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Introduction: Proceedings of the First National Conference on Cancer in Native Americans

JENNIE R. JOE AND JAMES W. JUSTICE

The first nationwide conference on the problem of cancer in Native American peoples was held in Tucson, Arizona, 26–28 October 1989. The conference was supported through private donations and was sponsored by the Native American Research and Training Center, which is part of the Department of Family and Community Medicine at the University of Arizona College of Medicine. The specific aims of this first nationwide Conference on Cancer in American Indians and Alaska Natives were (1) to share information, published and unpublished, about cancer in American Indians and Alaska Natives; (2) to discuss priorities for further research and program development; and (3) to determine if regional approaches to detection, treatment, prevention, and epidemiology are justified, thus necessitating periodic regional meetings of researchers and health care professionals.

BACKGROUND AND SIGNIFICANCE

During the past twenty years, a number of papers about cancer in American Indians have been presented at annual meetings of

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professional associations of the United States Public Health Service, the American Public Health Association, and other professional organizations throughout the United States and internationally (e. g., the International Circumpolar Scientific Congress, where cancers in Eskimos were discussed). However, these presentations were given at conferences convened to discuss broader issues in health care prevention and delivery and were not concerned specifically with the topic of cancer in Native Americans. In addition, few Indian Health Service (IHS) providers participated in these conferences, and, more importantly, proceedings from these conferences were not usually made available to tribal leaders.

In addition, most researchers studying cancer have virtually no access to Indian patients on Indian reservations. Conversely, the majority of the service providers in the Indian communities are from the IHS, whose primary mission is to provide health care, not conduct research. Therefore, the bringing together of researchers, tribal leaders, and IHS health care providers to a conference specifically about cancer in Native Americans represented a unique opportunity for the exchange of information and for initiating cooperative research and intervention programs.

The key purpose of this conference was to focus specifically on cancer in Native Americans by bringing together for the first time a cadre of experts in order to (1) evaluate what is known about the present state of cancer research and prevention for Native Americans; (2) identify similarities and differences in cancer incidence and mortality rates among various Indian groups and between Indians and other population groups; (3) analyze the problems of developing effective culturally sensitive cancer prevention strategies that will lead to improved survival rates among Indians; (4) discuss various cancer prevention strategies that may lead to improved survival rates for this population; (5) identify major research gaps, especially those that may contribute to a better understanding of the interplay between changing environments, cancer incidence, and individuals such as Native Americans who come from especially restricted gene pools; and (6) determine other future research priorities and directions.

The need for this scientific attention was viewed as especially critical in light of the current fragmentary, incomplete, and potentially misleading knowledge about cancer and American Indians. We do not know, for example,

1. what attitudes, knowledge, and beliefs Native Americans have regarding the treatment, prevention, and causation of cancer;
2. if each of the approximately 450 tribes within North America has a distinct cancer pattern, or if there are different regional cancer patterns applicable to many different ethnic Native Americans living in the same regional zones;
3. if cancer rates are increasing for Native Americans and if the proportion of certain specific primary cancers is changing;
4. if cancer rates for reservation residents are affected by exposures to urban influences and, if so, which specific primary cancers appear to be involved;
5. if the risks for the few genetically determined cancers found so far among some tribes depend on environmental exposures, or if the patients at risk are only from a specified extended family;
6. if the decreased survival time for the few primary cancers reported depends on lack of knowledge of early warning signs, lack of suspicion on the part of primary care providers, lack of use of screening tests, or environmental cofactors;
7. if Native American groups need a specific, ethnically oriented program of cancer education, prevention, and treatment;
8. how tribal leaders can best be approached about cancer research needs when their attention must also focus on health problems of more immediate impact such as accidental injuries and deaths, alcohol and substance abuse, and diabetes;
9. if the suspected deficit of children's cancer in some Southwestern tribes is also true for other groups of Native Americans; and
10. with so much validated research about alcohol abuse in so many different Native American ethnic groups, why does the rate for alcohol-related cancer appear to be low (e. g., esophagus, larynx, and liver primary sites).

OVERVIEW OF THE LITERATURE

In addition to the presentations at the conference, participants were given a bibliography of all articles published since 1800 about cancer in Native Americans. (See the last chapter in these proceedings.) The following brief review of the literature about cancer in American Indians serves to emphasize how fragmentary and limited the current knowledge about cancer is in this population group. Furthermore, this literature review shows that research questions and problems about cancer in Native Americans may also be applicable to other Americans of Asian ethnology as well as to other special populations.

