



Spiritual Care within Oncology Care: Development of a Spiritual Care Program at an Indian Health Service Hospital

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ABSTRACT

Spiritual care is essential in providing quality health care for patients and their families and is supported in the mission of the Indian Health Service (IHS). Their mission is to raise the physical, mental, social and spiritual health of American Indians and Alaska Natives to the highest level. This paper will describe the spiritual care programs at the Phoenix Indian Medical Center, an IHS hospital located in Phoenix, Arizona. Two hospital committees, the Volunteer Chaplains' Association and the Traditional Cultural Advocacy Committee, provide spiritual care for the medical center and work to sustain a presence of spiritual and cultural awareness and well being. In this paper, particular attention is focused on the ways in which these committees have worked collaboratively with community agencies, tribes in Arizona, and academic institutions, through National Cancer Institute funded grants to raise awareness of how spiritual and cultural understandings of American Indians play an essential role in cancer care.

Key Words: Spirituality, American Indians, Traditional Indian Medicine, Chaplain, Oncology Care

The mission of the Indian Health Service (IHS) is "to raise the physical, mental, social, and *spiritual health* of American Indians and Alaska Natives to the highest level." It recognizes the importance of spiritual care in providing quality health care for patients and their families (Indian Health Service, 2011). In this paper, we describe the spiritual care infrastructure, history, activities and collaborative efforts with community agencies, tribes in Arizona, and academic institutions, aimed at sustaining a presence of wellbeing and spiritual and cultural awareness at Phoenix Indian Medical Center (PIMC), an IHS facility located in Phoenix, Arizona. These efforts are guided by two PIMC committees, the Volunteer Chaplains' Association and the Traditional Cultural Advocacy Committee (TCA), both of which provide spiritual care at the medical facility. The collaborative efforts of the committees to specifically address the spiritual needs of patients and their families going through a cancer experience were funded by National Cancer Institute grants (Grant Numbers **UO1 CA 86122-02** and **UO1 CA11469**), aimed at decreasing cancer health disparities.

BACKGROUND

Indian Health Service and the Phoenix Indian Medical Center

The IHS, an agency within the Department of Health and Human Services (DHHS), is responsible for providing healthcare services to members of the approximately 564 federally recognized tribes in 35 states. Phoenix Indian Medical Center (PIMC, one of the largest facilities in the IHS with an approximate 60 inpatient bed capacity, is accredited by The Joint Commission (TJC) and the medical staff is employed in a staff-model medical practice.

PIMC provides healthcare through approximately 300,000 outpatient visits per year and offers a range of comprehensive care including pediatrics, surgery, emergency, primary care, dental, eye, behavioral health, and oncology. Inpatient care includes specializations in intensive care, general medical and surgical care, and obstetrics and gynecology. Patients live in metropolitan Phoenix, while others are transported urgently or emergently from outlying remote areas for health care unavailable at their home reservation clinic. Many patients have utilized the IHS as their primary, and often only source of health care for their entire lives, as have their parents and grandparents.

Diversity of Spiritual and Cultural Understandings

American Indian and Alaska Natives (AI/AN) look to elders, healers, practitioners, pastors and ministers when needing spiritual guidance for health and healing. Often, assistance will be sought from more than one group, as there can be much diversity as to beliefs about spirituality and healing within a family and within a tribal community. As expressed by Linda Burhansstipanov, 2001;p. 211: "...a large group are bicultural who use both Traditional Indian medicine (TIM) as well as modern western medicine for their health care problems." An important facet of AI/AN societies and tribes is respect for individual autonomy and this includes a person's spiritual beliefs (Ellerby, et al., 2000). Just as each tribe has its own language and culture, so it is with practices and beliefs related to spiritual and religious understandings. Trust and respect earned by spiritual leaders is highly valued among AI/AN and relationships between the leaders and those they serve are of upmost importance. There are many AI/AN for whom traditional tribal understandings and customs embody and define their spiritual worldview and identity.

Whether living on their home reservations or not, many AI/AN have close cultural and spiritual ties to their families and communities. When seeking healthcare, particularly for a hospitalization or an illness requiring specialized treatment, patients are often separated from their families, sometimes for extended periods, and enter into a technological environment, which is both isolating and intimidating (Kelly & Minty, 2007).

Spiritual ties to communities are not simply a descriptive term but can have far-reaching implications for a person's physical and spiritual health and wellness. For example, in the Navajo tradition, one's spiritual strength, identity and protection are found within the four Sacred Mountains where the creation stories and spiritual beings reside and form the homeland "boundaries" of the tribe (Nabokov, 2007). Being far away from one's support system and one's home leaves many AI/AN's feeling vulnerable spiritually and emotionally. It is not unusual for those living in urban areas to seek out support, culturally and spiritually, through various organizations and gatherings, but also to make it a priority to get back to one's home reservation or community for ceremonial and community events. These gatherings are not viewed exclusively as social events but can often be held for spiritual reasons to restore and maintain spiritual balance and harmony.

