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Cancer Control Research Among American Indians and Alaska Natives: A Paradigm for Research Needs in the Next Millennium

MARTIN C. MAHONEY AND ARTHUR M. MICHALEK

ABSTRACT

Cancer represents an increasingly important health problem impacting the health status of American Indians and Alaska Natives (AI/ ANs). At the turn of the century and as recently as the 1950s, cancer was such an uncommon occurrence among AI/ ANs that they were thought to be immune. Today, malignant disease represents a leading cause of death among these peoples. This relatively sudden increase has left communities and health agencies unprepared. This paper presents the framework for approaching cancer control research among AI/ ANs, including the development of accurate surveillance systems; enhanced public and professional education; research

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focused on risk-factor prevalence and etiology; improved communication between Native communities and researchers; comprehensive evaluation of cancer control programs; dissemination of successful intervention programs; and research to examine factors responsible for the low risk of specific cancers among Native populations. Moreover, results from a series of national surveys providing a comprehensive overview of the limited cancer control programs directed toward AI/AN populations are highlighted. Efforts to maximize the health status of American Indians and Alaska Natives through cancer control efforts will rely upon a cooperative approach between individual tribal groups along with the proactive involvement of federal and state public health agencies, as well as the support of appropriate private and nonprofit organizations.

INTRODUCTION

While cancer was an uncommon occurrence among American Indians and Alaska Natives at the turn of the century, it currently ranks as the second leading cause of death among these populations.¹ American Indians and Alaska Natives (AI/ANs) comprise a minority group which includes more than two million members. AI/ANs are dispersed throughout each of the fifty states, with the largest numbers located in Oklahoma (n=252,420), California (242,164), and Arizona (203,527).²

American Indians and Alaska Natives, also referred to as Native peoples, tend to be younger than the majority population, with a median age ten years younger than that for the general population (AI/AN median age = 24.2 years versus 34.4 years for U.S. whites).³ Life expectancy among AI/ANs is seventy years compared with seventy-five years in the general population. In addition, AI/AN populations exhibit higher rates of poverty (32 percent of AI/AN versus 13 percent U.S. all races) and unemployment (16 percent AI/ANs versus 6 percent U.S. all races) and lower rates of educational attainment (65 percent of AI/ANs high school graduates versus 75 percent U.S. all races; 9 percent of AI/ANs college graduates versus 20 percent U.S. all races). More than 70 percent of American Indians reside in places other than reservation areas, with estimates that 50 percent and more reside in urban areas. At present, there are more than five hundred federally recognized tribes, each with a unique and diverse cultural identity result-

ing in somewhat unique health concerns. As a result, each tribe has unique cultural and health concerns.

The Indian Health Service has been charged with providing and coordinating medical care, including cancer control activities, to AI/ANs residing within the thirty-three "reservation states." Even in communities with IHS facilities, it is estimated that less than half of eligible Natives utilize IHS services.⁴ Since passage of the Indian Self-Determination Act in 1975, tribal groups have been encouraged to operate and manage their own health programs directly. A small urban Indian health program is maintained by the IHS; however this particular program represents just 2 percent of the IHS budget compared with estimates that 54 percent to 68 percent of the AI/AN population resides in urban areas. It is worth noting that IHS does not possess sole responsibility for AI/AN health care and seeks to incorporate support from federal and state agencies.

Data from a variety of sources, including regional, state, and community-level data, suggest that cancer has emerged as an increasingly important health problem impacting the health status of American Indians and Alaska Natives in the United States.⁵ Interestingly, historical scientific publications dating to the late nineteenth century and early twentieth century make reference to the paucity of malignant disease within Native communities.⁶

