Cancer Disparities among American Indians and Alaska Natives

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1. **Introduction**

Racial and ethnic disparities in the receipt of health care are those differences that are unwarranted, unfair, and undesirable, often arising from unequal access to health information, treatment, or prevention. Differences may also be the result of different choices made by the groups, different distributions of risk factors and disease exposures, and genetic differences in susceptibility. All healthcare disparities arising from unequal access should be eliminated, and efforts should be made to address (through education and other means) risk factors and unequal risk exposure whenever possible.

The purpose of this paper was to explore the following questions:

1. How do American Indians and Alaska Natives (AIAN) differ from other groups with regard to cancer epidemiology and outcomes?

2. How do differences in access to care influence AIAN cancer outcomes?

3. What efforts are being made toward addressing disparities and barriers to access among AIANs?

1.1. **Population**

According to the official Federal government definition, an American Indian or Alaska Native (AIAN) is “a person having origins in any of the original peoples of North and South America (including Central America), and who maintains tribal affiliation or community attachment.” The 2006 Population Estimates from the US Census Bureau estimated that there are about 2,369,431 AIANs in the US, or 0.8% of the entire population. Some states have much higher concentrations, such as Alaska (13.1%), Arizona (4.5%), Montana (6.3%), New Mexico (9.7%), North Dakota (5.2%), Oklahoma
Cancer is the second-leading cause of death among AIANs, yet the incidence and outcomes of cancer among AIANs have not been well reported or monitored in the past. Race is usually documented by cancer registries according to patients’ medical records, but many registries, state death records, and researchers have historically misclassified AIANs as another race (or simply as “other” and lumped in with Asians). A recent effort by the American Cancer Society (ACS), National Cancer Institute (NCI), Centers for Disease Control and Prevention (CDC), and Indian Health Service (HIS) attempted to rectify this data gap by matching all registry cases for patients diagnosed from 1995 to 2004 with the IHS patient registration database to identify AI/AN cases that were misclassified as non-Native. This resulted in a much more comprehensive view of cancer incidence, prevalence, and survival among AIANs (summarized in section 3 below).
1.3. **Brief overview of the IHS**

The Indian Health Service (IHS), which is a division of the Department of Health and Human Services, was established in 1955. The IHS currently provides medical services to approximately 1.5 million American Indians and Alaska Natives who belong to more than 557 federally recognized tribes in 35 states. Eligibility criteria are determined by individual tribes and typically refer to a percentage of “blood quantum” or fraction of AI/AN ancestry, with some tribes requiring only proof of descent from an AI/AN ancestor and others requiring as much as one-half ancestry. The provision of medical care by the Federal government arose from a number of treaties in which tribes ceded land and/or resources in exchange for government promises of services. The IHS is a national health system of sorts, providing primary care via 33 hospitals, 59 health centers, and 50 health stations (mostly near or on reservations). The system also provides limited specialty services through contracts with private providers.

Most AIANs (60%) do not live on or near reservations and cannot access IHS services, forcing them to rely on other sources of coverage or become uninsured. Even for those who are eligible for and close to IHS clinics, the system struggles with a number of limitations, including shortages of healthcare workers, funding shortfalls, and mismanagement. With an annual, discretionary appropriation of approximately $3B, there is a large funding gap between spending on AIAN healthcare and spending on other Federal healthcare programs, such as Medicare.
2. Cancer epidemiology and outcomes among AIANs

2.1. Screening

AIANs have the lowest use rates of mammography, Pap smears, colorectal cancer screening, and prostate cancer screening of any racial/ethnic Medicare beneficiary group (Figure 1). 

Figure 1. Screening rates among Medicare beneficiaries, 2003

Source: Bonito 2005.

2.2. Incidence

AIANs have lower incidence rates of cancer than any other racial group. Across all sites, the incidence rate (per 100,000 persons) for AIANs overall is 297.4 for men and 243.2 for women, but the rates are higher for AIANs living in or near tribal lands (Figure 2).
2.3. Stage at diagnosis

AIANs are more likely than non-Hispanic whites to be diagnosed with regional or distant colorectal, breast, cervical, or prostate cancer, reflecting the low screening rates in this population (Figure 3).\textsuperscript{5}
Figure 3. Stage at diagnosis, 2000-2004

![Bar chart showing stage at diagnosis for CRC, Breast, Cervix, and Prostate for White (non-Hispanic) and AIAN populations.]