The published literature about neoplasms and cancer risks in Native Americans has been limited in scope by both the types of neoplasms and by the number of tribes on which research has been conducted. Research on the health status of Native Americans has tended to focus instead on other major health issues that confront this population, with particular emphasis on accidental injuries, alcoholism, diabetes, mental health, and infectious diseases.

In Barrow's bibliography [1] of the health status of American Indians, Eskimos, and Aleuts covering 169 years from 1800 through 1969, only sixteen citations were listed in which cancer was the primary subject. The next general bibliography, which was compiled by Justice [2], covered the following ten years and listed fifty-two primary citations and seven secondary ones about neoplasms in the same groups of Native Americans. Since 1979, an additional sixteen articles about cancer in this population have been cited in *Medline*. The majority of these recent articles have been about case histories or have been devoted to a specific type of primary cancer.

Of the total of eighty-four articles published about cancer in Native Americans, less than twelve have presented a total view of the cancer experience of a specific tribal group. Those tribes most studied in this manner are the Alaska Natives (i. e., Indians, Aleuts, and Eskimos) [3, 7]; Southwestern tribes such as the Pima [9] and Navajo [4], and Tohono O'odham (formerly called Papago) [5]; several groups in Oklahoma, such as the Choctaw, the Cherokee, and the Pawnee [13]; and several of the Pueblo tribes and the Apache in New Mexico [6, 4].

A number of these articles have restricted their subject matter to cancer mortality patterns only. One of the most recent of these reviews is by Sievers and Fisher [14]. The most recent data for American Indians reported from all sites covered by the SEER programs (Sur-

veillance, Epidemiology, and End Results programs of the National Cancer Institute [NCI]), both incidence and mortality by primary sites, 1978 through 1981, was published by the NCI [34]. However, this source lends a bias in favor of Southwestern tribes, since over 75 percent of these cancers were from tribes in New Mexico and Arizona. Other locations reported by NCI included Native American residents in four urban areas (Atlanta, Detroit, San Francisco, and Seattle) and five states (Connecticut, Hawaii, Utah, New Mexico, and Iowa). Of these SEER project areas, only New Mexico can retrieve cancer rates by specific ethnic groups, but not by specific tribe (i. e., specific ethnic groups are Apache, Navajo, Pueblo, etc.; however, the Apache, for example, now live in four separate tribes: Mescalero, Jicarilla, San Carlos, and White Mountain.)

If the specific tribes or Indian ethnic groups had a similar overall incidence of cancer and similar proportions of primary site cancers, then it would make sense to report them altogether as "Indians." However, the evidence to date supports the view that each cancer pattern of each tribe or ethnic group is unique.

In addition to the New Mexico SEER program and tumor registry, which was established for Indians in 1974 and included data backloaded since 1966 [9], only two other sources can provide enough data to compare decade changes in incidence of cancer in Native Americans. The Arctic Investigations Laboratory of the Public Health Services Centers for Disease Control has collected data from 1960 to the present [3,7,8,9]. The second long-term tumor registry was established in 1976 for the Tohono O'odham people of southern Arizona [10] and contains cases from 1961 through 1984, when it was discontinued. Justice [33] compared incidence data for the two decades this registry was in use and found that primary site incidence had decreased in both sexes only for pancreatic cancer; for females, decreases were also found for stomach, liver, ovary, gallbladder, and blood cancers. Increases in cancer rates were seen in both sexes for renal carcinomas and melanomas. There were increases in breast, cervical, and uterine endometrial cancers of females and increases in testicular, lung, lower intestinal, prostate, and stomach cancers in males. These increases were almost exclusively in those resident in urban areas. Decreases in these cancers were noted for residents on the reservations, at least at the time of the diagnosis [33].

Other comparative studies have been conducted in Alaska, where changes in primary cancer sites over time have been reported. However, these changes in both populations lacked statis-

tical significance because of the extremely small number of cases involved (i. e., for the Tohono O'odham, a total of ninety cancers occurred from 1961 to 1970 and 141 from 1971 to 1980). In Alaska Natives, Lanier [3] reported over a fourteen-year period increases in lung, liver, prostate, and cervical cancers. Lung cancer increases since the 1950–65 era were also reported by Schaefer et al. for Canadian Eskimos for 1965 through 1974 [12].