Site-specific cancer rates among American Indians and Alaska Natives often exceed comparable rates in the general population. This observation might be overlooked if only overall rates are considered. For example, for the period between 1988 and 1992, the rate ratios for cancer incidence among American Indians (in New Mexico) were 0.41 and 0.51 among males and females, respectively, relative to non-Hispanic whites.⁷ Cancer mortality data for this period reveal rate ratios of 0.57 and 0.69 among American Indian males and females, respectively. Between 1988 and 1992 cancer incidence rate ratios among Alaska Natives (in Alaska) were 0.77 and 0.98 in males and females, respectively. Rate ratios for cancer mortality in this group were 1.04 and 1.25 among males and females, respectively. As illustrated in Table 1, closer inspection of these data reveal incidence excesses among American Indians for cancers of the kidney, liver, and gallbladder, and among Alaska Natives for cancers of the colon and rectum, stomach, kidney, lung, and cervix uteri. Mortality excesses were noted among American Indians for cancers of the stomach, liver, gallbladder,

and cervix uteri, while Alaska Natives exhibited excesses for deaths resulting from cancers of the colon and rectum, stomach, kidney, nasopharynx, and pancreas.

Similar excesses for cancer incidence and cancer mortality among American Indians and Alaska Natives have been noted.⁸ Data from the Indian Health Service⁹ demonstrate several regions where cancer mortality exceeds that experienced by the general population, including Alaska and areas of the Midwest (for instance, the Billings, Aberdeen, and Bemidji service areas).

Survival information, based on Surveillance Epidemiology and End Results data from New Mexico and Arizona, illustrate that American Indians demonstrate the poorest survival among any racial group for all sites combined and for eight of ten leading cancer sites.¹⁰ Following a cancer diagnosis, American Indians demonstrate an overall relative survival of 35 percent compared to 50 percent among whites. Ratios of cancer incidence to cancer mortality (1988-1992) were generally low among American Indian males (rate ratio = 1.59) and females (rate ratio = 1.81), as well as Alaska Native males (rate ratio = 1.65) and females (rate ratio = 1.94). Lower incidence-to-mortality ratios are considered to demonstrate high case fatality, although this observation might also be attributable to racial misclassification on death registration records.¹¹ Although several hypotheses have been put forth in an attempt to explain these marked differences in survival, exact reasons for poorer survival remain obscure.

Detailed descriptions of cancer patterns among American Indians and Alaska Natives have been published previously.¹² These reports have presented Native cancer patterns at the state level and within selected tribal communities.¹³ Efforts to consolidate findings from multiple data sources have proven challenging.¹⁴

FUTURE DIRECTIONS

Marked differences have been identified in disease frequency and outcomes among racial/ethnic groups. In the Healthy People 2000 document,¹⁵ the Public Health Service developed objectives to improve the overall health status of all peoples, with special emphasis on disparities among minority groups, including American Indians and Alaska Natives.

The Special Populations Studies Branch of the National Cancer Institute has sustained the ongoing activities of the Network for Cancer Control Research among American Indian and Alaska Native Populations since its inception in 1990. It is the mission of this network to reduce cancer morbidity and mortality to the lowest possible levels and to improve cancer survival through culturally sensitive research. This network has struggled with developing approaches to promote and facilitate cancer control activities in Native communities.

In 1992, the AI/AN Network released a National Strategic Cancer Plan for federal agencies (for example, Centers for Disease Control and Prevention, National Institutes of Health, Agency for Health Care Policy and Research, Public Health Service, Indian Health Service, Office of Minority Health, Office of Disease Prevention and Health Promotion) to enhance the awareness of the cancer problem among Native populations. This was followed in 1994 by a Strategic Plan for State Public Health Agencies.¹⁶ Both plans are organized around a framework of selected "issues" as identified in Table 2. Action items and outcome measures relevant to each issue, as well as specific types of cancer control research, are contained in the respective strategic plans. The cancer control research needs of American Indians and Alaska Natives appear in these plans.

Selected elements from these plans are referenced below along with the authors' call for action. Those items of greatest relevance will be presented. It should be noted that these items and responses were developed by the Network for Cancer Control Research among American Indian and Alaska Native Populations. Network membership is represented by fifteen members, at least two-thirds of whom are of American Indian or Alaska Native descent. Thus these plans represent the collective thoughts of individuals who are not only expert in the field but are sensitive to the cultural context in which this research must be conducted. Each of the "issues" shown in Table 2 have been paraphrased below.

ACCURATE SURVEILLANCE SYSTEMS

1. Underreported incidence and mortality from cancer and other inaccurate cancer data on American Indians and Alaska Natives should be recognized by federal agencies and state public health agencies. The process of data collection should be

corrected to prevent misleading and erroneous conclusions.

