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# Establishing Palliative Care for American Indians as a Public Health Agenda

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## Abstract

The circumstances of death in the United States have changed compared to the previous century because of successful public health programs. More Americans including ethnic minorities now suffer more from chronic lifestyle diseases. As a consequence, some minorities endure prolonged periods of debility, limited resources and culturally-inappropriate medical care. Although several studies have investigated health disparities among minorities with terminal illness, very few have addressed the end-of-life (EOL) issues of American Indians. Palliative care for American Indians may qualify as a public health agenda based on four criteria: (1) high burden of death and suffering, (2) major impact on individuals and society, (3) possibility for intervention and (4) involvement of socio-ecological determinants of health. As a public health issue, palliative care for American Indians requires multisectoral collaboration, community cooperation, involvement of public agencies, health care providers and the public health sector.

## INTRODUCTION

The circumstances of death and debility in the United States have changed compared to the previous century because of successful public health strategies such as immunization, sanitation and access to effective medical treatment. [1] With these advances, death is more likely to occur as a result of chronic illness at an advanced age. [2] This ushers the need for palliative care and other long term care services. However, palliative care has attracted little attention from the public health sector. Moreover, palliative care is sometimes considered beyond the scope of public health. [2]

In this paper, I will present arguments that validate palliative care as an essential public health intervention especially if applied to disadvantaged ethnic minorities like the American Indians. Their end-of-life (EOL) issues will be examined based on standard criteria for establishing public health priorities to prove that the lack of comprehensive palliative care services for Native Americans is a public health issue. Lastly, general strategies for addressing EOL issues for American Indians will also be presented.

## REVIEW OF LITERATURE

Public health has been traditionally defined as an initiative for the prevention of diseases and promotion of health. [3] Previous descriptions about public health services and goals

mention nothing about end-of-life care. [4] The emergence of the New Public Health concept expands the scope of public health services. Tulchinsky and Varavikova define the New Public Health as: "a comprehensive approach to protecting and promoting the health status of the individual and society... coordinated with a wide range of curative, rehabilitative and long-term care services". [3] The inclusion of long term care services in the new public health's definition affirms that palliative care is an essential component in the promotion and maintenance of health. The WHO definition of health as "not merely the absence of disease, but optimal physical, mental, and social well-being" [3] could be extended to include those who are terminally ill who may benefit from health programs that alleviate suffering, maintain functional capacity and optimize their quality of life. [3] The revitalized concept of public health not only seeks to promote health but also to foster social justice for those who are disproportionately at risk to illness and injury. It also recognizes the increased vulnerability of people with terminal illness.

In hospices, minorities only represent 5 to 7% of the patient population. [6] Many minorities experience unequal access to pain relief as compared to their white counterparts. [7] Although there are previous studies that investigate health disparities among minorities with terminal illness very few

specifically address the EOL issues of American Indians. Terminally ill individuals are prone to endure futile therapy and procedures that may run contrary to their values and health beliefs. They may suffer not only from physical pain but also from spiritual and emotional anguish in their dying process. [8]

### **DISCUSSION**

Rao et al. propose that issues which qualify as public health priorities have the following characteristics: (1) significant burden, (2) high impact on individuals and society and (3) must have potential intervention. [2]] In addition, I would like to propose a fourth qualifier to this list. I believe that issues which qualify as public health priorities by nature involve (4) socio-ecological determinants of health such as ethnicity, culture, health beliefs and socio-economic status.

### **SIGNIFICANT BURDEN OF DEATH AND SUFFERING**

Elderly American Indians with chronic disease and disability are increasing in number. With a life expectancy of more than 70 years, the elderly American Indians have increased to nearly 10% of the entire Native American/Alaskan Indian population in the last decade. [9, 10] Parallel with the increase in longevity is the rise of chronic illnesses. American Indians experience disproportionately high mortality and morbidity rates from diabetes as compared to all U.S. races. Their common causes of death are the complications of diabetes, heart disease, chronic liver disease and cancer. [11] With chronic illnesses, more than half of terminally ill individuals experience unrelieved pain and prolonged suffering. [12, 13] Because of limited health care resources, only 6.5 % of American Indian elders receive quality EOL care. [10]] As a result, many American Indian elders suffer so much in the process of dying. If ever long term care is made available, hospice and long term care facilities are usually far from their families and tribal communities.

