Department of Health & Human Services, Centers for Medicare & Medicaid Services

LTSS Research: Literature Review

Hospice in Indian Country

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Glossary of Terms

Advance Directives	A document stating how an individual wants medical decisions to be made if they lose the ability to make them for themselves.
Advocate	A person who provides support or protects an individual's rights.
Caregiver	A person who helps care for someone who is ill, disabled, or aged.
Cultural Sensitivity	The ability to relate to and meet the needs of people in a manner that respects and supports their cultural values, as stated by the individuals receiving the care or service.
End-of-Life Care	Support and care provided to individuals that allows them to live as they wish at the end of their lives.
Facility-Based Care	Care provided in and structured around institutions, such as skilled nursing facilities (nursing homes), assisted living residences, and adult family homes. Note: In some states, the care received in a non-nursing facility environment (assisted living or adult family home) is considered home- and community-based care, not institutional care.
Health Care Provider	A person or place trained and licensed to give health care.
Hospice	Care designed to give support to people in the final phase of a terminal illness that focuses on comfort and quality of life, rather than a cure. The goal of hospice care is to enable patients to be comfortable and free of pain to help them live each day as fully as possible.
Indian Health Care Improvement Act	Provision of health care to American Indians and Alaska Natives that was created in 1976, and made permanent in 2010, as part of the Patient Protection and Affordable Care Act.
Indian Health Service	The principal federal health care provider and health advocate for Indian people with the goal of raising tribal member health status to the highest possible level.
ITU	Umbrella term referring to the Indian Health Service (IHS), a tribe (or tribal organization), and/or an urban Indian health organization carrying out an IHS program.
Palliative Care	Palliative care improves the quality of life for patients and their families facing problems associated with life-threatening illnesses through assessment, symptom management, suffering prevention, and spiritual and psychosocial goal support.

Executive Summary

Background

American Indians and Alaska Natives (AI/ANs) have a unique relationship with the federal government. It is unlike any other population in the United States, based in part on treaties negotiated with sovereign Indian nations beginning in the colonial period and continuing after the establishment of the United States into the late 1800s. These treaties have established a unique government-to-government relationship, based upon the cession of millions of acres of land in exchange for certain promises, benefits, and reserved rights. These treaties have helped secure the federal obligation to provide health services to AI/ANs. The Snyder Act[1] was authorized by Congress in 1921 to provide health care access to Indian people throughout the United States. Later, the Indian Health Service (IHS) was established under the U.S. Public Health Service to carry out this responsibility under the Transfer Act in 1955.[2]

Health programs funded through IHS serve more than two million AI/AN people from 566 federally recognized tribes and 34 urban Indian communities. While there has been steady progress in health care services since 1955, the health status of AI/AN populations still lags far behind that of other populations, exacerbated by poverty, poor nutrition, lack of exercise, obesity, substance use disorders, violence, and injuries. Trends show that AI/AN populations suffer from higher rates of death and disease than their counterparts. As health services to AI/AN communities improve, so does the longevity of AI/AN populations. Ironically, as people live longer, they are more likely to grapple with issues of chronic disease[3] and need palliative care late in life.

Compounding the health issues that AI/ANs face are geographic isolation, poverty, and a lack of access to health care and health insurance. It is because of this that AI/ANs are projected to seek care at later stages of disease, which lowers survival rates.[4] Delayed access to health care leads many to frailty, deteriorated health conditions, and skilled nursing facility or hospice care. A lack of cultural sensitivity in facilities and hospitals serving AI/ANs might cause Native populations to seek care at later stages of their disease.[5] Another factor for this delay is the lack of tribal community services. Leaving their communities to seek care burdens their families with travel and distant caregiving expenses, while the patients are burdened with the loss of cultural and spiritual supports they would receive at home.

Hospice is care designed support people in the final phase of a terminal illness and focuses on comfort and quality of life, rather than a cure. The goal of hospice care is to enable patients to be comfortable and free of pain to help them live each day as fully as possible. Palliative care improves the quality of life of patients facing problems associated with life-threatening illness and their families through assessment, symptom

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[1] Public Law 67–85
[2] H.R. 303. Public Law 568
[3] Finke et al. 2004, Hampton 2005, Indian Health Service 2006, Kitzes 2003, Arenella et al. 2010
[4] Kitzes 2002, Arenella et al. 2010, Marr et al. 2012, Portman and Garret 2006, National Cancer Institute 2011
[5] Hendrix 2003

management, prevention of suffering, and spiritual and psychosocial goal support. IHS[6] draws on the World Health Organization's definition of palliative care, which defines it as:

> The active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social, and spiritual problems is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families (2).

Palliative care may be offered while patients continue to look for curative treatment, while hospice care involves pain management and support to patients no longer seeking curative measures. Further, hospice care is typically offered when the patient is likely in the last 6 months of life.[7] Both palliative and hospice care involve more than just pain management; they entail end-of-life planning and supporting patients and their families in that process.

Palliative and hospice care requires an interdisciplinary team of professionals, including doctors, nurses, allied health professionals, social workers, faith leaders, and psychologists, to help patients receive care at the end of life.[8] Informed patients, and family members, are critical to providing effective treatment and appropriate care.[9] Integral to hospice care is listening to patients and families about their needs and their belief systems and designing services to meet those needs in culturally relevant ways.

American Indian and Alaska Native Use of Hospice

Decisions about options for end of life care—location of death, levels of care, and intervention—have become increasingly important for AI/ANs, but hospice services that would educate them about their options and choices are largely unavailable to tribal members.[10] Minority use of hospice has been lower than their white counterparts.[11] A 1995 study by the National Palliative Care and Hospice Organization showed that 83% of white patients chose hospice care compared to only 6% of American Indians.[12] In 2008, Domer and Kauer reported that only 2.8% of Medicare patients at New Mexico IHS hospitals enrolled in hospice care, compared to a 30.8% state average. Barriers to hospice services in tribal communities include regulation, reimbursement policy, and internal management.[13] Geography and low population density prevent tribal hospice programs from being successful and a lack of cultural sensitivity in non-tribal programs keeps tribal members away.

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[6] 2006
[7] Schrader et al. 2009
[8] Robinson et al. 2009, Indian Health Service 2006
[9] Colclough and Brown 2013, Van Winkle 2000
[10] Finke et al. 2004, Robinson et al. 2009
[11] Myers et al. 2006
[12] Valente and Haley 2003
[13] Carlson et al. 2007

Hospice program financial rules and regulations are sometimes at odds with AI/AN communities' cultural beliefs and needs, contributing to the lack of hospice programs in tribal communities. The required prognosis of less than 6 months of life for hospice care at a Medicare-certified facility is culturally problematic. Further, some palliative care and hospice programs demand advance directives for their patients, which can be seen as planning for the inevitability of death and may not be culturally acceptable for some AI/AN communities.

Culture and Values

Cultural perspectives about death and dying in AI/AN communities are noted as a common barrier to seeking hospice care.[14] Culture influences how people think, talk, and make decisions about death and illness.[15] Culturally sensitive care can increase AI/ANs' access by making services responsive to values, beliefs, and traditions.[16] Cultural sensitivity includes behaviors, attitudes, and guidelines that support work among organizations, departments, and professionals in cross-cultural settings.[17] AI/ANs' traditional values and beliefs are sacred and personal. The healing process, practices, and context of spirituality, community, environment, and self are critical for medical professionals to understand in supporting decision-making for AI/ANs at the end of their lives.[18] It should also be noted that the substantial cultural heterogeneity in AI/AN communities makes it important for programs to avoid a "one size fits all" cultural mentality[19] in rural and urban communities.[20]

Proposed Solutions and Recommendations

There are a number of suggested recommendations for overcoming barriers and supporting the development of culturally appropriate and effective hospice services.