2. The overall quality of cancer data should be carefully reviewed; statistical data should attempt to address racial misclassification, diagnostic errors, and other sources of inaccuracies.

Proposed Action: Methodological concerns about various databases have complicated precise interpretation of available data on cancer patterns among AI/ANs. Extant surveillance data are generally a blending of multiple regional and/or community-based data sources; no national database is available. For example, data commonly cited by the National Cancer Institute Surveillance, Epidemiology and End Results program are not generalizable since they are based largely on data from New Mexico, as well as limited areas in Arizona. In other areas of the country, racial misclassification in vital records results in inaccuracies in surveillance data. Problems with denominator data include undercounts of Native respondents to census surveys and inconsistent responses to items requesting information on "race." IHS data are based on encounters with a "user population" (i.e., individuals who have used IHS facilities within the last two years) from predominantly rural areas limited to thirty-three reservation states. Thus, there is an urgent need for investigators across the country to work with Native populations in their region to develop more accurate surveillance systems.

PUBLIC AND PROFESSIONAL EDUCATION

1. State and federal public health agencies should support public education to increase awareness of cancer as a threat to the health of American Indians and Alaska Natives through policy development, increased communication, and the commitment of staff and financial resources.

2. These agencies should support professional education of scientists, health professionals, and care givers to enhance their awareness of cancer in these indigenous populations.

3. Investigators should also be sensitive to their role and the tribal community's perception of their research. Success can

only be achieved if tribal members are engaged as *active* members of the research team. This benefits the researcher with insight into community norms and benefits the tribe by sharing research skills that the involved tribal member(s) may transfer to other projects of benefit to his or her community.

Proposed Action: Health agencies should demonstrate their commitment to these populations through policy development, the commitment of staff and financial resources, and the hiring of AI/AN professionals to guide these efforts. Support for the training of Native researchers should be provided. Community development strategies designed to empower local communities in educational efforts should be promoted.

RESEARCH NEEDS

1. The reasons for the poor cancer survival rates among American Indians and Alaska Natives require examination.
2. Etiologic research should focus on cancers both common and uncommon to American Indians and Alaska Natives.
3. Federal and state health agencies should fund research to identify cancer risk factors prevalent among American Indians and Alaska Natives.

Proposed action: The disproportionate rates of gallbladder, gastric, nasopharyngeal, and pancreatic cancers argue for focused etiologic research aimed at reducing high incidence and mortality rates. Tribal differences in rates for more common cancer sites also warrant further investigation. Analyses should consider associations with genetic, nutritional, and environmental risk factors as well as care-seeking behaviors related to prompt diagnosis and treatment.

Moreover, the study of rare tumor types in populations at higher risk may yield insights that will be of benefit to all populations. Equally important, the etiologic study of cancers uncommon in Native populations may yield clues to prevention that may be directly transferable to other populations.

Data on cancer risk factors are limited to specific tribal groups and/or geographic regions. More comprehensive and specific risk-factor data would aid in the interpretation of can-

cer patterns as well as assist in the development and implementation of intervention programs targeting risk reduction and behavior modification.

ENHANCED COMMUNICATION

1. The unique relationship that exists between the United States government and American Indian and Alaska Native nations, tribes, and communities must be recognized as this relationship directly affects the delivery of health care.
2. State and federal agencies should maintain an ongoing dialogue regarding health problems among American Indians and Alaska Natives.
3. Federal and state agencies need to acknowledge the cultural diversity of American Indians and Alaska Natives, and recognize how they differ from the rest of the United States population.

Proposed Action: Whenever possible, collaborative approaches to cancer control projects should be considered. Researchers need to recognize and acknowledge cultural distinctions present within Native communities. The failure to acknowledge these cultural differences may serve as a barrier to prevention, early detection, and treatment of cancer in these populations. This again argues for the inclusion of and ownership by the Native community rather than the historical role of exclusion.

