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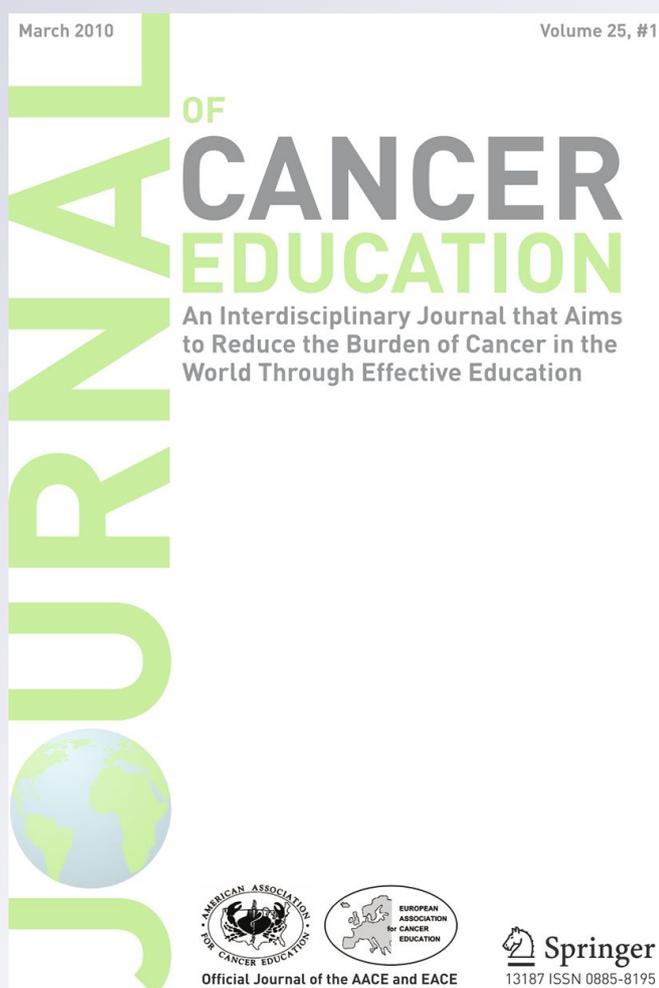
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American Indian/Alaska Native Cancer Policy: Systemic Approaches to Reducing Cancer Disparities

Donald Warne · Judith Kaur · David Perdue

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Abstract Members of American Indian and Alaska Native (AI/AN) tribes have a unique political status in the United States in terms of citizenship, and that political status determines eligibility for certain unique healthcare services. The AI/AN population has a legal right to healthcare services based on treaties, court decisions, acts of Congress, Executive Orders, and other legal bases. Although the AI/AN population has a right to healthcare services, the Indian Health Service (the federal agency responsible for providing healthcare to AI/ANs) is severely underfunded, limiting access to services (including cancer care). In order to overcome distinct cancer health disparities, policy changes will be needed. This paper reviews the historical pattern of AI/AN healthcare and the challenges of the complex care needed from prevention through end-of-life care for cancer.

Keywords Native cancer policy · Cancer disparities · Healthcare services

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Background of American Indian Healthcare

Trust Responsibility

Members of American Indian and Alaska Native (AI/AN) tribes have a unique political status in the United States in terms of citizenship and subsequent eligibility for certain unique healthcare services. Members of AI/AN tribes are born with a legal right to healthcare services based on treaties, court decisions, acts of Congress, Executive Orders, and other legal bases, including the Indian Health Care Improvement Act (reauthorized in March 2010 as part of the Patient Protection and Affordable Care Act) [1]. Hundreds of treaties (essentially contracts between tribal nations and the federal government) were executed in which the tribes exchanged vast amounts of land and natural resources for various social services, including housing, education, and healthcare [2]. The non-Indian population of the USA does not have an equivalent right to healthcare based on *trust responsibility* [3].

The federal government has a trust responsibility to provide services to AI/ANs, and the Bureau of Indian Affairs and the Indian Health Service (IHS) are the primary federal agencies charged with the responsibility of carrying out the federal government's obligation to provide these services. In addition, AI/ANs are citizens of both their tribal nations and the US, as well as being residents of their states. This "tri-citizenship" status means that AI/ANs are eligible for healthcare services provided by the:

- IHS (as tribal citizens)
- Medicaid and related programs (as state residents)
- Medicare and related programs (as US citizens)

Challenges can and do occur in trying to coordinate health services for AI/AN patients among numerous

agencies, multiple levels of government, and the private sector. This paper will review the historical pattern of AI/AN healthcare and will examine the challenges inherent to coordinating cancer prevention and treatment services among tribes, IHS, state Medicaid, private health systems, and public health programs.