Source: Espey 2007.5

2.4. Mortality rates

As with incidence rates, AIAN mortality rates are quite low – only Asians/Pacific Islanders and Hispanic women have lower mortality rates than AIANs (Figure 4).5
2.5. Survival

AIANs have lower cause-specific survival rates and higher adjusted odds ratios (OR) of dying from cancer than other racial/ethnic groups. For all sites combined, the age-adjusted OR compared to non-Hispanic whites is 1.69 (95% CI, 1.59-1.79) for men and 1.54 (95% CI, 1.45-1.64). Disparities in survival persist even after adjustment for stage at diagnosis: the age- and stage-adjusted OR for death from breast cancer among AIANs compared to non-Hispanic whites is 1.55 (95% CI, 1.32-1.81).
Figure 5. Five-year cause-specific survival rates, 1992-2000

Source: Jemal 2004

2.6. Cancer-related disparities and barriers to access

What accounts for the survival disparities between non-Hispanic whites and AIANs? Some evidence suggests that delayed treatment is to blame, although little research has been conducted to date. One analysis of Surveillance, Epidemiology, and End Results (SEER) data linked to Medicare claims revealed significant disparities in the timing of treatment for breast cancer of American Indian women enrolled in Medicare, including a longer time interval from diagnosis to first cancer-directed surgery and a longer time interval from breast-conserving surgery to radiation among AIAN women with early-stage disease. The travel distance between women’s homes and place of treatment may have been a factor—18% of AIAN women lived more than 50 miles from the place of
treatment, compared to 7% of non-Hispanic whites. Similarly, a report from the National Breast and Cervical Cancer Early Detection Program reported a time interval from diagnosis to cancer treatment at least 2 times greater among AIAN women than among white women.\textsuperscript{12}

In addition to geographic isolation, funding and staffing shortages may be another contributing factor to delays in treatment. Most cancer surgeries, chemotherapy, and radiotherapy are administered outside of the IHS system through contract health care, which is subject to severe rationing because of inadequate funding. Individuals living outside of a tribal area must usually move to a reservation in order to become eligible for care under IHS, after which referral by IHS to a cancer specialist occurs through bureaucratic channels subject to delays.\textsuperscript{11} The lack of AIAN physicians—there are only 2 AIAN medical oncologists in the US\textsuperscript{13}—and low participation of AIANs in clinical trials are additional factors that may influence disparities.

As mentioned in section 1, over half of AIANs have family incomes under 200% of the Federal poverty line, or FPL (in 2006, the FPL for a family of 4 with 2 children was $20,444, and for a single person over age 65 it was $9,669).\textsuperscript{14} More AIANs are uninsured (19% vs. 12% of whites) and fewer have employer-based private health insurance (49% vs. 83% of whites). The lack of private insurance is partly a reflection on the lower income distribution and partly a reflection of the higher unemployment rate (12.3% vs. 5.3% in the general population\textsuperscript{15}), but even AIANs making \textgeq 200% of the FPL are less likely than non-poor whites to have employer-based insurance (80% vs. 92%). About 16% of AIANs are covered only by the IHS.\textsuperscript{5}
Cultural factors may also be barriers to access for AIANs. AIANs may prefer to use native medicine and healers rather than Western medicine; in addition, many AIANs distrust white authority figures, Western medicine, and medical research.\textsuperscript{16}

3. **What is being done to address disparities among AIANs in cancer care and outcomes?**

From a public health perspective, one of the most important efforts in recent years related to AIANs has been to accurately record race in health-related records. Until 1980, Federal agencies (Social Security, Medicare, etc.) recorded only three racial identifiers: White, Black, or Other. These categories were expanded in 1980 to include non-Hispanic White, non-Hispanic Black, Hispanic, Asian/Asian-American/Pacific Islander, and American Indian or Alaska Native. Despite the expanded categories, Medicare continued to classify race/ethnicity into three categories plus “Unknown” by collapsing the five expanded codes into the original three codes: White, Black, or Other until 1994. When the expanded race data from the SS-5 forms were used to correct race/ethnicity information on the EDB, more than 2.5 million beneficiaries were reclassified. Further, CMS has recently partnered with the IHS to identify Medicare beneficiaries who are recognized as American Indian or Alaskan Native by IHS, finally allowing researchers to monitor and measure healthcare variables for AIAN Medicare beneficiaries.\textsuperscript{9}

In an effort to decrease the amount of time that elapses between diagnosis and treatment yet still accommodate AIAN patients’ need for traditional healing modalities, the National Native American Cancer Survivors Support Network has worked with traditional healers to create abbreviated pre-treatment ceremonies, complemented by a full post-surgical ceremony.\textsuperscript{17} In addition, a major community-based participatory
research project known as Spirit of Eagles has conducted a wide range of cancer control activities, from funding educational grants for AIAN students interested in medicine to creating culturally appropriate educational materials.\textsuperscript{13}

4. Conclusion

The burden of cancer on AIAN patients is a complicated one. The low incidence rates among AIANs may be more a reflection of the low screening rates than a true lack of incident cancers in this population, and while death rates are related to incidence, 5-year survival rates are more related to stage at detection and receipt of treatment. The cancer burden is more severe for AIAN patients in part because of barriers to access, including financial, cultural, and geographic factors. Although some efforts have been made to address these disparities, a critical lack of studies and data hampers efforts to measure and monitor progress, especially for urban Indians outside of the IHS system.

5. References


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