EVALUATION AND DISSEMINATION

1. Cancer prevention and control interventions in place among American Indians and Alaska Natives should be appropriately evaluated with the assistance of federal and state agencies when necessary.
2. The development of community partnership and program ownership between tribal communities and federal and/or state health agencies should be advocated.
3. Information regarding successful intervention efforts and models for replication in other American Indian and Alaska

Native communities should be disseminated and replicated through cooperative endeavors with public and private resources.

Proposed actions: Shared ownership and effective communication would improve community cooperation with future cancer prevention and control efforts and provide feedback to both the community and researchers about benefits to subjects from participating in interventions. In all cases, American Indians and Alaska Natives should be fully informed about cancer prevention and control projects and actively involved as members of the research team. Prior written approval and consent should be obtained from the appropriate tribal governmental bodies before these programs are initiated. Appropriate Institutional Review Board clearance need also be granted by the IHS.

CANCER PREVENTION

1. Efforts to examine the low risk of specific cancers (e.g., breast, lung, prostate) among some American Indians and Alaska Natives should be supported at the federal and /or state level.
2. The unusually low incidence rates demonstrated by some Native groups relative to incidence patterns in the general population may provide important insights into methods to prevent these cancers in other communities.

CANCER CONTROL INTERVENTIONS FOR AI/ANS

Limited data are available concerning cancer control activities accessible to American Indian and Alaska Native communities. To address this knowledge gap, three national surveys investigating cancer control programs for American Indians and Alaska Natives were recently completed by Network members.¹⁷ These surveys were focused at three organizational levels in an attempt to comprehensively assess cancer control activities offered by state public health agencies, tribal health departments, and urban Indian clinics.

A cross-sectional survey of state chronic disease program directors was completed in 1992 to elucidate the extent of can-

cer prevention and control programs for AI/ANs directly supported by state public health agencies.¹⁸ Forty-four percent of the directors reported that cancer was as important or somewhat more important than other health problems among AI/ANs. However, more than one-half of the respondents did not know whether there had been any change in AI/AN cancer rates. The extent of AI/AN cancer control programs supported by state public health departments was limited.

The second survey examined the perceptions and priorities ascribed to cancer among directors of tribal health departments.¹⁹ Compared to other health problems, cancer was rated as "somewhat more important" or "much more important" by 45 percent and 21 percent of health directors from Alaska Native and American Indian tribal groups, respectively. This survey also revealed that cancer represents a single disease entity among several health issues which confront Native peoples at a community level. Among Alaska Native health directors, cancer ranked behind alcohol and injuries in relative importance. American Indian tribal health directors ranked cancer fifth behind diabetes, alcohol, heart disease, and injuries. Thus, despite statistics which support the importance of malignant disease among AI/ANs, the presence of other diseases should not be overlooked.

To ascertain the extent of cancer control programs for American Indians resident in urban areas, a survey of IHS urban clinics was undertaken.²⁰ While 71 percent of urban health clinic directors felt that cancer incidence was stable or increasing, 25 percent indicated that they were unfamiliar with incidence patterns. Similarly, 67 percent of urban clinic directors reported that American Indian cancer mortality was stable or increasing, while 33 percent did not know incidence trends. Only 21 percent of respondents felt cancer was as important or more important than other health problems. As a health problem, cancer was ranked fifth among seven health problems by urban health directors. Most urban clinics reported sponsoring programs for smoking control, as well as breast and cervical cancer screening services.

In aggregate, information from these three surveys provides a comprehensive overview of the limited cancer control programs directed toward AI/AN populations. In addition, findings from these surveys underscore a need to better sensitize health professionals and tribal leaders to the cancer problem in Native communities.

CONCLUSIONS/SUMMARY

Secular trends in cancer incidence and mortality demonstrate steadily increasing rates among Native populations. Our limited knowledge concerning cancer, let alone health in general, among Native populations is based primarily on the experience of reservation populations. Little research has focused on urban populations despite that fact that most American Indians reside in urban areas. Recent papers have reported marked disparities across a variety of health status measures,²¹ including increased trauma rates,²² among urban AI/ANs. The historical void of cancer-related information in Native communities is further attested to by findings from a recent bibliometric analysis.²³ The reader is directed to a special issue of *Cancer* for detailed descriptions of research projects involving these populations.²⁴

Currently, Native Americans are at greater risk of death than the U.S. general population for causes such as tuberculosis, diabetes, liver disease, pneumonia, accidents, homicide, and suicide.²⁵ During the course of only several decades, AI/AN populations have experienced dramatic changes in diet, environment, lifestyle, and occupation, as well as the inherent stresses of assimilation, cultural estrangement, and integration of traditional values. Combinations of these factors have resulted in shifts in competing causes of death and increased longevity. As a result, more Natives are achieving ages at greatest risk for developing cancer. The occurrence of cancer in Native American populations has been transformed from the oddity it was at the beginning of the century²⁶ to a common occurrence.