History of the Indian Health Service

The origins of the Indian Health Service began in the early 1800s under Department of War. It was the role of army physicians to work at military outposts to contain the spread of contagious diseases like small pox and measles. Beginning in 1832, the federal government began a trust responsibility through treaties with tribes to provide healthcare, housing, and education to AI/ANs in exchange for land and natural resources. In 1955, the Indian Health Service (IHS) in its current form was established under the Department of Health Education and Welfare, now the Department of Health and Human Services [4]. AI/AN healthcare continues under this structure today, with some significant modifications including increasing tribal control of healthcare programs, services, and functions, as well as greater integration with Medicare and Medicaid.

The most significant recent law affecting the provision of health services to the AI/AN population is the Indian Self-Determination and Education Assistance Act (PL 93-638). This law allows tribes to assume the management and control of healthcare programs from the IHS and to increase flexibility in healthcare program development [5]. Under PL 93-638, tribes have the option to contract or compact with the IHS to manage the delivery health services using pre-existing IHS resources (formula-based shares tables determine funding for various IHS sites), third party reimbursements (Medicaid, Medicare, etc), grants, and other sources.

Typically, tribes develop their own non-profit healthcare corporations to provide services to their community, and as a result are eligible for grants and other types of funding not available to federal agencies like IHS. As a result, “638 tribes” generally are able to provide more services to their community members, including cancer-related services, than they were able to under IHS control. Currently, over half the IHS budget is distributed to tribes through 638 contracts and compacts, and numerous tribes have improved access to healthcare services and have increased flexibility of health programming for their communities. For example, there are over 560 federally recognized tribes in the USA. Over 200 exist in Alaska, and over 100 exist in California, and all of these AI/AN tribes are managing their healthcare under 638 contracts and compacts. Other Areas of the IHS have varying degrees of tribal and federal management of health programs (Fig. 1).

Indian Health Service Areas



Fig. 1 Indian Health Service areas

I/T/U System

The AI/AN healthcare delivery system is called the “I/T/U” system (IHS/tribal/urban). Each component of the delivery system has unique funding streams and systems of governance. IHS is predominantly funded by Congressional appropriations with some additional funding in the form of third party revenue. Tribal programs are funded through the 638 mechanism previously described, and the Urban Indian Health Centers (UIHCs) are funded through Title V of the Indian Health Care Improvement Act (PL 94-437). UIHCs represent a small fraction of overall IHS funding, despite Census data documenting that over two-thirds of AI/ANs are now in urban settings. Most UIHCs provide primary care and/or referral services, and typically do not have oncology programs. Nationally, there are currently 36 UIHCs in 21 states [6].

Health Disparities and Funding Disparities

The AI/AN population suffers from among the greatest health disparities in the USA. Rates of death due to preventable causes such as type 2 diabetes, alcoholism, infant mortality, unintentional injuries, suicide, and numerous other causes, including cancer, have led to what should be considered a national public health crisis. The age-adjusted death rate (all causes) for the AI/AN population is 1,059 per 100,000 population, whereas the non-Indian death rate is 872 per 100,000 [7].

In addition to health disparities, the AI/AN population also faces significant healthcare funding shortfalls. The Indian Health Service is significantly underfunded [8]. Although AI/ANs have a legal right to healthcare services and the federal government has a trust obligation to provide these services, the annual Congressional appropriation for IHS is funded at a significantly lower per capita rate than other federally funded healthcare systems. Per Capita funding for the IHS in the 2009 budget was \$2,690. This

compares to \$6,826 for general US population [9]. Although the AI/AN population has a birthright to healthcare, the funding for IHS has been and remains inadequate to meet all complex health needs, including cancer care. Underfunding of the health system also limits expenditures and access to health promotion and disease prevention activities [10].