Overall, the incidence rates for Native Americans for all cancers are usually less than corresponding rates for all races, or for whites or Blacks. The NCI reported an age- and sex-adjusted rate of 164 cancers per 100,000 per year for Native Americans in the SEER programs, compared with rates of 335 and 373 for whites and Blacks, respectively [34].

These results may be misleading, because few tribes other than three of the Southwestern cultures have been reported. Lanier reported age-adjusted rates of incidence of 314 per 100,000 for both sexes of Native Alaskans [3], which are much higher than the SEER Indian rates reported by Baquet and Ringen [34] and are not significantly different from the rates for whites and for all races.

The Lakota (e. g., Oglala Sioux) females age-adjusted rate of 288 cancers per 100,000 in South Dakota from 1970 to 1979 was not statistically different from the United States white female rate of 297 for 1975 [5]. On the other hand, the all-Oklahoma tribes mortality rates for cancer for both sexes were 58 percent less than the reported Oklahoma white cancer death rates [13].

Until more tribes are studied and reported, generalization should not be made to the effect that all Indian tribes' cancer incidence rates are more, less, or equal to rates for other races in the United States. The most striking differences between Native American cancer rates and that of the United States all races, shown by the few studies reported, have arisen from the comparisons between tribes (or ethnic Native American cultures) for certain primary cancers. Some tribes show extremely high rates for cancers that are rarely seen in non-Indians or even in other Native American groups.

For example, Alaska Natives have one of the highest rates for nasopharyngeal cancer in the world—age-adjusted at 9.8 per 100,000 per year [3]. This site ranks as their eighth most frequent invasive cancer, with 3.5 percent of the total cancer for over fifteen years. Of the 290 invasive cancers reported during twenty-five years among the Tohono O'odham, only one case of nasopharyngeal cancer was reported. Even more striking differences between

Alaska Natives and Arizonan desert dwellers were seen for cancers of the lung and colon, representing 12 percent each of all cancers reported for Alaska Natives [3], compared with 1.4 percent each of all Tohono O'odham cancers [5]. On the other hand, the Tohono O'odham have one of the highest incidence rates (27 per 100,000 per year, females, age-adjusted) in the world for primary cancer of the gallbladder, which is their highest ranked cancer (15 percent). Stomach cancer, ranked number two, accounted for 11 percent of all cancers for the Tohono O'odham, 4.6 percent of all Alaska Native cancers, and 6.3 percent of all Lakota neoplasms (see article by Justice in these *Proceedings*).

One other study compared desert dwelling Tohono O'odham cancers with cancers in the Oglala Sioux for the decade 1970 through 1979 [5]. The cancer profiles of the Tohono O'odham were as different from those of the Lakota as either was from the Alaskans or from the Navajo as well as other groups of New Mexico Indians as reported by Key et al. [6]. For example, while the Lakota colon cancer incidence rates for 1970–79 are half the rate for all races (30.4 per 100,000 per year, age-adjusted), and colon primary cancers count for 2.3 percent of all neoplasms, there was no colon cancer at all in the Tohono O'odham during that time period. There are countless other examples of what seem to be unique proportions and rates of primary cancers that may vary either by tribe or by regional ethnic groups. However, it is too early to draw specific conclusions about these differences, because virtually no cancer information is available for most tribal groups representative of the Eastern Woodlands, Midwest, Northwest, or Great Basin native peoples. Sparse mortality data from the Indian Health Service and studies by Sievers and Fisher [14] for all Oklahoman tribes also show extreme regional differences for certain specific neoplasms.

Comparisons of Indian cancer rates with other ethnic groups within the same ecological zones (and therefore, somewhat similar environments) have been reported rarely, except for those at the University of New Mexico's SEER program. According to Black and Key [4], "the incidence rates for nearly every major cancer are either markedly lower or higher for Indians (i. e., this is biased, since Navajos account for 75 percent of the Indians reported, and therefore these statistics are not applicable for all Indians) than for Anglos. Hispanics always occupy an intermediate position between the two, suggesting 'dose response' relationships" [4,14].