1. Gain support from tribal leadership, program staff, and community on palliative and end-of-life care.[21]
2. Create partnerships with national and local entities.[22]
3. Embed tribal consultation into programs to allow for more seamless cultural integration.[23]
4. Develop a cultural sensitivity training curriculum for new and existing health care workers.[24]

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[14] Domer and Kauer 2008, Marr et al. 2012, Kitzes and Berger 2004, DeCourtney et al. 2010

[15] Valente and Haley 2003

[16] Myers et al. 2006

[17] Hendrix 2003

[18] Portman and Garrett 2006

[19] Baldridge et al. 2011, DeCourtney et al. 2010, Kitzes and Berger 2004, Manataka n.d.

[20] Hendrix 2003

[21] Kitzes and Berger 2004, Hampton 2005, Finke et al. 2004

[22] Hampton 2005, Finke et al. 2004

[23] Domer and Kauer 2008, Finke et al. 2004

[24] Domer and Kauer 2008, Finke et al. 2004, Kitzes 2003, Michalek et al. 2005, Schrader et al 2009

5. Build flexible programs to adjust to patient needs and personnel shortages.[25]
6. Establish trust between patient and health care provider.[26]
7. Educate patients and families about the purpose and benefits of hospice care.[27]

Successful palliative care programs have been identified as having the following elements:[28] defined vision, strategy for the use of available resources, leadership support, ongoing team-building and education, targeted data collection, communications strategy, and national, regional and local partnerships. Building culturally sensitive and sustainable palliative care and hospice programs in Indian Country should be a priority in the coming years to meet the needs of the aging AI/AN population in rural and urban areas. In order to do this, tribes and communities need these elements in place. Purposeful planning and a collaborative approach to building and maintaining community-linked programs will support the development of successful programs.

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[25] Finke et al. 2004, Van Winkle 2000
[26] Hendrix 2003, Indian Health Service 2006, Kitzes 2002, National Cancer Institute 2011
[27] Kitzes 2002, Schrader et a. 2009
[28] End Byock et al. 2006, Finke et al. 2004, Kitzes 2003, Valente and Haley 2003

Hospice in Indian Country (Literature Review Reports)

Arenella, C., Finke, B., Domer, T., Kaur, J. S., Merriman, M. P., & Ousley, A. (2010). Adaptation, Dissemination, and Evaluation of a Cancer Palliative Care Curriculum for the Indian Health System. *Journal of Palliative Care, 26*(1), 15-21.

Arenella and coauthors acknowledge how the increasing aging American Indian and Alaska Native (AI/AN) population is also increasing the number of elderly AI/ANs living with chronic illnesses, especially cancer (15). Elder AI/ANs lack access to health care, generally live in poverty, are geographically isolated, and may have limited health insurance (15). Consequently, they seek medical relief during later stages of disease (15). This means AI/ANs will have poorer rates of survival for chronic illnesses (15). Due to a lack of programs, resources, and trained palliative doctors within the Indian health system, proper end-of-life care is largely unavailable (15).

The Quality of Cancer Care Committee of the National Cancer Institute (NCI) conducted a survey inviting Indian Health Service (IHS) directors to respond to palliative care service conditions in their communities. The responses suggested developing education programs, especially for pain management. In 2006, NCI and IHS worked together to do just that:

> "Culturally adapt and disseminate the EPEC-O curriculum throughout the Indian health system; improve the capacity and competency of clinicians in the Indian health system to provide palliative and end-of-life cancer care to the AI/AN population" (16).

The EPEC-O, or Education in Palliative and End-of-Life Care for Oncology, was developed in 2003. The EPEC-O provides "comprehensive, multimedia, train-the-trainer curriculum" (16). The program focuses on pain management, palliative care, communication, and advanced care planning. Some of the AI/AN-focused EPEC-O programming includes (17):

- Identifying unique AI/AN communication and cultural issues
- Learning the origins of mistrust for Western medical models
- Understanding traditional Indian medicine concepts

The authors describe how this collaborative effort differed from other hospice and palliative care trainings. They explained that the NCI-IHS program combined self-study with seminars, multimedia, video vignettes, training materials, and modeled presentations, like a mock negotiation session (20). The program was interdisciplinary versus doctor-focused (20). The adapted EPEC-O curriculum accomplishments for AI/ANs, cited by the authors, include: increasing self-reported clinician knowledge and confidence, encouraging the incorporation of palliative care principles, and developing previously unavailable palliative services.

Baldridge, D., Garrett, M., Williams, E., Aldrich, N., & Benson, A.W. (2011). *Moving Beyond Paradigm Paralysis: American Indian End-of-Life Care.* **Retrieved September 19, 2014, from http://aidpc.ouhsc.edu/documents/DB-AIEndoofLife.pdf**

Baldridge and coauthors agree that culture is always changing. The authors note that previous research with American Indians often points to the taboo nature of discussing terminal illness or death among many American Indian groups (1). They point to the lack of end-of-life and palliative care within tribal communities (2). The authors argue that hospice and palliative care services simply need to be culturally sensitive and responsive to be effective. The authors highlight four palliative care programs that serve Indian Country.

Fort Defiance Home-Based Care Program
- This program worked with Navajo social workers to plan messaging about end-of-life care that matched cultural perspectives.
- It used two models: the Program of All-Inclusive Care of the Elderly and Medicare hospice benefit.
- The program did not apply for the Medicare hospice benefit licensure and reimbursement because the 6-month life expectancy requirement was out of step with the cultural perspective (4).

Cherokee Nation Home Health Services (CNHHS)
- CNHHS is made up of three departments using different funding streams:
- Cherokee Nation Outreach—state Medicaid Advantage program
- Cherokee Nation Home Health—Medicare- and Medicaid-certified home health program
- Hospice of the Cherokee—Medicare and Medicaid certified in-home hospice service (7).

New Mexico the Zuni Home Health Care Agency (ZHHCA)
- ZHHCA is a partnership between tribes and the Indian Health Service-area hospital to provide interdisciplinary palliative care.
- It also holds an alliance with the University of New Mexico Medical School to provide staff training and technical assistance (8).
- ZHHCA used focus groups to better understand the community need and culturally appropriate approaches (7).
- IT is not a CMS-certified hospice because it was not a financial fit and the 6-month life expectancy requirement was "culturally troublesome" (8).

University of New Mexico Hospital (UNMH) Palliative Care Program
- UNMH is an urban- and hospital-based program that provides consulting and referral services to all patients, not just American Indians.
- It "sees the highest percentage (10.3%) of American Indian and Alaska Native patients among total admissions of any academic hospital in the country" (9).
- UNMH staff conduct respectful conversations and work with patient to set goals in end-of-life planning (10).

Carlson, M. D. A., Morrison, R. S., Holford, T. R., & Bradley, E. H. (2007). Hospice Care: What Services Do Patients and Their Families Receive? *HSR: Health Services Research, 42*(4), 1672-1690.

Carlson and coauthors use the National Home and Hospice Care Survey results conducted by the National Center of Health Statistics to identify hospice services received by patients from 1992 to 2000. The authors used definitions from the National Consensus Project's Clinical Practice Guidelines for Quality Palliative Care to narrow which hospice services best represent quality care and which services were offered to patients from 1992 to 2000. This list marks hospice services that are telling of quality care (1675):

- skilled nursing
- doctor services
- volunteer services
- dietary counseling

- homemaker services
- physical, occupational, and speech therapy
- transportation services

- counseling
- social services
- medication management

Carlson and coauthors identified that two million individuals, with an average age of 72 years, received hospice care from 1992 to 2000. Eighty percent of those individuals were white, non-Hispanic; 71% had Medicare as primary source of payment; 92% received care from a Medicare-certified hospice; and 84% received care from a nonprofit hospice (1679). Eighty three percent of patients received care from a hospice in an urban setting (1679).

Carlson and coauthors identified regulations, reimbursement policies, and internal hospice service management as hospice program barriers (1686). Medication management, spiritual care, durable medical equipment and supplies, dietary counseling, and social services saw significant increase in use by hospices during the 1990s (1684). Overall, this report summarizes key hospice statistics during a period of growth for the industry and offers a profile of typical hospice patients and the care they received.