Overview of AI/AN Cancer Health Disparities

Cancer Incidence and Mortality Rates

Significant differences exist in rates of cancer incidence and in cancer mortality among the various Areas of the IHS. Although nationally, the overall annual age-adjusted cancer mortality rate for the AI/AN population is lower than the general US population (161.9 v 191.2/100,000 population), in some IHS Areas the rates of death due to cancer are significantly higher than the non-Hispanic white population [11]. In comparing the cancer death rates across the IHS, the Northern Plains (Billings, Aberdeen, and Bemidji Areas) and the Alaska Area have the highest rates of death due to cancer (Fig. 2) [7].

Cancer Prevention and Screening

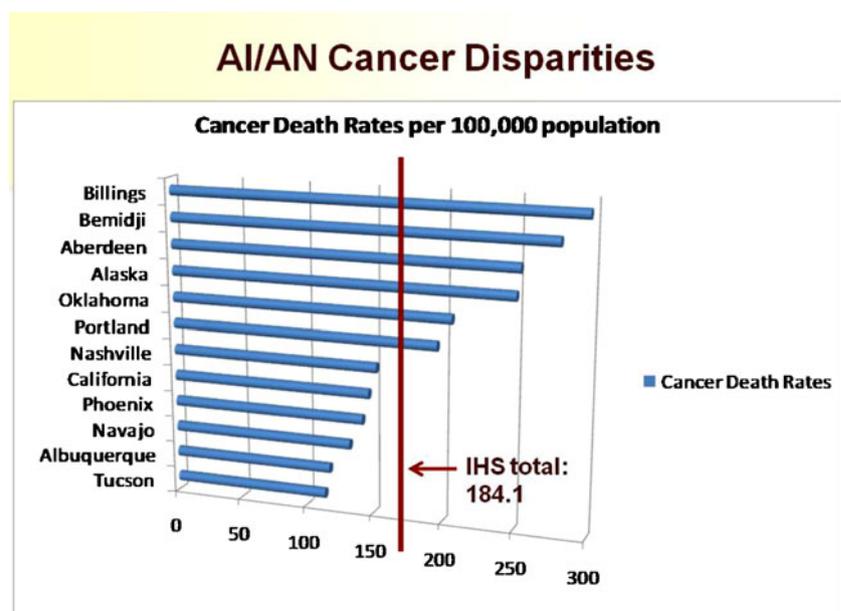
Not surprisingly, the cancer death rates in the Northern Plains and Alaska Areas mirror rates of cigarette smoking in the IHS. Use of commercial tobacco products and second-hand smoke are well-known causes of many types of cancer. AI/ANs have the highest smoking prevalence in the US, with some of the highest rates of smoking occurring specifically among Northern Plains tribes (44.2%). The rate of

smoking among AI women of reproductive age (44.3%) and the prevalence of smokeless tobacco use among men (24.6%) are higher for the Northern Plains tribes than any other population. From 2005–2009, eight of the Aberdeen Area tribes completed the American Indian Adult Tobacco Survey. Nearly two-thirds (60.8%) of the survey respondents reported being current smokers. Almost three fourths (74%) reported weekly exposure to second-hand smoke inside of their home, a vehicle, or workplace [12]. In South Dakota, AI adult smoking prevalence is more than twice the state average (49.1% to 20.4%, respectively). Data are similar for the other states in the Northern Plains and Alaska.

Public health outreach to reduce addictive tobacco use among AI/ANs has also been limited by underfunding. As sovereign nations, tribes were excluded from the tobacco industry Master Settlement Agreement, leaving them without adequate access to resources for tobacco prevention and cessation at the same time that tobacco-related chronic diseases such as cancer were markedly rising [13]. The tobacco industry specifically targets AI/ANs by sponsoring cultural events such as powwows and rodeos and by using AI/AN imagery in packaging and advertising. Counter-marketing, increased coordination with other agencies/efforts, tribal smoke-free policies, increased taxes on commercial tobacco sales, and culturally appropriate tobacco policy development are essential strategies to reduce tobacco use among AI/AN tribes [14].

In addition to expanding public health education and awareness to prevent cancer, improvements are also needed in screening and early detection, which are secondary prevention efforts. Screening for several forms of cancer has been shown to improve survival (e.g., colon, breast, and cervical) [15]. Unfortunately, the AI/AN population typically faces

Fig. 2 Rates of death due to cancer



later-stage diagnosis of cancer than the non-Indian population, even for cancers that can be screened and diagnosed early, including colon, [16] breast, [17], and cervical cancer [18]. Limited access to screening services that is driven by IHS underfunding is contributing to these disparities. Typically, the cancer incidence and rates of death are highest in the Northern Plains and in Alaska, though all IHS areas are experiencing increased rates of death due to cancer now compared to the past [19].