IMPORTANCE OF CANCER STUDIES IN NATIVE AMERICANS

Once a cancer pattern in a tribe is known, investigations can be initiated if an unexpected change occurs. By this method, unsuspected causes of cancer can be discovered that help elucidate cancer risk factors and implement preventive strategies that are applicable to all races. One case in point was the recognition of a cluster of lung cancers only in those Navajos who worked in uranium mines and did not smoke tobacco [15,16,17]. These studies focused on the need to adhere to and enforce specific safety features in uranium mines to prevent future epidemics [16,17]. A rapid increase in breast cancer in young Navajo Indian females [4] and an increase in endometrial cancer for Pima and Yuman tribes in Arizona [11] have prompted similar searches for unsuspected risk factors; however, insufficient funds resulted in termination of these studies before sufficient information was collected for analysis.

Studies of American Indian cancers have found unsuspected genetic susceptibilities to cancers, e. g., a study of nonpolyposis colorectal cancer in Navajos [18], osteosarcomas [19], retinoblastoma [20], and a familial concentration of primary gallbladder carcinoma [21] in New Mexico's Indian populations.

Additional dividends to be derived from studies of cancer in American Indians are suggestions for early diagnosis, screening, and prevention of cancers that occur in high incidence in other special populations (in addition to specific American Native groups) but are rare in non-Indian group in the United States. Examples from research among Alaska Natives include the use of Epstein-Barr virus antibody titers to detect subclinical nasopharyngeal carcinoma at a stage when survival is possible after treatment [22]; the development of the alpha-fetoprotein serum test to detect early primary liver cancer, which can then be successfully treated and cured [23]; and the use of hepatitis B vaccine to prevent primary liver cancer in Eskimos [24]. This knowledge will benefit liver cancer control for populations from Asia and Polynesia, where these primary types occur more frequently than in European people.

One cancer of higher incidence among various, disparate tribes, with respect to their overall patterns of primary cancers, has been squamous cell carcinoma of the cervix. This was one of the first cancers to be found where rates for Native Americans exceeded by 100 percent or more those for all races, for whites, and for Blacks

in the United States. High rates for cervical cancers first appear in reports about Alaska Indians [25], several tribes in the Southwestern states [26], and in Nebraska [27] in the mid 1960s.

For twenty years, specific nationwide efforts have been made by the Indian Health Service to expand the use of screening tests (i. e., the cervical Pap smear slide test) for early diagnosis [28]. The mortality rates for several tribes have dropped, while incidence rates for some have risen or stabilized [29]. This is the only screening and prevention program that seems to have been effective across many different tribal groups. Survival rates for American Indians five years after diagnosis and treatment for cervical cancer (68 percent) equal that for United States whites [34].

The survival rates for all other cancers that affect American Indians more than other races appear dismal. Baquet reports that the five-year survival rate for all Indians with all cancers is only 34 percent; survival rates for whites and Blacks are 50 percent and 38 percent, respectively. Indian stomach cancer patients have only a 9 percent five-year survival rate, which is the lowest survival rate for this neoplasm among the eight ethnic groups listed by Baquet and Ringen [34]. Similarly, gallbladder cancer survival rates reported by Morris [30] and Justice [31] for Southwestern Indians were less than five percent.

SUMMARY

This brief review of the sparse and incomplete literature about incidence, prevalence, and mortality from neoplasms suffered by American Indians, Aleuts, and Eskimos justifies few generalizations at present, and exceptions to each of the following may occur as knowledge expands:

1. Total cancer rates in Native Americans will usually be lower than age- and sex-adjusted rates for whites or Blacks in the United States. This seems to be especially true for childhood cancer rates [32] in Southwestern tribes;
2. the proportion of each type of primary neoplasm for any given ethnic group of Native Americans (i. e., tribe) will vary considerably as much or more between tribal groups as between European ethnic societies and will probably vary more than rates between third-generation European stock resident in the United States;

3. all rates are statistically unstable, because they have large confidence intervals as a result of the small numbers of cancer cases in each tribe, and both completeness of reporting and accuracy of diagnosis vary considerably from tribe to tribe;

4. total cancer rates seem to be increasing for those few tribes where adequate studies have been repeated over two or more decades [3,33]. A number of primary types never or rarely diagnosed before 1975 have been seen for the first time in a few tribes during the period 1975–85; and

5. with the exception of cancer of the cervix, survival time after cancer diagnosis seems not to have improved and remains less than for United States whites for most primary types. However, missing information about stage (or extent) of the tumor at the time of diagnosis makes these comparisons difficult.

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