” explained Dr. Kaur, “and within each tribe both families and individuals may interpret these differently, especially as they confront issues of mortality.” She said that a number of studies have reaffirmed the critical role of cultural sensitivity, understanding, and consideration in devising successful palliative care programs for American Indians and Alaska Natives.

Researchers have found that it is important to develop trust in order to establish a successful palliative care program. There is no shortcut. “You need to take time to learn the unique customs, religious beliefs, and practices of the people services are directed to. This frame of culture will determine 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,” she said.

Awareness of how each patient and family may experience and open up to palliative and end-of-life care is a first principle, but there are themes that may cut across tribes and regions.

Hospice programs, which often encourage talking directly about death and dying, need to be sensitive to the fact that such direct discussion may be uncomfortable for many American Indians and Alaska Natives. It can sometimes be useful to develop a “code” for such communication. For example, in one hospice program, at the Fort Defiance Indian Hospital on the Navajo Nation in Arizona, the social workers devised a gentle, indirect statement that addresses advance directives, which patients and families can read and sign.

Patients receiving palliative care may prefer a hospital setting to their home, although preferably a hospital on tribal land. The challenge comes in trying to establish a setting that reflects their culture and creates an atmosphere in which they can die in peace and with dignity.

Training Trainers to Build the Programs

About half of all American Indians and Alaska Natives receive health care through the Indian Health Service (IHS), a government-funded program on 163 reservation and urban sites serving 332 tribes. In 2005, an NCI-funded study of IHS tribal health directors found that a majority of Native American communities were not receiving pain management services, advanced care planning, physical therapy, traditional medicine, bereavement support, care for the dying and hospice care.

Meanwhile, the National Cancer Institute had developed a comprehensive educational curriculum for health care providers, known as EPEC-O, or Education in Palliative and End-of-Life Care for Oncology. In 2006, the IHS and NCI partnered to modify EPEC-O to target the AI/AN population and to re-fashion it for use by an interdisciplinary team of health providers that includes physicians, nurses, social workers, chaplains, pharmacists, nursing assistants, and cultural liaisons. In 2007 and 2008, the partners provided three train-the-trainer seminars for 89 physicians and healthcare providers from IHS service units throughout Indian country.

The training has proved successful. Four out of five of those trained said they had used what they learned and incorporated these palliative care principles into their practice settings. About half were planning to train others, and more than half had started new palliative services, such as consultations about advance planning, grief and loss, pain management, and palliative services—often recruiting interdisciplinary teams of care providers from within their health centers to deliver these services. The program has even been enhanced by specific hands-on training at the Mayo Clinic in Rochester, MN, with development of an “intensive case-based palliative care program.”

The CD-ROM and DVD for [EPEC-O](#) with American Indian and Alaska Native Cultural Considerations is available from NCI. November is National American Indian and Alaska Native Heritage Month. NCI leads the National Cancer Program and the NIH effort to dramatically reduce the burden of cancer and improve the lives of cancer patients and their families, through research into prevention and cancer biology, the development of new interventions, and the training and mentoring of new researchers. For more information about cancer, please visit the NCI web site at www.cancer.gov or call NCI's Cancer Information Service at 1-800-4-CANCER (1-800-422-6237). More articles and videos in the culturally relevant Lifelines series are available at www.cancer.gov/lifelines.