

Cancer in American Indian Women

INTRODUCTION

Four salient facts about cancer incidence in American Indian women are discussed in this chapter. First, there is substantial variation in overall cancer rates and rates for specific cancers, by geographical area as well as by tribal group. Second, although overall cancer rates are lower among American Indians than among the general U.S. population, rates of certain cancers (e.g., cancers of the stomach, liver, gallbladder, and cervix) in some tribes exceed the national rates. Third, the 5-year survival rate among American Indian women for all types of cancer (46 percent) is significantly lower than the 5-year survival rate for cancer among the White U.S. female population (62 percent), according to the National Cancer Institute's (NCI) Surveillance, Epidemiology, and End Results (SEER) data (NCI/SEER, 2000). While cancer mortality rates for American Indian women declined during the 1990s, it was at a slightly slower rate than for White women (NCI/SEER, 2000). Fourth, cancer is the second leading cause of death for American Indian women (Indian Health Service [IHS], 1993b).

The high cancer mortality rate among some American Indian women is attributed to late detection of the disease and underutilization of available treatment. Furthermore, because most Indian patients do not participate in clinical trials or other cancer studies, researchers do not know the extent to which known cancer risk factors are applicable to Indians. Only recently have researchers begun to look at risk factors such as poverty, behaviors (such as sedentary lifestyles and dietary patterns), perceptions about health, and limited knowledge of and experience with cancer. In spite of the paucity of data, research has recently begun to address cancer prevention and control, both for American Indian women and youth.

This chapter is primarily about cancer in American Indian women. Cancer among Alaska Native women is discussed in another chapter in this monograph. However, there is overlap because many of the existing data combine American Indians and Alaska Natives. When data are reported that include Alaska Natives, the combined racial category is usually referred to as "Native American." Also, only recently have cancer researchers begun to report separately on males and females, and to include comparisons between the sexes.

BACKGROUND

To understand the health problems of Indian people, and particularly cancer in American Indian women, it is necessary to frame this topic within a larger context of history, federal and state government relations,

ethnicity, health resources, migration, and cultural changes. This will be helpful toward understanding why such a young population has comparatively high cancer morbidity and cancer mortality rates.

The 2000 Census indicated that there are 2.48 million self-identifying American Indians/Alaska Natives in the United States (approximately 106,000 of whom are Alaska Natives) (U.S. Census Bureau, 2001). This is a 29.8 percent increase from the 1.91 million American Indians/Alaska Natives reported in the 1990 Census (Johnson, 1991), but is still less than 1 percent of the U.S. population. There are about 825,700 American Indian adult women. These figures are based on respondents to Census 2000 who reported only Native American racial identification; an additional 1.6 million people reported Native American plus at least one other race. Hence, approximately 4.12 million people, or 1.5 percent of the total U.S. population, reported Native American alone or in combination with one or more other races (U.S. Census Bureau, 2001).

The Indian population is increasing, although there was a time when American Indians were viewed as a vanishing race. For example, James F. Fraser symbolized this notion in his famous equestrian statue, "The End of the Trail," which was exhibited at the 1915 San Francisco Exposition. The sculpture depicts a defeated warrior slumped over with fatigue on a weary mount (McNickle, 1973).

In comparison with the low proportion of American Indians in the United States today, pre-Columbian Indian population figures have been estimated at 15 million (Sale, 1992). Contrary to the views of some Europeans who settled the Americas, the land was not an open wilderness but a continent occupied and utilized by many different nations of indigenous peoples. These nations or tribes had different languages, different cultures, and various subsistence lifestyles.

Those who lived near the coastlines subsisted on food from the ocean, small game, roots and berries, and other foods obtained through trade. They made clothing from animal hides or wove them from a variety of plant fibers. Indians who lived in the woodland areas hunted for small and big game and cleared land for planting corn, squash, beans, and other crops. Women in most tribes tended small plots and gardens. Therefore, women were equal partners in providing subsistence.

When the Europeans arrived, most tribes had well-developed governments and religions and a diverse folklore rich in songs, stories, and legends. Resources for healing included persons with knowledge and training about the use of herbal medicine and the ways of spiritual healing. Many tribal rules accented ways of keeping healthy by maintaining harmony or balance.

This view of harmony or balance emphasized disease prevention and the interrelationship of body, mind, spirit, and emotions. Within this holistic view, illnesses or misfortune could have multiple causes, both natural and supernatural. Therefore, treatments often called on both natural and supernatural interventions. Although not much is known about the prevalence of specific diseases among the inhabitants of the Americas prior to European contact, archaeological and other evidence indicates that arthritis and other chronic diseases such as cancer were present.