Colclough, Y. Y., & Brown, G. M. (2013). End of life treatment decision making: American Indians' perspective. *American Journal of Hospice & Palliative Medicine, 31*(5), 503-512.
The authors analyze the environment under which end-of-life treatment decision-making discussions occur between American Indian patients and health care providers. Informed consent is the ethical practice for treatment in end-of-life care, but it is often difficult to construct between a doctor and patient because two components are necessary—patient autonomy and information (503). This can be difficult to attain because patient, family, and doctor definitions and perceptions of these components can influence the level of involvement a patient or doctor will have in making a decision (503). The authors note that influence is due to culture, values, beliefs, emotions, or life experiences (503).

The authors "identify tribal values and contributing factors that influence end-of-life decision making" (504). The results reflect the understanding, misunderstanding, barriers, and perceptions of doctors, families, and patients in the decision-making process (506):

- Treatment decision-making was believed, by doctors, to be made autonomously by patients, while patients and families indicated the doctors made the decisions (507).
- Patient and family medical knowledge is limited to their own experiences and those of relatives or people they know who work in the health care field, as well as to information shared in brochures (508).
- Patient barriers to understanding illness include believing in their ability to heal, denial of or depression about their circumstance, and the pervasive thought, "Why me?" (508).
- Family barriers to understanding illness involve emotions and mental states. The authors note that the level of family support indicated acceptance of circumstance (508).

Overall, patients and families respected their doctors, but viewed them as authoritative, which suppressed their self-worth (509). This attitude by patients and families affected their informed consent during treatment decision-making by negatively influencing their level of involvement in the discussion. Markers from the study highlight American Indian perceptions about their patient autonomy (509):

- Patients accepted their diagnoses at "face value" and perceived them as being "given."
- All outcomes were perceived as acceptable.
- No blame was placed on the doctors for treatment decisions.
- Patients did not feel they were a part of the process or heard by their doctors.

As for the second component of informed consent—information—the authors indicate doctors did not perceive patients as being capable of making decisions, therefore trust was never developed (509).

In order to increase patient autonomy and access to information, the authors recommend improving "cultural sensitivity, attunement, or humility of health care providers" and to "seek exchange of information using understandable words" to encourage dialogue (510) and increase American Indian awareness of their autonomy during the decision-making process. The authors example this suggestion with "information" training programs, which would teach patients how to ask questions, or where to find information (510).

Conner, S. R., Tecca, M., LundPerson, J., & Teno, J. (2004). Measuring Hospice Care: The National Hospice and Palliative Care Organization National Hospice Data Set. *Journal of Pain and Symptom Management, 28***(4), 316-328.**

Conner and coauthors report on the National Data Set (NDS), a database created by the National Hospice and Palliative Care Organization. The NDS tracks the progress of hospice programs across the country to create industry standards (317). The National Hospice and Palliative Care Organization (NHPCO) decides hospice program rules to guarantee effective service delivery. NHPCO is not a regulating authority, but uses NDS results to support standard hospice care across the nation.

The information reported from the NDS looks at five key questions (317):

- Who provides hospice care?
- Who are the patients cared for by hospice?
- How much and what type of care do patients receive?
- How much does hospice cost?
- How good is the care that is provided?

Table 2 of the report combines the survey results from 2000 to 2002 that were received from hospice providers, including (323):

- Half of all hospice programs were freestanding or operating independent of a parent organization, hospital, or corporation (an increase from both 2000 and 2001);
- Nonprofit hospice programs have decreased by 8% since 2001; and
- 97% of hospice agencies were certified by Medicare.

The report also describes hospice patient characteristics from 2002, such as (323):

- 1/3 of hospice patients are 85 years old or older,
- 50% of hospice care patients are cancer patients,
- 80% of patients are funded by Medicare,
- 11 to 13% were funded by private payers,
- The majority of patients were at home to receive hospice services,
- 20 to 24% were in a nursing home,
- The average length of stay for a hospice patient was 50 days ,
- Patients received about 4.2 visits per week from staff, and
- Patient's families received about two to three rounds of grief counseling or support.

The NDS includes replies from a wide range of hospice programs that include freestanding, nonprofit, state hospice organizations, and hospices in urban, suburban, and rural populations (326). Information from the NDS can be used to compare programs, help support clinical practice, and inform health-service management. The NDS can also help hospice programs determine goals, set operating targets, and improve practices (327).

DeCourtney, C. A., Branch, P. K., & Morgan, A. K. (2010). Gathering Information to Develop Palliative Care Programs for Alaska's Aboriginal Peoples. *Journal of Palliative Care, 26*(1), 22-31.

DeCourtney and coauthors outline the ways in which they collected information to create a culturally sensitive palliative care program for Alaska's Aboriginal peoples as part of the Robert Wood Johnson Foundation's "Promoting Excellence in End-of-Life Care" program.

Drawing on their earlier experience working with Alaska Natives, the research team gathered information about (23):

- How the dying were traditionally cared for,
- What the current preferences and values are around death are,
- What kind of support caregivers need, and
- How palliative care programs might support families caring for the dying.

There has long been a belief that death is a topic to be avoided in American Indian and Alaska Native communities but many point to need for "cultural humility," an approach that allows for flexibility to take the cultural beliefs of individuals into account (23). In this way, palliative care workers and others can learn what individuals and families want and need in end-of-life care without necessarily causing offense by discussing advance directives and imminent death.

DeCourtney and the research team traveled to four Aboriginal communities throughout Alaska in order to talk to all of the major cultural groups in the state about palliative care through focus groups. The findings from this study helped to form the Helping Hands Program and all related material. The research team found that remote communities were finding it difficult to care for elders in their homes due to the shift from subsistence living to a cash economy and caregiver support, such as respite care and paperwork, after a family member passed away. Further, the team found that community health workers often felt overwhelmed, as they were often the only people in their communities to provide medical care and support, and they often worked double duty, as they are sometimes asked to care for family members in their role as community health workers.

Recommendations for a culturally sensitive palliative care program were (30):

- Develop a succinct information guide with step-by-step instructions for managing post-death,
- Separate the roles of community health workers as health resources and family members,
- Be aware that clinics in remote areas do not have ready access to supplies, so discharge patients with medications needed,
- Offer "just-in-time training" to those with family members near death,
- Develop ways to talk about advance directives and other end-of-life issues that are not culturally offensive, and
- Conduct more research on how traditional healing can be combined with modern medicine for more effective end-of-life care.

DeCourtney, C. A., Jones, K., Merriman, M. P., Heavener, N., & Branch, P. (2003). Establishing a Culturally Sensitive Palliative Care Program in Rural Alaska Native American Communities. *Journal of Palliative Medicine, 6*(3), 501-510.

The Helping Hands Program was created out of a desire to provide culturally competent palliative care for Alaska Natives. Alaska does not have hospitals or nursing home facilities in remote areas where many Alaska Natives live. Many elderly Alaska Natives are transported to major cities such as Dillingham, Anchorage, and Ketchikan. This travel removes them from their families, traditions, and food. This often has harmful effects on the patients and unfavorably affects their families who feel a sense of loss. Many elders do not return home before they pass on.

It was this situation that led the Bristol Bay Area Health Corporation to create the Helping Hands Program to mix "cultural practices with contemporary medicine to allow Alaska Natives and others living in remote communities to be cared for at home through the end of life" (502). The Helping Hands Program teaches village volunteers and regionally located doctors and home health nurses how to deliver palliative care in remote communities (502).

The outcome was a primary caregiver for each patient and trained workers in every village to provide care for and support to end-of-life patients. The program focuses on pain and symptom control and training for family, health care providers, and volunteers (504). Due to the physical remoteness and geographic realities of Alaska, the authors note that the Helping Hands Program "would never be able to meet existing state and federal rules and regulations regarding hospices" and did not to seek Medicare certification for the program (504). Culturally competent steps taken by program developers include:

- Consulting with village elders and medical personnel via focus and advisory groups;
- Translating training materials into Yup'ik, the prevailing language in the Bristol Bay area;
- Combining traditional indigenous end-of-life practices with palliative care practice;
- Accounting for village lifestyles, such as villagers leaving elders to fish in the summer (505).