Treatment and Palliative Care

The patient's journey through cancer care from initial presentation to either return to health, survivorship, or end-of-life is extremely complex. For all patients, their journey is largely determined by their individual healthcare financial resources and/or insurance [20]. AI/AN patients' tribal affiliations and the geographic locations of their home of record determine the healthcare resources available to them through the IHS healthcare system. Patients generally fall into four broad categories of healthcare resources: (1) IHS direct care only, (2) contract health services eligible, (3) Medicaid, or (4) private insurance.

To be eligible for care in an IHS facility, an AI/AN patient typically must provide a Certificate of Degree of Indian Blood (CDIB) or be a descendent from a federally recognized AI/AN tribe. The CDIB is issued by tribes and verifies that the person is an enrolled tribal member. There are over 560 federally recognized tribes, and each individual tribe determines their own tribal membership eligibility requirements, and, on that basis, the tribe issues a CDIB. During the patient registration process at an IHS clinic, patients typically provide their CDIB as documentation of tribal enrollment and degree of AI/AN blood. At this point, regardless of tribal affiliation or geographical location of primary residence, all AI/AN individuals are eligible for "direct care services" [21]. Direct care services are those services that are provided in the IHS facility. This process is fairly consistent across the IHS system to describe how patients receive direct services at IHS or tribal facilities.

Patients that are "direct care" eligible and have no other resources can be diagnosed and treated at the IHS facility at no cost to them provided that they do not need specialized imaging studies such as magnetic resonance imaging, positron emission tomography scans, or nuclear medicine-related scans or other services that are not typically available directly at an IHS facility, and therefore have to be performed at outside facilities. If the patient is only "direct care" eligible and has no other healthcare resources, including not eligible for contract health services (CHS), then the patient would be responsible to pay directly for any diagnostic testing or other services that have to be done in the private sector. For example, since radiation therapy is

usually not available at an IHS facility, a "direct care only" breast cancer patient needing radiation treatment would be responsible for the entire cost of that service. In this circumstance, patients eligible only for direct care in the IHS may go without medical services if they are unable to pay. Unfortunately, due to high rates of poverty, many patients do indeed go without these services, leading to increased morbidity and mortality as previously described.

For those patients who are eligible for CHS, they are referred to private sector facilities as appropriate, and IHS pays for these costs *if funding is available*. Unfortunately, due to chronic underfunding of the IHS, CHS funds typically run out prior to the end of the fiscal year, further limiting AI/AN access to specialty services, including oncology, in the private sector [22]. If a patient is enrolled in Medicaid or has private insurance, the referrals made to the private sector are typically guided by the third party payer with varied results in terms of follow-up and case management with the IHS providers and facilities.

Great Plains American Indian Cancer Policy Consortium

The public policy issues related to cancer in the AI/AN population are quite complex and exist in numerous arenas (e.g., federal funding, coordination with states and the private sector, etc). Due to the high incidence of cancer morbidity and mortality in the Great Plains region (Billings, Aberdeen, and Bemidji Areas), the Great Plains American Indian Cancer Policy Consortium (GPAICPC) was developed in 2009. Key stakeholders include:

- Tribes
- Indian Health Service
- Aberdeen Area Tribal Chairmen's Health Board
- Northern Plains Comprehensive Cancer Control Program
- State health departments
- American Cancer Society
- Mayo Clinic Spirit of EAGLES program
- American Indian Cancer Foundation
- Private sector providers (e.g., Sanford Health, etc.)
- Academic institutions

The purpose of the GPAICPC is to:

- Establish a Great Plains AI cancer key stakeholders group
- Identify regional AI cancer policy core issues
- Develop policy and legislative strategic plan
- Develop implementation strategy and follow-up plan

Consortium meetings were held in Minneapolis, MN, in November 2009; Sioux Falls, SD, in February 2010; and in Rapid City, SD, in July 2010. This manuscript is an outcome

of Consortium activities. While the focus of the GPAICPC was on the Great Plains American Indian cancer disparities, most of the policy issues identified are relevant to other regions of the IHS as well. Key policy issues that have an impact across the cancer care continuum from prevention through screening, treatment, aftercare, and data/research were identified (Fig. 3).