The Europeans forever changed the demographics, health status, and lifestyles of the American Indians. Rapid declines in the population followed epidemics of communicable diseases introduced by the Europeans. Indians had no immunity to many of these diseases, and over time, recurring epidemics of smallpox, measles, diphtheria, and other infectious diseases destroyed some tribes while crippling others that survived (Duffy, 1951; Thorton, 1987; Cook, 1973). Scientific advances have helped curb many of these problems, but other forms of infectious diseases have continued to plague many Indian communities. Also, high rates of maternal and infant mortality continued well into the 20th century.

As the population of Native Americans plummeted, their land bases and other resources also decreased dramatically. Tribes in all parts of the United States faced dispossession, displacement, and forced removal. Many were moved to government-designated federal reservations. High mortality rates accompanied the removal and relocation, which was further exacerbated by malnutrition and poverty on the reservations.

The epidemics and removal took the lives of the most vulnerable—that is, many elders and young children. The loss of tribal elders was devastating, as they were the repository of tribal knowledge and healing practices. Thus, for some tribes, the knowledge of herbal medicines and many of the tribal healing ceremonies was lost forever. With this loss also came the loss of cultural heritage and identity.

There are numerous American Indian tribes. According to the 1990 Census, the most populous tribes were the Cherokee (369,000), Navajo (225,000), Sioux (107,000), and Chippewa (106,000) (U.S. Census Bureau, 1995). The majority of American Indians live in a small number of states, mostly in the Southern and Western regions. As of 1999, the states with the highest total number of American Indians (excluding Alaska) were California, Oklahoma, Arizona, New Mexico, Washington, and North Carolina. Texas, Florida, and Nevada had the greatest increases since 1990. Another indicator of the extent of American Indian presence is the proportion of states' total population who are Indian. The five states with the greatest percentage of American Indian residents in 1999 were New Mexico (9.5 percent), South Dakota (8.2 percent), Oklahoma (7.8 percent), Montana (6.5 percent), and Arizona (5.5 percent) (U.S. Census Bureau, 2001).

Defining American Indians

Data relating to cancer and health are often complicated by racial or ethnic misclassification. This is especially true for American Indians, some of whom are misclassified because they may not appear to be Indian. The other difficulty is that most of the health data on American Indians reflect only tribal members who use federal resources for health care.

Access to health care for most American Indians, unlike other minority populations in this country, is determined not only by place of residence but also by genetics—that is, degree of Indian blood or tribal enrollment. Indians are not recognized, served, or counted as American Indians by the federal government unless they fall within certain definitions.

To be eligible for federal Indian health care, for example, an American Indian must be an enrolled member of one of the more than 550 federally recognized tribes (IHS, 2001). Enrollment in most tribes requires one-quarter or more Indian blood. In addition, there are Indian tribes that have only state recognition (e.g., in New York and California) and not federal recognition. In other instances, a tribe may have neither federal nor state recognition, even if it maintains a strong tribal land base and culture. Aside from state or federal recognition, many American Indians rely on tribal land base to define their identity.

Colonization and Health

By the mid-1880s, when most Indians were moved to reservations, the severity of their health problems had become increasingly visible. Sickness combined with poverty and unsafe living conditions fueled the concern of advocates, who asked the federal government to improve the situation. In response, Congress allocated some funds to pay for the services of physicians and for medical supplies. Thus, health care for American Indians began as emergency aid. The federalization of health care services for American Indians originated from various laws, some based on terms negotiated in treaties. In other cases, health care services originated from other priorities, such as protecting the health of non-Indians living in or near Indian communities.

This emergency-oriented health care delivery system gradually became institutionalized. In 1954, Congress authorized the transfer of responsibility for Indian health from the U.S. Department of the Interior to the U.S. Public Health Service, thus instituting the Indian Health Service (IHS).

The health status of American Indians greatly improved under IHS, but as mortality and morbidity associated with most infectious diseases have declined, there has been an increase in other health

problems (particularly chronic diseases), such as cancer, diabetes, cardiovascular disease, and multiple health problems associated with alcohol abuse.

On-Reservation Health Care System

Today, IHS delivers health care predominantly to American Indians residing on or near federal Indian reservations. IHS is managed at the national level by a director (an Assistant Surgeon General) who oversees 12 geographic regions called IHS Areas. Similar to state health departments, these area offices coordinate and administer a network of health care delivery facilities, or service units, within their regions.

The IHS service units include various facilities: hospitals, community health centers, health stations (clinics), and school health centers. Nationwide, IHS operates 37 hospitals, 64 community health centers, 50 health stations, and five school health centers (IHS, 2001). In addition, 34 urban Indian health projects provide a variety of health and referral services. With the exception of three hospitals that have more than 100 beds, IHS hospitals are small, and many do not have facilities for specialties such as surgery and obstetrics.