The program found that their basic premise of "decentralized services with central technical support" using home health nurses and traditional cultural practice were successful. The Helping Hands Program worked in the following way:

1) Patient is referred to the program
2) Home health nurse reviews the patient's chart and schedules an on-site visit
3) Home health nurse coordinates with the village health aide visits
4) Nurse determine patient's needs and goals and creates a care plan for the patient

DeCourtney and coauthors feel that the Helping Hands Program model is "transferable to other indigenous populations and remote communities in Alaska and beyond" (507). They feel that the key learning from the Helping Hands Program experience is to use evaluation and focus groups to create programs that are responsive to a populations' cultural practices, and to identify and address population concerns with traditional beliefs and practices. Further, they point out, working closely with communities assures acceptance and engagement with regular feedback (507–508).

Domer, T., & Kauer, J. S. (2008). Palliative Practice in Indian Health. *South Dakota Medicine, Special Edition,* **36-40.**

Domer and coauthors cite that, although American Indians and Alaska Native (AI/ANs) experience a lower average lifespan than Whites in the United States, they lack access to palliative and hospice care even though these services significantly aid the suffering of chronic illness (37). From 1999 to 2003, "only 2.8 percent of Medicare patients at two [Indian Health Service (IHS)] hospitals [in New Mexico] were enrolled in hospice when they died…compared to a state average of 30.8 percent" (37). The authors identify programs in Indian Country, which have been successful in developing services, that increase access and use culturally appropriate models. Common barriers are also identified along with efforts made by IHS to address end-of-life health issues.

Negative cultural perspectives about death and dying among AI/AN communities is a common barrier cited for low hospice program use. Domer and coauthors reason that the lack of hospice services available to AI/ANs is a more accurate explanation of low hospice enrollment by AI/ANs, as there are no CMS-accredited hospice programs serving a "significant" number of patients living on reservations (37). Since the passage of the Indian Self-Determination and Education Assistance Act, many tribes assume responsibility to provide health services to their own communities rather than seek care from IHS. Programs operating under tribal directors allow cultural considerations and traditions to be more easily integrated into programs (38), and better positioned to maneuver cultural misgivings.

Several tribal programs have been successful in developing their own palliative care programs, one being the Pueblo Zuni in New Mexico. Planners in this community gained tribal leader support who provided guidance to approaching end-of-life practices within the community (38). The same approach was used by the Tohono O'odham Nursing Care Authority's skilled nursing facility, which developed specific language and words to describe end-of-life care (38). Before establishing the Fort Defiance Home-Based Care (HBC) program, which provides palliative and hospice care in the home of its patients, many community members were forced to leave their homes in order to receive care (38). The HBC program is designed after the Medicare Hospice Benefit and the Medicare Program for All-inclusive Care for the Elderly. The HBC integrates social workers, nurses, and doctors, and can include cultural liaisons (38).

AI/AN health advocates demand that culturally competent and accessible care be standard for Indian Country. The IHS began addressing these demands by partnering with other health organizations to develop training curriculum and strategies. The effort began with a national conference held in 2001, Talking Circle: Palliative Care and End-of-life Care for American Indian Communities. Since then, investment and training has been made available to IHS staff annually. *Guideline for Palliative Care Services in the Indian Health System* was published in 2006, which covers "structure, process, and physical, psychiatric, psychological, social, and spiritual aspects of palliative care" (39).

Finally, IHS partnered with NCI, to adapt and develop the EPEC-O curriculum to be used by IHS, which addresses and trains individuals in "fundamental skills and philosophies of end-of-life care, centering on communications skills, interdisciplinary patient-centered team care, ethical decision-making, and symptom management" (39).

End Byock, I., Twohig, J. S. Merriman, M., & Collins, K. (2006). Promoting Excellence in End-of-Life Care: A Report on Innovative Models of Palliative Care. *Journal of Palliative Medicine, 9(1)*, **137-146.**

Promoting Excellence in End-Of-life Care is a national program of The Robert Wood Johnson Foundation (RWJF). The RWJF funded 22 demonstration projects that worked to develop and implement new models of palliative care. These projects worked to determine practicality, access, quality, and financial effects in host programs. The demonstration projects were located in urban, suburban, rural, and remote rural locations. The various health settings include integrated health systems, hospitals, renal dialysis clinics, urban public health and safety systems, nursing homes, cancer centers, and outpatient clinics (138). The results of Promoting Excellence in End-of-Life Care revealed that palliative care service could be expanded by individualizing care, using existing resources, and case management (138).

Project evaluation methods were determined by a practicality assessment in context of available resources, and the acceptance of new methods by administrators, payers, and patients and families. Indicators that measured service access were the levels of service use, tracking patient enrollment, and lengths of stays at home or in facilities (139). Professional training and education accompanied survey instruments to measure quality. Programs' financial impacts were measured by resource use and interviews with financial decision-makers (139). Outcomes were positive and included increased confidence and comfort in caring for patients at end-of-life and increased understanding of hospice services by caregivers; administrators who supported funding new service lines and encouraged expansion; patients who were comfortable discussing their illnesses and needs; and families that felt better prepared to handle death (139).

A common strategy used by demonstration projects to increase access was team-based care with a focus on beginning palliative care earlier—starting with diagnosis. This meant most patients received more care than the average hospice care of 50.6 days (140). Partnerships were established with local health systems to develop new uses for existing benefits to increase payment options for patients. Advanced care planning was adopted by all demonstration programs (143). Table 4—Essential Ingredients for Building Successful Palliative Care Programs, lists these elements of successful palliative care programs (144):

- Defined vision
- Strategy
- Leadership support
- Ongoing team-building and education
- Targeted data collection
- Communications strategy

Two of the Promoting Excellence projects, Helping Hands and When Cure is No Longer Possible, focused on Native American communities and cultural competency Helping Hands focused on developing a culturally sensitive end-of-life care service for Alaskan Native villages in the Bristol Bay area. When Cure is No Longer Possible focused on creating a palliative care network in rural communities and assisted Zuni Home Health Agency in establishing a palliative care program. The Zuni project developed a Palliative Care Education, Referral, and Training office in the University of New Mexico's Health Sciences Center.

Finke, B., Bowannie, T., & Kitzes, A. J. (2004). Palliative Care in the Pueblo of Zuni. *Journal of Palliative Medicine*, *7*(1), 135-143.

Finke and coauthors outline the process by which the Pueblo of Zuni developed a palliative and hospice care program. They begin by noting that the American Indian and Alaska Native (AI/AN) population is fairly young and that life expectancy is better now than ever before; however, AI/ANs are much more likely to suffer from chronic diseases than before. Living longer paired with chronic disease often means a slower dying process than was previously experienced in AI/AN communities (136). The authors note that, "As a result of this change, decisions about location of death and intensity of medical intervention in the period before death have become critically important" (136).

The Pueblo of Zuni has operated the Zuni Home Health Care Agency (ZHHCA) since 1980 as a non-profit, state-licensed tribal initiative that is Medicare and Medicaid certified. In 1997 the ZHHCA partnered with the Zuni Comprehensive Community Health Center (ZCCHC), which is the Indian Health Service's area hospital, to apply for the Robert Wood Johnson Foundation's (RWJF) Promoting Excellence in End-of-Life Care program to create a hospice program at the ZHHCA. The ZHHCA and the ZCCHC eventually worked with the University of New Mexico Health Science Center, which was funded by the RWJF grant, to create a hospice program at ZHHCA.

The ZHHCA program began by interviewing community members to determine what issues to address and how to address them for a sometimes taboo subject, such as death. The ZHHCA staff also recognized the issues they faced living in a rural setting that left a small staffing pool to draw from for their hospice program. To address this, they trained existing employees to do the work and recruited others from the part-time work pool at the ZCCHC. Additionally, the ZHHCA partnered with the ZCCHC to provide 24-hour access to medications. Lastly, the ZHHCA worked with the rural New Mexico hospice network for support.