Responsibility for maximizing the health status of American Indians and Alaska Natives will rely upon a cooperative approach by tribal groups along with the proactive involvement of federal and state public health agencies. Implementation of a comprehensive cancer control research program for American Indians and Alaska Natives will require government resources, at both the federal and state levels, as well as funding from private and nonprofit organizations where available. It is hoped that this overview might serve to stimulate enhanced cancer control efforts involving American Indians and Alaska Natives, including projects which both assess and expand cancer control services as a means of addressing this important health issue.

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TABLE 2

Issues to Facilitate Promotion of Cancer Prevention and Control Research among American Indians and Alaska Native Populations: Federal and State Strategic Plans

Issues:

- I. Cancer is a major health problem for American Indians and Alaska Natives.
- II. American Indians and Alaska Natives should be made aware that cancer is a growing health problem.
- III. American Indians and Alaska natives have among the poorest survival rates from cancer of all racial groups. Specific cancers occur at unusually high rates in the American Indians and Alaska Natives and warrant special attention.
- IV. Communication barriers often exist among American Indians and Alaska Natives, health care providers and research scientists.
- V. Cancer prevention and control intervention efforts and research in American Indians and Alaska Natives require a continuing evaluation for program accountability.
- VI. Variability in incidence rates for certain primary cancer sites in American Indians and Alaska Natives provides an opportunity to investigate cancer etiology and cancer prevention strategies. (state plan only)

TABLE 1

Leading Cancers among American Indians and Alaska Natives, 1988-1992

	AMERICAN INDIANS: (New Mexico)		ALASKA NATIVES:*	
	Cancer Incidence 1988-1992 (site - rate ratio†)	Cancer Mortality 1988-1992 (site — rate ratio)	Cancer Incidence 1988-1992 (site - rate ratio)	Cancer Mortality 1988-1992 (site - rate ratio)
Male	1. prostate - 0.41 2. colon & rectum - 0.32 3. kidney - 1.30 4. lung - 0.18 5. liver - 4.03	1. prostate - 0.68 2. stomach - 1.87 3. liver - 3.03 4. lung - 0.14 5. colon & rectum - 0.36	1. lung - 1.03 2. colon & rectum - 1.38 3. prostate - 0.33 4. stomach - 2.83 5. kidney - 1.58	1. lung - 0.94 2. colon & rectum - 1.16 3. stomach - 3.15 4. kidney - 2.63 5. nasopharynx - 38.67
Female	1. breast - 0.27 2. ovary - 1.08 3. colon & rectum - 0.33 4. gallbladder - 5.28 5. corpus uteri - 0.47	1. gallbladder - [unable to calculate] 2. breast - 0.31 3. cervix uteri - 3.20 4. pancreas - 1.06 5. ovary - 0.89	1. breast - 0.68 2. colon & rectum - 1.72 3. lung - 1.16 4. kidney - 2.83 5. cervix uteri - 2.11	1. lung - 1.38 2. colon & rectum - 1.54 3. breast - 0.58 4. pancreas - 2.21 5. kidney - 2.31

*Alaska Area Native Health Service.
 †rate ratio = age-adjusted incidence rate among American Indians or Alaska Natives/age-adjusted incidence rate among white, non-Hispanics, based on reference (8).

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13. *Ibid.*, Mahoney and Michalek, "Meta-Analysis of Cancer Incidence"; and Lanier, "Alaska Native Cancer Update."

14. See Mahoney and Michalek, "Meta-Analysis of Cancer Incidence" and

"Bibliography of Cancer" (full citations in note 12).

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