### **HIGH IMPACT ON INDIVIDUALS AND SOCIETY**

Elderly American Indians utilize nearly 25% of the Indian Health Service (IHS) health care spending as proof of their increased burden of chronic diseases. [10]] Yet, there is limited number of long term care facilities in tribal communities. In fact, the IHS has never provided for long term care services. Government-funded health insurance in the form of Medicaid remains as the only source of long term care support for the terminally ill American Indians. [14] In 2002, the National Indian Council on Aging (NICOA) identified only 12 Indian nursing homes with a total capacity

of 627 beds in the entire United States. [10]] It is estimated that 60-70% of Native Americans living in urban centers have no access to palliative care services that have the expertise to take care for their special needs. [15] Many elderly American Indians are compelled to be institutionalized in long term care facilities outside their tribal communities. In the 2002 NICOA survey, 50% of American Indian elders complain that long term care facilities outside tribal communities lack cultural sensitivity aside from their poor medical services. Suffering is not only limited to the terminally ill themselves. Families of dying patients endure significant financial burden, physical stress and emotional fatigue. [16, 17] Family members who have served as caregivers for the terminally ill patients also have increased chances of developing adverse health effects aside from common depressive symptoms. [18]

### **POTENTIAL FOR INTERVENTION**

In palliative care, the goal is not to prolong or hasten death but to alleviate pain, suffering and alienation in the dying process. In public health terms, this would mean the pursuit of the highest quality of life possible for the dying. There is certainly great potential for pain management, psychosocial support, health care financing and provision of accessible and quality palliative care services to American Indians. Effective palliative care services have been documented to prevent undue stress and psychosocial problems for patients, families and caregivers. [18]

Public health, as a science, can play an essential role in palliative services. Tools in public health such as epidemiology can be used to analyze the problems of the chronically debilitated and terminally ill. Public health policy can contribute in improving health systems that support palliative services. Social and behavioral health projects can be done on a community level to come up with community-based initiatives for the terminally ill and chronically debilitated American Indians.

### **INVOLVING SOCIO-ECOLOGICAL DETERMINANTS OF HEALTH**

Elderly American Indians have been disproportionately affected by disease and disability especially in the context of historical trauma. [19, 20] American Indian elders have the highest work disability among racial minorities in the United States [10]]. Even in death, American Indian elders have lower number of available long term care facilities compared to the general population. [10]] In the Study to Understand Prognoses and Preferences for Outcomes and Risks of

Treatments (SUPPORT), race influenced the quality of medical interventions even for the dying and seriously ill. [21]

Even in advance care planning, American Indian elders are disadvantaged. The U.S. Patient Self Determination Act of 1991 which mandates the use of advance directives is based on western legal principles of patient autonomy and informed consent. [22] Advance directives require full disclosure of possible adverse events such as death or extreme debility in seeking medical care. In the Navajo culture, statements of death and debility are avoided as they are believed to change into reality. Therefore, such statements are avoided in clinical discussions. In a survey by Carrese & Rhodes, 86% of their Navajo informants considered the discussion of advance directives as a violation of their traditional values.[23]

Aside from ethnicity and culture, rural isolation and poverty can place American Indians outside mainstream public services and medical care. Almost 27% of American Indians age 64-74 live below the poverty level without access to transportation. [14] They are entirely dependent on Medicaid for long term care. This dependence can place many restrictions on elderly American Indians as to their choice of long term care facilities, accommodations and type of hospice services.

### **ADDRESSING EOL ISSUES FOR AMERICAN INDIANS**

Acknowledging the EOL issues of American Indians as a public health priority implies the need for multisectoral collaboration. Public health issues occur within a web of causation where one strategy may not be sufficient to provide all the available solutions. More studies and collaboration with American Indian communities are needed to raise awareness regarding their specific needs and perceptions about palliative care.

There is a need to establish a local Indian healthcare system that integrates culturally-appropriate palliative care services. There is a great need for hospice and long term care services for tribal communities and American Indians living outside their tribal land. [10, 15] Any long term care or hospice institution must be sufficiently funded on long term basis. Tribal leaders and their political representatives must realize that without sustainable funding, palliative care will not be effective as it is intended.

In communities with limited resources, local volunteers can

play essential roles in the delivery of basic EOL services. This was highlighted in Alaskan native communities which organized community-based palliative care services. [24] The Bristol Bay Area Health Corporation, a tribal health organization, integrated palliative care into its primary care services. It organized and trained local volunteers who will provide palliative care in 34 native villages. Instead of the tribal elders dying in institutions miles away from home, locally organized services provided accessible culturally-appropriate and quality palliative care.

Health care providers dealing with American Indians must be keen in addressing EOL issues. It is not enough to be merely familiar with American Indian society. It is wrong to assume that all tribal communities share the same values. In addressing sensitive issues, they must seek assistance from local resources or trained health workers to guide them. Ideally, advance care planning involves step-wise strategies that highlight careful cultural assessment and sincere communication. [25] Through this process, patient autonomy is respected in the spirit of mutual understanding and cultural sensitivity.