Finke and coauthors outline the following eight programmatic lessons they learned from the ZHHCA experience:

1) Services to support family caregivers will be welcome in most communities.
2) Local tribal leadership must lead the development of a palliative care program.
3) Tribal cultural and spiritual consultation is essential for the development of a program.
4) Family interviews can be helpful tools in the planning and implementation of a program tailored to a community's specific cultural values.
5) An effective reservation-based end-of-life care program will cross many boundaries and involve multiple agencies, including federal, state, or private health systems, and tribal social services
6) Personnel shortages make it difficult to obtain and retain qualified professional staff. Flexibility and cooperation on the part of local health systems.
7) The effort to implement a tribal home-based hospice, whether or not it becomes Medicare- and Medicaid-certified, serves as a stimulus to expand local health system awareness of the need for improved end-of-life care.
8) Communities will likely need the support of regional hospice networks and university centers to expand capacity for end-of-life care (142).

Hampton, J. W. (2005). End-of-Life Issues for American Indians: A Commentary. *Journal of Cancer Education, 20*(1), 37-40.

Hampton explains key elements of planning, implementing, and operating a hospice program. He uses the Hospice of Oklahoma as the example for his commentary. He begins by introducing the American Indians' history of health care and stating that the federal government's history of providing health services to American Indians is the result of an agreement between tribal sovereign nations and the U.S. federal government through the cessation of lands in exchange for health care. The Indian Health Service (IHS) was established by the federal government as an agency to provide health care to tribal communities. Hampton further identifies that the federal government has never appropriated sufficient funds to the IHS to provide adequate health care to tribal communities (37).

Hampton identifies that American Indians and Alaska Natives (AI/ANs) are "living longer and dying of chronic diseases, such as diabetes, heart disease, and cancer" (37). He cites numerous physiological and psychological impacts of living with a chronic disease to include increased metabolic rate, impaired immune function, anxiety and depression, loss of hope, and even risk of suicide (37). He outlines palliative and hospice care as, "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" (37).

Hampton discusses that support from leadership, staff, and community are instrumental to a hospice program. He recommends that these areas be developed through national and local partnerships with associations, consortiums, funeral homes, health care providers, doctors, lawyers, clergy, social workers, and media. He suggests using a community-driven model to develop programs, as it values and relies on volunteers, and community engagement to fulfill fundraising and other operational roles. Hampton highlights that the Hospice of Oklahoma used this model, which prepared them to support their large population of Native Americans. Through creative partnerships, Hospice of Oklahoma leveraged community engagement, integrating and accommodating cultural concerns without being a tribally operated hospice program.

Hampton briefly discusses how AI/AN communities generally perceive palliative and hospice care and underscores why culturally competent care is important. He cites that, generally, AI/ANs' cultural perceptions of hospice care include distrust toward federal government-sponsored health care systems and policies. Hampton implores that more consideration is necessary when health care staff consult with AI/ANs. Ultimately, for non-tribally operated facilities, local tribal communities should be a large part of the research and planning phases in developing a culturally competent hospice program, as well as key advisors of the implementation and operation of the services.

Hendrix, L. R. (2003). Intercultural Collaboration: An Approach to Long Term Care for Urban American Indians. *Care Management Journals, 4*(1), 46-52.

Hendrix begins by reminding the reader that culture is dynamic and multi-layered, noting that these include "community, ethnic group, individual patient, and practitioner levels, as well as the culture of the health care system, all of which need to be addressed in a knowledgeable and competent manner by health care providers for maximum efficiency and effectiveness in allocation of scarce health care resources" (46). Hendrix promotes the importance of communication between patients and care givers in order to shape positive care outcomes. The emphasis of this article is the importance of culture and ethnicity and how they affect how people view care based on "language, cultural expectations, and barriers to access" (46).

Hendrix's focus on urban American Indian and Alaska Native (AI/AN) communities sheds light on "invisible Indians" who live outside of reservation communities and face even more difficulty receiving culturally competent care than their reservation-based counterparts. The fear is that lack of culturally competent care for urban Indians may lead them to eschew palliative care through managed care facilities until they are in "severe distress" (47). The definition for cultural competency here is drawn from the Office of Minority Health and is defined as "a set of congruent behaviors, attitudes, and policies that come together in a system, agency, or among professionals that enables effective work in cross-cultural situations" (47). For many AI/AN populations, including those living in urban areas, establishing trust is an important first step, as well as creating a collaborative relationship that does not rush patients to make decisions. Hendrix provides the reader with two charts to demonstrate the differences between American Indian and Euro-American attitudes and cultural values on pages 50 and 51. These serve as guidelines to help providers better serve their AI/AN patients while recognizing that AI/AN patients are individuals who all have different backgrounds and experiences both culturally and personally.

Indian Health Service. (2006). Guidelines for Palliative Care Services in the Indian Health System. Retrieved September 15, 2014, from http://www.uaa.alaska.edu/elders/upload/ihs_palliative-care-services.pdf

American Indians and Alaska Natives (AI/ANs) suffer from higher rates of death and disease than their counterparts. As health services to AI/AN communities have improved, so has the longevity of AI/AN populations. As more people live longer, they are more likely to grapple with issues of chronic disease and need palliative care later in life. The Indian Health Services (IHS) draws on the World Health Organization's definition of palliative care and sees it as "the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families" (2).

The IHS Guidelines outline the ways in which providers should work to address these needs through their facilities. The areas where IHS makes recommendations on how to approach and manage palliative care in the IHS system include the:

- Structure and process of care;
- Physical aspects of care;
- Psychological and psychiatric needs;
- Social aspects of care;
- Religious, spiritual, and cultural aspects of care;
- Care for the imminently dying; and
- Ethical and legal aspects of care.

In all of these areas of care, the overarching message is to use an interdisciplinary approach, to be responsive to patients and their family members, and to support families through responsive care and respite services when needed. Further, the guidelines recommend providing families with the knowledge to help care for their loved ones. Collaboration between doctors, families, and patients that is built on listening to patient needs is the cornerstone to the IHS guidelines to help address end-of-life care needs.

Kitzes, J. A. (2002). Guidelines for Discussing Palliative Care and End-of-Life Planning in American Indian/Alaska Native Communities. *IHS Provider, 27*(5), 89-92.

Kitzes defines palliative care as "the active, total care of a person when cure is not possible," noting that "palliative care services enhance medical care through emphasis on the relief of physical, psychosocial, and spiritual pain and other symptoms" (89). It is recommended that people start to think about end-of-life care before it is a necessity. Kitzes points to the Patient Self-determination Act (PSDA) of 1991 that "requires all health care institutions that participate in Medicaid/Medicare programs to inquire upon admission whether patients have advance directives and, if not, to help them prepare them, if desired" (89). However, research shows that only between 10 and 25% of patients complete an advance directive and these are usually from individuals suffering from terminal illness or individuals of higher socioeconomic status. With this in mind, Kitzes suggests that perhaps written advance directives are not as useful as they should be for all populations. She recommends that discussions about the potential need for palliative care take place over a time before they are really needed. This helps patients think about their needs and can help to build trust with providers regarding end-of-life care. Kitzes warns that these conversations should be approached in a circumspect manner rather than directly, which may scare or offend patients.

Kitzes points to some commonly held views in the American Indian and Alaska Native (AI/AN) community regarding death and dying. She notes that many accept death as a natural part of life, even if it is not openly discussed. There is an infinite amount of diversity in AI/AN beliefs about death and dying. Patient autonomy is respected, but it is "balanced with consensus and cooperation" with others, such as the family and community, in the form of traditional or spiritual healers (90). The article further outlines indicators for having conversations about palliative care with patients, as well as what questions providers might ask in order to spur a culturally sensitive conversation around end-of-life care. Like many others who write about end-of-life care, Kitzes recommends that providers work to educate patients and families about what the procedures entail and what that may mean for patients. She concludes by highlighting the use of active listening techniques and open-ended questions to allow patients and their families to adequately express their needs, concerns, and desires for end-of-life care.