Provision of Spiritual Care Services

It is essential to understand that AI/AN individuals see themselves as not only a physical self, but also a mental, social, and spiritual being. Healing is described as a process that brings these parts of oneself together at a deep level of inner knowledge (Hunter, 2006). Therefore, healthcare providers must recognize and respect that the journey to wellness for the patient must not only address the physical, but must also address the spirit. The community recognizes that by restoring harmony to the person, the ceremony improves the harmony of the people as a whole (Coulehan, 1980).

Within IHS, a practitioner or provider of Traditional Indian Medicine is designated as a Traditional Medicine Practitioner, and defined to be "a person who is trained in a Native American community, and applies culturally specific knowledge and skills in the diagnosis, treatment, or referral of patients to promote their well being physically, mentally, socially, and spiritually." (IHS Provider Class File, RPMS). Some IHS sites employ practitioners on site, while others access spiritual care providers known to the patient and their family, through community contacts.

At PIMC, spiritual care is provided for patients, families and staff through the work of two committees: the TCA and the Chaplains' Association. Both groups meet monthly, having established guidelines and procedures that meet requirements necessary to function within a healthcare facility. The authors are not aware of other IHS sites employing chaplains or utilizing a formal mechanism for pastoral care.

History of the Traditional Cultural Advocacy Committee (TCA)

Prior to 1989, requests from PIMC patients regarding their spiritual needs was addressed on an individual basis with assistance from the health care provider and hospital's administration. In 1989, community members and health care providers, in response to inconsistencies in care, created what would later be known as the Traditional Cultural Advocacy (TCA) Committee. Currently, the committee is made up of approximately 15 individuals some of whom are hospital staff members and other individuals from the community who as Elders, "... hold[s] certain qualities and maintain a certain lifestyle and knowledge base." (Ellerby 1999). Initially, the TCA committee was set up to address the needs of the AI/AN patients who wanted their own Traditional Indian Medicine (TIM) ways practiced but their role expanded by also providing educational programs for employees in the area of cultural competency, especially as it pertained to the spiritual needs of patients. A partnership program with a TIM provider, Mr. Monetatchi, Jr. and an urban Catholic faith-based health system is described by Ann Hubbert. According to Mr. Monetatchi, Jr "The intent of the partnerships and education was not to 'learn Indian healing ceremonies,' but rather to share the philosophy of TIM in a way that all people, including patients and healthcare professionals, could choose directions to enhance their own way of living." (Hubbert, 2008; p. 67). The TCA established formal policies and procedures that would protect patient rights under the American Indian Religious Freedom Act of 1978. To compliment the Act, in 1994, Dr. Michael Trujillo, then director of the IHS affirmed the agency's commitment to "protect and preserve the inherent right of all American Indians and Alaska Natives to believe, express, and exercise their traditional religions" with the inception of the Traditional Cultural Advocacy Program (TCAP)..Through policies it is required that IHS staff must inform patients of their right to practice native religions and healing practices, and when a patient or family member requests the services of a TIM, every effort will be made to address this request (Ross, 2000). In that same year, the PIMC Administration formally acknowledged the TCA, and the committee now falls under the direction of the hospital's Medical Executive Committee (MEC).

Today, the TCA continues to assist PIMC in providing educational opportunities for staff and

assisting in the coordination of a patient's practitioner of TIM. Additionally, the members maintain a site on campus for the use of a sweat lodge, open to all and led by ceremonial elders. Elders are asked by patients and hospital staff to provide spiritual blessings that can involve the practice of burning specific botanicals to assist with spiritual healing and restore balance when there are situations involving loss and grief, conflicts and unresolved issues.

History of Volunteer Chaplains' Association

In 1979, the PIMC administration asked an American Indian minister serving a congregation in Phoenix to work with the hospital's Director for Volunteer Services to organize a group of local clergy to provide onsite pastoral care services at PIMC on a volunteer basis. Many of the local clergy, representing various Christian affiliations, were already serving American Indians and were willing to volunteer their time ministering to patients at the hospital. As this group became more formalized, policies and procedures were put into place for pastoral care services. Pastoral care services provided by chaplains can include the following: visiting patients in the inpatient and outpatient settings, providing religious resource materials, conducting weekly Sunday services at the hospital and hosting an annual Easter Sunrise Service open to community members, providing coverage 24/7 through an on-call pager service for emergent/urgent requests, and officiating at special occasions such as baptisms, funerals and weddings.

Oncology Care and Funding for Spiritual Care Services

Despite the tremendous volunteer support from the community clergy, a gap in the provision of pastoral care services remained. Hospital administration supported the development of a permanent pastoral care position; however, funding was not available within the hospital and attempts to accumulate sufficient outside financial support from several church denominations met with various obstacles. In 2001, funding was made available to support the work of a chaplain to develop a spiritual care program through a National Cancer Institute grant (Grant Number UO1 CA 86122-02).