The AI/AN cancer policy issues identified by the GPAICPC fell into seven broad categories:

1. Cross-cutting issues—including full funding of the IHS, implementation of the IHClA, involvement of traditional leaders and cultural competence across the continuum of cancer prevention and care, coordination of I/T/U cancer efforts with individual state efforts, and a Special Cancer Program for Indians similar to the Special Diabetes Program for Indians that would allow for more local cancer program development.
2. Education—including efforts focused on community members, providers, and policy makers, expanded tribal schools outreach and community outreach to increase awareness of cancer prevention and screening, expanded media outreach including radio, print, social media, and television, and development and distribution of tribal cancer policy toolkits to tribal leadership.
3. Prevention—including expanding efforts at commercial tobacco prevention, early intervention and cessation, environmental exposure assessments including testing of water sources, and expanded public health outreach in tribal communities.
4. Screening/diagnosis—including expanded community education to increase awareness of screening guidelines, developing men's health and women's health screening clinics as appropriate for tribal cultures, and developing mobile screening technologies and clinics.

5. Treatment—including improved case management and care coordination among private sector cancer centers and the I/T/U system, expanded patient navigation programs at private sector facilities that is culturally appropriate for AI/ANs, improved payer coordination (Medicaid, CHS, etc.), promote continuity of care and continuity of providers.
6. Follow-up care—including case management and care coordination through survivorship, improved pain management in the I/T/U system, increased access to palliative care services in the I/T/U system, and development of culturally appropriate long-term care and hospice services.
7. Data and research—including data coordination among multiple sectors (states, IHS, tumor registries, private sector, tribes, etc), develop model data sharing agreements for tribes, ensure tribal data ownership, identify appropriate models for handling and ownership of samples, increase access to and participation in cancer clinical trials in AI/ANs, and consider developing culturally appropriate AI/AN bio-specimen and tissue banking programs.

Conclusions

Cancer is increasing in AI/AN populations and has distinct geographic patterns that are associated with poverty and behaviors. The impoverished environments many AI/ANs live within contribute to behaviors that put community members at higher risk for numerous cancers. The unique historic relationship between tribes and the federal government has led to a unique healthcare system for the AI/AN population. However, significant underfunding of the IHS adversely impacts prevention activities and decreases access to screening services and treatment of cancer in this patient population. In our current assessment, improvements in cancer health disparities cannot be made without significant health policy changes at multiple levels, including federal, state and tribal governments, and in the private sector. The Indian Health Care Improvement Act was passed as part of the Patient Protection and Affordable Care Act in 2010. However, without adequate funding of the IHS, the provisions affecting cancer prevention and screening cannot be implemented. Opportunities to improve cancer prevention, screening, and treatment as part of general health insurance reform need to be coordinated with the I/T/U system, and these opportunities need to be maximized as provisions of the Act are implemented in the coming years.

Conflict of Interest The authors declare that they do not have a conflict of interest.

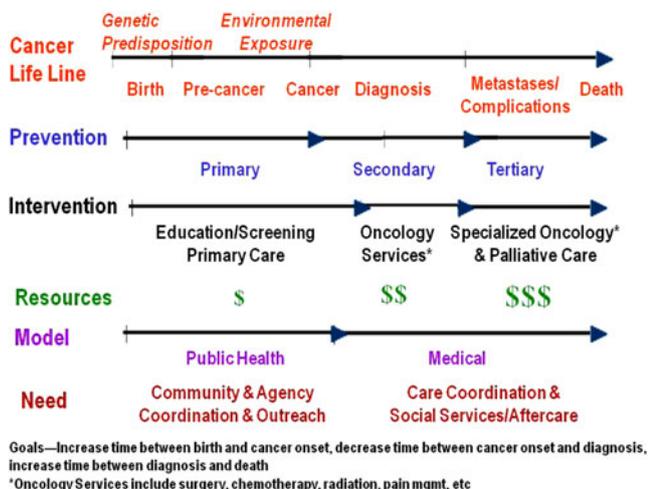


Fig. 3 Cancer life line and associated policy issues

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