Kitzes, J. A. & Domer, T. (2003). Palliative Care: An Emerging Issue for American Indians and Alaska Natives. *The Journal of Palliative Care Pharmacotherapy, 17*(3/4), 201-210.
Kitzes and coauthors recognize that an increased American Indian and Alaska Native (AI/AN) elder population has elders living with chronic diseases longer, increasing the need for palliative and end-of-life care. End-of-life care discussions have only recently emerged within AI/AN health systems (202). This report identifies key partnerships among tribal health care leaders to promote palliative care in Indian Country.

During the Innovations in Eldercare conference in 2000, elements for a model eldercare program were developed. The elements include strategic use of available resources; integrating state, federal, and local funds; planning around the local or tribal community; and emphasizing home-based care. Tribal values in planning and relying on family to provide care were identified, as well (204).

The Talking Circle: Palliative and End-of-Life Care for American Communities was the first conference held by the Indian Health Service (IHS) for IHS regional staff to discuss palliative care. This resulted in an agreement statement: "National American Indian/Alaska Native leadership action is needed to promote implementation of palliative and end-of-life care services" (205). Education was identified as a key factor to the development of palliative care. In 2002, IHS sponsored a training conference. Topics covered include pain management, spiritual care, family and patient support, and identifying potential problems (205).

Kitzes and coauthors highlight several IHS and tribal health programs that successfully developed palliative care programs. Each program uses methods that work for their local communities' resources, and funds. Some of the methods include (206-209):

- Cross-training staff
- Establishing a "high touch, low tech," structural approach
- Allowing family and community to be primary staff
- Contracting hospice care with local companies
- Developing their own hospice program
- Encouraging the tribal government to pass and support resolutions
- Maintaining a distinct palliative care home health chart
- Developing formal palliative care policies at local hospitals

Kitzes, J., & Berger, L. (2004). End-of-Life for American Indians/Alaska Natives: Insights from One Indian Health Service Area. *Journal of Palliative Medicine, 7***(6), 830-838.**

Kitzes and Berger provide results from their examination of the palliative care service offered at an Indian Health Service (IHS) facility in the Albuquerque IHS area. IHS oversees 12 IHS area regions in the United States, which includes 35 states. IHS was established in 1955 to "raise the health status of American Indians and Alaska Natives to the highest possible level" (831). IHS facilities offer direct and contract care, financial support to tribally operated care services, and urban projects. The Albuquerque IHS service area includes 20 Pueblos, 3 Navajo Nation chapters, 2 Ute tribes, and individual members of tribes living in the area (831).

This report notes that end-of-life care has been unattended in IHS and tribal health care systems because of "sensitivity of these issues from a cultural perspective… institutional orientation toward prevention and treatment of acute illnesses; and limited financial and staff resources" (832). Medical reports of deceased individuals who lived in the Albuquerque IHS service area and received services from IHS, hospitals, and health centers were examined. Data was collected informing on inpatient care, emergency care, and outpatient care.

The results revealed that management staff did not have a financial management strategy in place, none had experience in developing palliative care policies and procedures, and there were no indicators for palliative and end-of-life care within their quality management plan (834). Medical records showed insufficient documentation of patient care and even less when patient death was imminent (833). Also, there were no procedures in place to discuss patient end-of-life (EOL) care, pain management, or medical conditions and care preferences with family (833). Finally, 52% of records did not list "place of death" and 55% of records "lacked a standardized form ensuring privacy, confidentiality, and patients' rights" (834).

Kitzes and Berger do note that all hospitals had reserved areas for the performance of traditional ceremonies, and fulfilled families' preferences for care of body after death (835). Finally, results note that cultural practices vary among tribes and individuals within communities and are obvious by individual and family responses to advance directives, autopsy permissions, and body preparation for burial (835).

However, formal cultural insensitivities remain, causing barriers for American Indians and Alaska Natives seeking end-of-life care. This is met with no official guidance from tribal leadership on palliative or end-of-life care (836). Kitzes and Berger offer 10 administrative recommendations to improve tribal and IHS palliative care and EOL services. Some of these recommendations include:

- Adopt a palliative care policy.
- Add palliative care data to all forms.
- Require staff to obtain pain and EOL continuing medical education.
- Develop a national tribal consensus on palliative care needs.

Manataka American Indian Council. (n.d.). Native American Spirituality. Retrieved September 23, 2014, from
http://www.geneticcounselingtoolkit.com/pdf_files/Native_American_Spirituality[1].pdf
Native American Spirituality is a guide developed by the Manataka American Indian Council to support and provide information to public and private establishments in education, health care, or any other sector about Native Americans religion and practice. This guide introduces aspects of Native American religion and how each sector should expect, appropriately respond to, and provide support. The right to practice religion, including Native American religion, is protected under the U.S. Constitution, and other legislation. The guide specifically references this legislation, which includes the American Indian Religious Freedom Act of 1978 and the Native American Graves Protection and Repatriation Act of 1990.

Native American Spirituality established that Native American religious practices are generally classified as Complementary and Alternative Medicine (CAM). The National Institute of Health Center for Complementary and Alternative Medicines define CAM as "a broad range of healing philosophies, approaches, and therapies generally defined as those treatments not widely taught in medicals schools, not generally in hospitals, and not usually reimbursed by medical insurance companies" (4). CAM courses that also include Native American religion material are seeing an increasing presence in medical and health care curriculum as the perception of Native American religion changes and is increasing viewed as supplemental to patient health care (5).

The guide offers descriptions and protocols for ceremonies, sacred objects, and land and offers suggestions on how to handle these moments within a public and private sector establishment. Some of the recommendations include keeping a list of all local Native American spiritual elders for contact, establishing communication with local CAM providers, allocating designated areas for ceremonies, specifying support for Native American religious practices on educational material, and recognizing and respecting spiritual elders as same they would clergymen (13).

The guide notably provides insight to general recognition of Native American spirituality and preferred modes of treatment toward patients who request the presence of medicine men or healers. The guide also notes that many Native Americans practice Christianity along with a Native American religion (6). The ultimate message is that Native Americans should have access to their religious leaders "without barriers of policy" (7).

Marr, L., Neale, D., Wolfe, V., & Kitzes, A. J. (2012). Confronting Myths: The Native American Experience in an Academic Inpatient Palliative Care. *Journal of Palliative Medicine, 15*(1), 71-76. Marr and coauthors conducted a study in an attempt to discredit the notions that American Indians and Alaska Natives (AI/ANs) will not discuss death or dying that AI/AN patients and families refuse Do Not Resuscitate (DNR) orders, and that AI/ANs will not use hospice care. The article begins by recounting how AI/ANs suffer from much higher death rates and from a variety of conditions compared to their counterparts. Despite the health of many AI/ANs improving moderately in the last 40 years, there is a greater need for chronic disease management and end-of-life care (71). It has been widely documented that hospice and palliative care provides much needed care and support to patients and families at the end of a patient's life. However, many AI/ANs do not have access to these kinds of programs in their communities. Marr and coauthors purport that cardiopulmonary resuscitation (CPR) is the standard treatment option preferred by many private, emergency, and Indian Health Service facilities unless a DNR order is in place. The authors consider the low numbers of AI/ANs discussing advance directives is due to a lack of information and the cultural incompetence of the health care providers (72).

The authors draw on the example of the University of New Mexico Hospital (UNMH), which provides referral and consultative services on palliative care and treats the most AI/AN individuals in the United States (72). UNMH uses an interdisciplinary approach to address palliative care consultation, drawing on the expertise not only of doctors and nurses, but also AI/AN health educators, religious figures, and traditional medicine providers (72). The primary techniques that UNMH staff use when approaching the topic of end-of-life care include talking to patients about who they want to have present and how they want to receive information on the topic, providing translators when requested, using the third person when approaching the subject, and always assuring patients and families that no harm is meant in having the conversation. Other steps in the UNMH end-of-life conversation process are to let patients know that the best outcome is always hoped for, care providers are mindful of their use of eye contact and touch, and patients and their family members are allowed to set the pace of the conversation. UNMH also encourages scheduling meetings at convenient times for family members; supports and encourages patients to have traditional healers present at meetings; and encourages care providers to permit time for processing so that patients and families do not feel pressured into making decisions (73).