The PIMC chaplain works in partnership with the Southwest American Indian Collaborative Network (SAICN), the Volunteer Chaplains' Association, TCA, and members of the medical center's oncology staff to specifically address the spiritual care needs of those seeking cancer care at or working in the medical center. As a member of the multi-disciplinary oncology clinic team, the chaplain meets with patients during chemotherapy treatments, clinic visits and hospitalizations and assists with end-of-life discussions with patients and families, requiring careful and sensitive communication, as many American Indians do not speak directly about death.

A cancer diagnosis can provoke fear and the journey of seeking care has many challenges, physically, financially, emotionally and spiritually. These challenges are felt acutely among American Indians, as health care disparities already present before a cancer diagnosis becomes magnified can sometimes overwhelm patients, families and tribal communities. These challenges were clearly described by one of the PIMC chaplains who expressed his desire to learn not only more about cancer as a disease, but how he and other spiritual care providers could learn to respond to the spiritual and emotional needs of patients and families going through cancer. In order to provide this education, the "Spirituality and Cancer" conference was planned for February of 2002.

COLLABORATIVE WORK PROMOTES SPIRITUAL WELL BEING FOR THOSE WITH CANCER

Cancer Care Conferences

The planning of the conference, as well as the conference itself, brought together the spiritual care providers at PIMC as well as those in the communities and organizations serving American Indians. Approximately 40 patients, traditional healers, and clergy attended the one-day event which featured keynote addresses as well as panel discussions on topics such as "Traditional AI/AN Treatment and Practices for Cancer," "Self Awareness and Self Care for the Spiritual Provider," and "Beliefs about Cancer: Stories and Experiences."

The conference findings reaffirmed the centrality of family and tribal community life in the spiritual healing process of the person with cancer, and, as one participant stated, "family support is your spirituality and how you live." Despite the importance of those ties, these relationships and ties within families and community are typically the ones most challenged by cancer. The participants expressed their concern that so few resources, such as support groups on their reservations, were available. They also expressed that they felt uncomfortable participating in support groups available through other organizations, including clinics and hospitals, because of cultural differences. Others expressed their distress at loved ones being sent far away from home for oncology care without the support of family. A tribal member whose family member had cancer shared the following concern: "There was no place to go, so she was sent off the reservation to people who didn't know Native people." As confirmed by Pelusi and Krebs from their findings at a National American Indian Cancer Survivor/Thriviers Conference "...healthcare providers should spend less time talking about the intricacies of cancer and its treatment and more time looking at, listening to, and trying to understand how cancer and its treatments affect the everyday lives of the people and families we treat" (Pelusi and Krebs, 2005).

The spiritual care conferences became a biannual event, with various themes, for those involved in the work of the NCI grants and for the members of the PIMC spiritual care program.

The conference, "Celebrations and Ceremonies for Life's Transitions: Implications for Cancer Care with American Indians" which was held in 2007 and sponsored by SAICN, attracted over 200 attendees. In one of the presentations, "Cancer Care: Transitions in the Journey," panelists shared stories about transitions of cancer from their lives or the lives of others with whom they lived and/or worked. A panelist, an American Indian physician, stated that it angers him when he hears of a doctor making the statement "I am sorry, there is nothing more we can do for you" because the patient has put their trust in that medical provider. There is always something that can be done to ease the suffering of a patient, even if a cure is not possible; being present for the patient and assisting the family throughout the dying process is healing, in and of itself."

Cancer Education Video Projects

In order to reach a wider audience with those lessons learned and stories shared, SAICN and the conference photographers, Lizard Light Productions, a small American Indian family contract photography and multimedia business, embarked upon what would become a year long project together to produce two videos. Few educational resources exist that address spiritual and cultural aspects for American Indians and are widely available.

The first video "Cancer Has Crept Among Us" features the story of Linda Havatone, an American

Indian cancer survivor and her family's multiple experiences with cancer in a rural reservation community in northwestern Arizona. Her story highlights cancer care disparities that are often present in American Indian communities.

The second video, "American Indian Attitudes and Values: An Integral Part of Cancer Care" features interviews with American Indian cancer survivors, family members, community leaders and providers on the importance of providing culturally and spiritually appropriate cancer care.

Both videos can be viewed via the Inter Tribal Council of Arizona, Inc. website at <http://www.itcaonline.com/saicn/Resources.html>. An accompanying guidebook with questions based upon the videos is currently being produced to facilitate group discussions for audiences viewing the videos and will also be made available via the Inter Tribal Council of Arizona, Inc. website.

CONCLUSION

Developing a spiritual care program that addresses the spiritual care needs of American Indian patients and their families should involve thoughtful and careful consideration of what patients express is important to them not only as individuals going through cancer but as part of a family or tribal community. Partnerships with community and ceremonial elders, pastors and other spiritual leaders as well as health care providers and organizations involved in the life of American Indian communities will be essential in laying the foundation for a responsive, respectful and relevant spiritual care program at a hospital or clinic serving American Indians.

ACKNOWLEDGMENTS

The project described was supported by Grant Numbers U01 CA 86122-02 and U01 CA114696 from the National Institutes of Health/National Cancer Center. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the IHS and NIH/NCI.

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