### **CONCLUSION**

End-of-life issues for American Indians fall within the scope of public health priorities. Elderly American Indians are a vulnerable population. They endure disparities in health care services and opportunities. The delivery of health services for the dying elderly American Indians is not easy to address in view of the ever increasing demand for publicly-financed health care services in the United States. It needs political commitment and strong public demand. Like most of the current public health issues, the agenda for improved palliative care will be an on-going struggle. As an emerging issue, it will go through phases of public discussions from the different sectors involved. What is important is that public health workers and concerned communities must keep continued public awareness. Only then will public health issues for American Indian communities truly become a public health agenda

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### **References**

1. Centers for Disease Control and Prevention. Ten great public health achievements, 1900-1999. MMWR

- 1999;48:241-3.
2. Rao JK, Anderson LA, Smith SM. End of life is a public health issue. *Am J Prev Med* 2002;23(3):215-20.
  3. Tulchinsky T, Varavikova E. *The New Public Health*. San Diego: Academic Press; 2000.
  4. American Public Health Association. The future of public health in America. *The Nation's Health* 1995 March 1995.
  5. D'Onofrio C, Ryndes T. The relevance of public health in improving access to end of life care. *Hastings Cent Rep* 2003;Suppl:S30-2.
  6. Center for Practical Bioethics. Disparities in care. *State Initiatives in End-of-Life Care* 2005:3.
  7. Center for Practical Bioethics. Unequal access to pain treatment. *State Initiatives in End-of-Life Care*. April 2005.
  8. Doyle D, Hanks G, Cherny N, et al., editors. *Oxford Textbook of Palliative Medicine* 3rd ed. Oxford: Oxford University Press; 2003.
  9. Kitzes J. Palliative Medicine, intractable pain, and end of life care. *The IHS Provider* 1998:143-144.
  10. Benson W. Long Term Care in Indian Country Today: A Snapshot. In: Kauffman J, editor. *American Indian and Alaska Native Roundtable on Long Term Care: Final Report* 2002. Albuquerque, New Mexico: IHS; 2002. p. 16-28.
  11. Indian Health Service. Differences in Indian health. In: Department of Health and Human Services. Office of Public Health; April 1998.
  12. A controlled trial to improve care for seriously ill hospitalized patients. The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). The SUPPORT Principal Investigators. *Jama* 1995;274(20):1591-8.
  13. Bernabei R, Gambassi G, Lapane K, et al. Management of pain in elderly patients with cancer. SAGE Study Group. *Systematic Assessment of Geriatric Drug Use via Epidemiology*. *Jama* 1998;279(23):1877-82.
  14. Dixon M. Opportunities for medicaid financing of long term care in American Indian and Alaska native communities. In: Kauffman J, editor. *American Indian and Alaska Native Roundtable on Long Term Care: Final Report* 2002. Albuquerque, New Mexico: IHS; 2002. p. 32-52.
  15. Forquera R. How do we address the long term care needs of urban Indian elders? In: Kauffman J, editor. *American Indian and Alaska Native Roundtable on Long Term Care: Final Report* 2002. Albuquerque, New Mexico: IHS; 2002. p. 85-92.
  16. Emanuel EJ, Fairclough DL, Slutsman J, et al. Understanding economic and other burdens of terminal illness: the experience of patients and their caregivers. *Ann Intern Med* 2000;132(6):451-9.
  17. Emanuel EJ, Fairclough DL, Slutsman J, et al. Assistance from family members, friends, paid care givers, and volunteers in the care of terminally ill patients. *N Engl J Med* 1999;341(13):956-63.
  18. Schulz R, Beach SR. Caregiving as a risk factor for mortality: the Caregiver Health Effects Study. *Jama* 1999;282(23):2215-9.
  19. Brave Heart MY. The historical trauma response among natives and its relationship with substance abuse: a Lakota illustration. *J Psychoactive Drugs* 2003;35(1):7-13.
  20. Struthers R, Lowe J. Nursing in the Native American culture and historical trauma. *Issues Ment Health Nurs* 2003;24(3):257-72.
  21. Borum ML, Lynn J, Zhong Z. The effects of patient race on outcomes in seriously ill patients in SUPPORT: an overview of economic impact, medical intervention, and end-of-life decisions. *Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments*. *J Am Geriatr Soc* 2000;48(5 Suppl):S194-8.
  22. Jonsen A, Siegler M, Winslade W. *Clinical Ethics*. 5th ed. New York: McGraw Hill; 2002.
  23. Carrese JA, Rhodes LA. Western bioethics on the Navajo reservation. Benefit or harm? *Jama* 1995;274(10):826-9.
  24. DeCourtney CA, Jones K, Merriman MP, et al. Establishing a culturally sensitive palliative care program in rural Alaska Native American communities. *J Palliat Med* 2003;6(3):501-10.
  25. Carrese JA, Rhodes LA. Bridging cultural differences in medical practice. The case of discussing negative information with Navajo patients. *J Gen Intern Med* 2000;15(2):92-6.

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