The findings from Marr and coauthors study regarding the effectiveness of palliative care conversations at UNMH clearly demonstrate the effectiveness of the intervention. Patients and families were significantly more likely to have family meetings on the topics of EOL care and DNRs. Further, they found that AI/AN "patients and their families choose hospice services at rates similar to non-Native patients seen by the Palliative Care Consultation Service" at UNMH (74).

Michalek, A. M., Mahoney, M. C., Gilbert, A., & Kaur, J. (2005). Palliative Care Services: A Survey of Tribal Health Directors. *The IHS Provider, 30*(5), 118-119.
As the demographics of Indian Country change, so do the needs of American Indian and Alaska Native (AI/AN) populations. More and more AI/ANs are living longer, but there are also more AI/ANs suffering from chronic conditions. This signifies a greater need for palliative care services in Indian Country. Because the perceived need for these services was unknown, a national survey among tribal health directors was undertaken.

The surveys were supported by the Spirit of EAGLES, a National Cancer Institute Special Population Network. Surveys were sent to tribal health directors listed in the Indian Health Service Health Directory and, after two mailings, there was a 37% response rate (118). The survey sought to gain information on 10 different areas of palliative care: "hospice, pain management, alternative medicine, psychosocial counseling, interdisciplinary care, spiritual counseling, bereavement support, advance care planning, staff support, and respite care for family care providers" (118). When responding to the greatest needs in their community, more than 50% of tribal health directors noted a great need to address pain management, "advance care planning, traditional medicine, physical therapy, bereavement support, care for the dying, and hospice contracts" (118). When asked what services were often not readily available in their local communities, respondents noted alternative medicine, advance care planning, staff support, hospice services, and bereavement support (118).

The findings of the study have important indications for palliative care in Indian Country. Findings and the wider literature on the topic suggest that there is a great need for culturally competent end-of-life care for AI/AN populations that takes into account the rural nature of many AI/AN communities. The study recommended creating and implementing culturally sensitive palliative care infrastructure to serve Indian Country. In the meantime, it is important to train providers, caregivers, and patients in pain management so that these services are available in communities that do not currently have access to them.

Myers Schim, S., Doorenbos, A. Z. & Borse, N. N. (2006). Enhancing Cultural Competence Among Hospice Staff. *American Journal of Hospice & Palliative Medicine, 23*(5), 404-411.

Myers Schim and coauthors examine the results of a cultural competency training program among hospice workers in the United States. The authors note that, in today's multicultural society, there is a greater need for culturally competent care across the board. And, in the case of hospice programs, cultural sensitivity is a mandate of the Joint Commission on Accreditation of Health Care Organizations and the U.S. Department of Health and Human Services Office of Minority Health (404). As hospice care has grown by leaps and bounds over the last 40 years or so, its use by ethnic minorities has remained low when compared to white counterparts. The push behind cultural competence in hospice care is, in part, related to making services more "accessible and acceptable" to different populations that might benefit from hospice care (405).

The article outlines different approaches and models for cultural competence and notes that inter-personal interventions tend to be more effective than those taught in a classroom or clinical setting. The authors note that, although the literature is clear on what kinds of interventions are most effective with regard to knowledge transfer, they do not account for which models are the most cost effective (404). Given the demand on hospice workers' time, the authors wanted to test the effectiveness of a one-hour class based on the End-of-Life Nursing Education Consortium training materials module. Therefore, they designed a quasi-experimental study whereby hospice workers were randomized into two groups. Both Group A and B were given a pre-test. Group A was then given the cultural competence training first while Group B received ethics training. A post-test was given and then Group B was given the cultural competence training and Group A received ethics training and a second post-test was given. Results showed that there were greater increases in cultural competence levels between the groups after the first training each group received, but that numbers were comparable for both groups after the second trainings for both groups were concluded (408). The authors found that "even a limited 'dose' of education in the form of a short talk and discussion raised cultural competence behavior scores, and those scores continued to rise for several months after the intervention" (409). The authors contend that more work needs to be done to find an effective mix of training methods that provide the greatest impact for the least cost.

National Cancer Institute. (2011, September 3). *A Look at End-of-Life Care Issues for Native Americans.* **Retrieved October 3, 2014, from http://www.cancer.gov/cancertopics/disparities/lifelines/2011/palliative-care-ai.pdf**

American Indians and Alaska Natives (AI/ANs) face a lack of access to health care, particularly in comparison to their counterparts in the United States. In part, this is attributed to the fact that many AI/ANs live in isolated areas where there are less health care resources. It is thought that because of this, even though AI/ANs have a lower occurrence of cancer than White Americans, they have a higher incidence of being diagnosed at the later stages of their disease. Further, they are less likely to have access to palliative or hospice care. The need for end-of-life care is not only an issue for AI/ANs facing cancer, but also for those suffering from a growing incidence of chronic conditions, such as "diabetes, tuberculosis, pneumonia, and influenza, and gastrointestinal and heart conditions" (1).

The number one thing needed to establish a successful end-of-life care program for AI/ANs is to build trust with patients who have cultural practices and beliefs that shape how they view and make sense of mortality. It is therefore important for caregivers and doctors to take their time in approaching the issue of palliative care, and to be culturally sensitive when broaching the topic. Direct discussions about death and dying may not always be appropriate, as is often common practice in many hospice programs. It is important to keep in mind that palliative care should be an effort to provide patients with what they need to die with peace and dignity (2). With this in mind, the National Cancer Institute developed the end-of-life and palliative care curriculum for health care providers called Education in Palliative and End-of-Life Care for Oncology (EPEC-O). They partnered with the Indian Health Service (IHS) in 2006 in order to modify the EPEC-O for use in IHS service units through a series of trainings for IHS health care providers. The trainings were done in 2007 and 2008 and "four out of five of those trained said they had used what they had learned and incorporated these palliative care principles into their practice settings" (2). Many said that they were planning to provide the training to others, and others noted that they had begun new services at their practice around palliative care planning.

Portman, T. A. A., & Garrett, M. T. (2006). Native American Healing Traditions. *International Journal of Disability, Development and Education, 53***(4),** *453-469***,** DOI: 10.1080/10349120601008647

Portman and coauthors stress that traditional healing is very sacred, personal, and between the healer and person seeking healing. It is key for health professionals to understand Native American traditional healing practices, the cultural context of the specific tribe they work with, and the relationship between healing and spirituality, community, environment, and self (455). The American Cancer Society describes the process as such:

> "Most Native American treatment is a slow process, spread over a period of days or weeks. It may involve taking time out from the usual daily activities for reflection, emotional awareness, and meditation. The healer may spend a great deal of time with the person seeking help. Healing is said to take place within the context of the relationship with the healer" (455).

The authors underscore that each Native American tribe has different traditional healing beliefs, and techniques, but asserts that there is a core perspective among Native American traditional medicine. Within the context of traditional healing and spirituality, the authors list seven core beliefs (456):

1) Belief in a single higher power
2) All living species have spirits
3) Mind, body, and spirit are interconnected
4) Wellness is balance among mind, body, and spirit
5) Natural un-wellness is breaking of sacred or natural law
6) Unnatural un-wellness is summoning harmful or destructive intentions
7) Each person is responsible for their own wellness through active self-awareness

The authors explain that "medicine" in terms of Native American culture means, "The essence of life or an inner power" (459). Uniting the core beliefs of traditional healing, medicine can take physical, spiritual, or mental forms. Its benefit brings wellness and balance to an individual's mind, body, and spirit. This means that a conversation with a friend, a hike, or ceremony are medicinal activities that help the mind, body, or spirit of an individual restore balance to that person's being. The degree of wellness needed by a person, and the type of medicine required, is dependent on the individual's personal state.

The authors identify that principles of behavior for Native Americans are passed from one generation to the next through tradition, ceremony, or oral stories. These guide individuals toward a balanced, "harmonious" life (459).

