

The Evolution of Palliative Care within the American Indian Health System

Judith Salmon Kaur and Blythe Winchester

*Corresponding author's email: kaur.judith@mayo.edu

ABSTRACT

Palliative care is now considered an important quality component within cancer care and essential to the continuum of cancer care programs nationwide. American Indian and Alaska Native patients have significant differences in mortality from various cancers, and therefore palliative care is very important while working in parallel towards improved survival overall. In fact, palliative care has in some circumstances even contributed to improved survival (Annual report to the Nation on the status of cancer 1975-2009. DOI:10.1093/jnci/djs491). This article recounts the efforts made over many years to institute quality palliative care programs that are culturally acceptable to Native populations and outlines "next steps".

KEYWORDS: Palliative care, American Indians, Alaska Natives

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INTRODUCTION

The Institute of Medicine produced two substantive reports, one in 1997 and the other in 2001, which outlined deficiencies in the provision of palliative care for persons with life-threatening illness, including persons suffering with cancer (National Academy of Science, 1997; Institute of Medicine and National Research Council National Cancer Policy Board, 2001). Both IOM reports highlighted the fact that minorities suffer disproportionately from the lack of provision of quality palliative care.

Within the American Indian and Alaska Native (AI/AN) populations the incidence of chronic diseases such as cancer, heart disease, cerebrovascular disease and diabetes mellitus are rising rapidly, and are now the leading causes of disability and mortality in this population (Indian Health Service, 2005). AI/AN populations have access problems to health care related to high rates of living in primarily isolated rural communities and having high rates of being uninsured. It is poorly understood that the Indian Health System (IHS) is not actually insurance (Kitzes and Domer, 2003; Gorospe, 2006).

Due to these issues and others, AI/AN's with cancer often present to the health care system at a later stage than do NHW's, and those AI/AN's diagnosed with cancer suffer the poorest survival of any ethnic group (National Cancer Institute, 2018; National Cancer Institute, 2016).

Beginning in 2001, several national and regional seminars in palliative care have been offered to practitioners who care for the AI/AN population. The Indian Health Service sponsored 3 national palliative care conferences, from 2001 through 2003, at which one team of health care providers

(consisting of physician, nurse and one of the following: social service, psychologist, spiritual counselor, or pharmacist) from each IHS area attended with the expectation that they, in turn, would train their colleagues. The Alaska Palliative Care Symposium, sponsored by the Alaska Native Tribal Health Consortium held annual events since 2005. Additionally, palliative care content has been incorporated into several conferences sponsored by the Spirit of EAGLES Program, including the CDC Comprehensive Cancer Leadership Institutes for Tribes.

In 2004, the Spirit of EAGLES Program (an NCI funded Special Population Network), under the leadership of a Native medical oncologist who also was board certified in palliative care and hospice (co-author JSK), performed a needs assessment for palliative care within the Indian Health System (Michalek, et al., 2005). Among the 10 suggestions related to the findings of the report were: "Education programs should be instituted and sustained, especially in pain management." As a part of this needs assessment, a survey of tribal health directors was commissioned by the Spirit of EAGLES to assess available and desired services related to palliative care. Over 50% of responding tribal health directors reported an urgent level of need for palliative services such as pain management (70%), advanced care planning (58%), care for the dying (53%), hospice contracts (54%), and bereavement support (52%). Conversely, a high percent of palliative care services were either not available, or available only outside of the local community (e.g., care for dying 53%; pain management 44%; respite care 48%; advanced care planning 44%; hospice services 42%) (Indian Health Service, 2006). In a national survey undertaken by the National Indian Council on Aging (NICOA) and the National Senior

Citizens Law Center (NSCLC), among the least available long term care services reported by the tribes was hospice care, and chronically ill elders were frequently reported as not having home care needs met adequately (Petersen, et al., 2006).

In response to the documented need for improvement in access and quality of palliative care within the Indian Health System, the Indian Health Service (IHS) has undertaken a multi-pronged approach to foster positive change. One component of the effort is to educate health care providers within the Indian health system to improve knowledge, attitudes, and skills in the provision of palliative care. The DVD sponsored by the National Cancer Institute is known as EPEC-O (Education in Palliative and End-of-Life Care for Oncology) with American Indian and Alaska Native Cultural Considerations) was used for multiple trainings of Indian Health Service teams at Mayo Clinic with an "Intensive Case-based Training for Indian Health" from 2010- 2012. In 2014 a webinar series was hosted by Blythe Winchester, M.D. with over 500 participants including physicians, nurses and allied health professionals. These programs were designed to fill gaps between current and desired practice to relieve suffering. The overwhelming response to the webinar series shows the perception that education in palliative care is recognized as a need to improve overall quality care within the Indian Health System.

Also, cross cultural approaches involving traditional healers have been valuable since indigenous patients will often consult with their traditional people for ceremonies and medicine to help them heal or cope with their illness. A traditional health model helps the person focus on their cultural roots for meaning, purpose, and acceptance of health and wellbeing. With a

renewed sense of empowerment, the holistic approach becomes a self-determined end of life care plan. Approaches using traditional approaches were presented at the Spirit of Eagles National Conference held in Niagara Falls, NY on Sept. 21-24, 2017.

A pre-conference workshop was also held in Niagara Falls dedicated to palliative care issues across AIAN populations. Over 60 multidisciplinary specialists and students attended. As noted previously, Alaska has been a true leader in the endeavor to provide palliative care to the Alaska Native population to overcome barriers associated with the huge geography and remote nature of villages there. A team from Alaska shared models of services to underserved patients with advanced serious illness, including cancer. Tools and resources were provided to educate and equip a broad variety of healthcare providers through the Alaska Tribal Health System particularly where palliative care resources are limited. The ANTHC group has also developed a framework on advance care planning tools for culturally diverse populations in urban and rural regions.

Project ECHO (Extension for Community Care Outcomes) is funded by the Agency for Health Care Research Quality (AHRQ) funding has included telehealth to train in palliative care best practices and involves several Indian Health Service sites including Alaska and New Mexico. (<https://healthit.ahrq.gov/ahrq-funded-projects/>)

Next Steps:

1. Now that Palliative Care is recognized within IHS as an educational and clinical need within the system, ongoing programs should be available

2. Dr. Winchester will report to IHS and provide an internal review of how those perceived needs have changed and improved over the past decade.
3. Data from Project ECHO and other programs should be disseminated widely within the Indian Health System and new programs identified and modified to meet local and regional needs.

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Conflict of interest

The authors declare that no competing or conflict of interests exists. The funders had no role in study design, writing of the manuscript, or decision to publish.

Authors' contributions

Judith Salmon Kaur: literature review and manuscript preparation. Blythe Winchester: a review of the Indian Health Service training to date and co-presenter at the Spirit of Eagles Palliative Care preconference workshop mentioned in this manuscript.

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