The authors emphasize that traditional Native American healing and medicine is very different than Western medicine and uses a holistic approach. Care takers and health providers need to take a Native American patient's traditional belief system of health and wellbeing into consideration and understand their perspective. The fundamental differences between Western medicine and Native American healing will have vast influences on the perception and reception of care.

Robinson, C. A., Pesut, B. Bottorff, J. L., Mowry, A., Broughton, S., & Fyles, G. (2009). Rural Palliative Care: A Comprehensive Review. *Journal of Palliative Medicine, 12*(3), 253-258. Robinson and coauthors evaluated a series of reports on the topic of palliative care to determine patient and caregiver perspectives and professional attitudes, knowledge, and practice issues. Generally, palliative care can be seen as a "patchwork" of services that require the combination, or integration of services or funding to provide the necessary care (253). The authors highlight that geography influences access to palliative care and, with a growing elder population, this is especially salient (253).

The authors' review of literature reveal limited research on palliative care is available. Available sources conclude that patients and their families believe options for place of death are limited; indigenous cultural considerations are not addressed; and that areas of pain, suicide, and advanced care plans need professional intervention (254). Also, technology is an identified factor that needs further development (254).

Professional attitudes, knowledge, and practical issues of rural palliative care are recognized as "important work that elicits a high degree of commitment" (255). However, palliative care can be difficult for professionals, as palliative care demands dual relationships with families and patients; social and geographic isolation; and "blurred distinctions" between private and professional lives (255). As far as models of palliative care, the interdisciplinary team approach, in one study, was reported to be more effective in an urban setting rather than rural (255). The report further sites barriers that prevent high quality palliative care. Some of these barriers include a lack of resources, support for family or caregiver, continuity in care, access to resources and funding (255).

Robinson and coauthors identify that education programs for professionals enhance confidence, knowledge, skills, attitudes, and networking, especially in a small group, conversational setting (255). However, training the trainer was viewed as an ineffective education model (255). Finally, a significant finding from this report is that hospice use is based on "rurality," and that rural patients "use hospice less and enter hospice later than their urban counterparts" (256).

Schrader, S. L., Nelson, M. L., & Eidsness, L. M. (2009). Reflections on End of Life: Comparison of American Indian and Non-Indian Peoples in South Dakota. *American Indian Culture and Research Journal, 33*(2), 67-87.

The authors surmise that death from long-term, chronic disease is increasingly likely and that with medical advances, philosophies have changed perceptions about end-of-life (EOL) care (67). The authors offer the following definition of palliative and hospice care:

> "Palliative care encompasses physical, psychosocial, and spiritual dimensions to promote quality of life at EOL, and by using a team approach, hospice care is typically provided during the last 6 months to terminally ill people and their families, whether in the home or an alternate setting" (67).

The authors also note that a nationwide study, *A Means to a Better End*, reported 70% of Americans prefer to die at home, painless, and with loved ones, while only 25% actually receive this preferred way of death (67).

The authors use and modify Life's End Institute's survey tool to assess the EOL perspective of American Indians living in South Dakota and to compare it to non-American Indians. Characteristics identified about the participating South Dakota American Indian population include: they are less likely to be married or live in urban areas, and they are more likely to live in large households, have household incomes below $30,000 a year, and experience a death in the family within past 5 years (68).

The authors used a framework that measured EOL perceptions in spirituality, family, health care, and self (69). A sample of the topic items used for each of the areas include (72–73; 75–77; 79–81):

- Spirituality: be at peace spiritually, value getting old, know that dying is an important part of life
- Family: want to attend funerals, do not want to be a burden to loved ones; be able to stay in their own home
- Health care: want honest answers from providers, have not heard of hospice, want to be free from pain
- Self: talking about death; important to be off machines that prolong life; be at spiritual peace

The authors report five patterns about EOL from an American Indian perspective (83–84):

1) It profiled American Indian attitudes, preferences, and actions related to EOL.
2) American Indians are likely to be concerned that doctors wouldn't believe and treat their pain.
3) American Indians are likely to agree that "good" patients don't talk about pain.
4) It noted the importance of spirituality at EOL.
5) It found similarities among American Indian and non-American Indian perspectives on EOL.

In lieu of these patterns, the authors suggest: addressing pain treatment and medication practices with American Indians, providing more education about hospice programs and services, increasing cultural competency among doctors, increasing community outreach by hospice programs, and increasing awareness of communication issues among patients, doctors and families (83–84).

Valente, S., & Haley, B. (2003). Culturally Diverse Communities and End-of-Life Care. *Care Management Journals, 4*(1), 44-45.

This article discusses the importance of culture, particularly in people's choices for end-of-life care. The authors point to how culture frames how people think and talk about death and illness, as well as how they make decisions about the dying process. The current recommendations on managing end-of-life care are to ask patients to fill out advance directives in order to ensure that their wishes are honored. A study done by the National Palliative Care and Hospice Organization found that patients who chose hospice were 83% White, 8% African American, 6% Native American, and 3% Hispanic (44).

The authors point to how culture influences how people see end-of-life care, as some see choosing palliative care as a "denial of care"—as is the case with many African Americans—whereas other groups feel that, when brain death occurs, there should automatically be a Do Not Resuscitate order (44-45). Discussing end-of-life issues can often be compounded by language barriers, as well as doctors' attitudes that death equals failure. Further, the role of the family can complicate care choices, as in many cultures, it is traditionally the family's place to care for their elders, so choosing an option, such as hospice, could be seen as a dereliction of duty. The authors recommend increasing research on the intersection of culture, communication, and dying to create a more positive environment for discussing and managing end-of-life care in a multicultural society (45). Moreover, they recommend that doctors work to better communicate with patients and families to understand what their desires are and to explain what kind of care is available in a jargon-free and linguistically appropriate manner.

Van Winkle, N. W. (2000). End of life decision making in American Indian and Alaska Native cultures. In K. L. Braun., J. H. Pietsch, & P. L. Blanchette (Eds.), *Cultural issues in end of life decision making (pp. 135–141)*. **Thousand Oaks, CA: Sage Publications, Inc.**

Van Winkle examines the role of autonomy and culture in decisions American Indians and Alaska Natives (AI/ANs) make about end-of-life care. The author describes autonomy as the right for individuals to make decisions for themselves. In 1991, the Patient Self Determination Act (PSDA) was legislated to safeguard patient autonomy by mandating health care facilities receiving federal funds to disclose information about patient conditions. This would create an opportunity for the patient to participate in decision-making of their care, which includes the right to accept or refuse treatment. The Act also directs that health care facilities educate staff and the community on advance directives, and provide information on state laws and hospital policies about patients' rights (135). The author notes that, despite the passage of the PSDA, advance directives are completed in low numbers, especially among minority groups (135). The author describes how cultural barriers between AI/ANs and health care providers have influenced patient autonomy during medical discussions and decisions.

The authors highlight several impacts of the PSDA on Native American patients that were caused by interpretations of the PSDA by health care providers who often overlooked cultural barriers. Some of the case studies mentioned by the authors include:

Discussion of negative information: By policy and implication, negative patient information would be included in patient-doctor discussions under the PSDA. However, in some traditional Native American cultures, mention of negative subjects in conversation can be just as harmful mentally and spiritually as the physical condition (135).

Context of decision-making: Facility policy to have patients sign advance directives or similar forms influence doctors to follow protocol, even though such action may cause disengagement with patient and family history about procedures and treatment and reluctance to sign forms or receive treatment (136).

Consensus and Cooperation: Principle of autonomy is aligned with Native American beliefs; however, so are the principles of cooperation and consensus. This means that decisions and end-of-life decisions will not be made without family and, in some cases, community consultation (138).

The author stresses that while the PSDA includes autonomy and principle of self-determination that agree with American Indian and Alaska Native cultural values, cultural barriers exist that deter effective communication. The author offers recommendations that address cultural barriers that health care providers, social service providers, and researchers can take into consideration when directing policies and providing care to American Indians and Alaska Natives. The recommendations include (139–141):

- Understanding the service population,
- Having the patients defines who "family" is,
- Implementing flexible hospital policies,
- Offering translation services, and
- Noting informal or verbal consent.

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