Because most IHS facilities lack specialists, such as oncologists, contracts often are made with other providers or health care agencies. IHS is allocated funds each year to pay for some of the contract care, but funds often are depleted before the end of the budget year, so patients may be put on waiting lists.

IHS also uses third party payments and encourages or assists eligible American Indian patients to enroll in Medicare or Medicaid programs. When patients have these health insurance resources, IHS is considered the payer of last resort. In these cases, IHS pays the difference after the other agencies have paid their share of a patient's costs. The IHS health care facilities collect and maintain most of the health information on American Indians. Thus, data are limited, or in some cases not available, for people not utilizing IHS facilities or IHS-contracted health care.

In the spirit of self-governance, the federal government is allowing a growing number of Indian tribes to contract or "compact" with IHS, which allows them to take over the operation of hospitals and clinics that serve their communities (IHS, 1993a). In these tribal facilities and in other IHS service units, women's clinics are becoming more common.

Approximately 1.5 million American Indians in 35 States used IHS services in 2001 (IHS, 2001). However, user rates vary from one IHS Area to another. For example, in 1991, 41 percent of the 1.13 million IHS user population were from the Navajo and Oklahoma Areas (IHS, 1993a). Of this user

population, 53 percent were women. Like women in the majority population, women are the primary users of American Indian health care services.

Off-Reservation Health Care

In the 1950s, the federal government initiated an aggressive program to relocate American Indians to selected cities. Relocation was offered to people who were looking for employment or job training. Although many young men and women enlisted, once in the city many found the initial urban experience bewildering and frustrating. The lack of health care was one of the most frustrating experiences. Many of the relocated American Indians had no health resources or were not familiar with the complex health care delivery system in urban areas. When they tried to access these services, many were refused by providers who assumed the federal government was responsible for their health care. Indeed, it was not uncommon for a pregnant woman to return to the reservation to deliver her baby.

Because of this need for health care services by urban American Indians, some urban community Indian organizations and their supporters initiated storefront clinics and began to lobby their state and the federal government for health care services for American Indians living in urban areas. Their efforts resulted in the passage of the Indian Health Care Improvement Act in 1976 (Public Law 94-437, amended 1992, now Public Law 102-573). The act (recently reauthorized) allows American Indian organizations in a number of cities to apply for federal funding to provide some health care services for low-income Indians.

Today there are 34 urban-based American Indian health programs in Los Angeles, Minneapolis, Phoenix, Oakland, and other cities (IHS, 2001). These health programs are operated by nonprofit organizations and remain solvent with cost reimbursements from a variety of sources, including the IHS.

DEMOGRAPHICS OF AMERICAN INDIAN WOMEN

Information about American Indian women and their overall health status before European contact is sparse. Some early explorers, trappers, missionaries, and traders made general comments about the robust health of the Indians that they encountered, but Indian men, not women, were most often the focus of these observations and descriptions. The male-oriented tradition continued into the 1900s, fostered initially by government agents and later by a growing cadre of social scientists, most of whom also were male.

Although the role of American Indian women remained significant during and after the early stages of colonization, little mention of them is made in the history books (Grumet, 1980; Terrel and Terrel, 1974). Discussion of Indian women was often stereotyped when it did occur (Oshana, 1981). Until high maternal

and infant mortality rates in this population became a source of national embarrassment, the federal government paid little attention to the health status of Indian women.

The high mortality rates spurred the government into action, and American Indian women became the subject of several health campaigns. Health care providers devised various strategies to encourage American Indian women to seek early prenatal care and to deliver their babies in hospitals. Women who delivered in the hospital were rewarded with a layette and a case of canned milk for the newborn.

Today, a majority of American Indian women deliver their babies in hospitals, and both infant and maternal mortality rates have been reduced. For example, infant mortality rates for American Indians decreased from 62.7 per 1,000 in the years 1954-56 to 10.9 per 1,000 in 1992-94. However, these rates are still slightly higher than the 8.4 per 1,000 for the United States overall (IHS, 1997). The maternal mortality rates for American Indians also greatly declined between the 1950s and 1990s. Maternal mortality rates for Indian women between 1957 and 1959 were 82.6 per 100,000; between 1992 and 1994, this rate had decreased to 4.0 per 100,000 (IHS, 1997).

Age Distribution, Life Expectancy, and Family Status

According to the 1990 Census, American Indian women slightly outnumbered men. The age distribution of American Indian women is skewed toward younger age groups, with 38 percent aged 19 or younger. As of 1992, 55 percent of American Indian women were younger than 30. Only 17 percent were older than 40 (U.S. Census Bureau, 1992). In the 1980 Census, the median age for American Indians was 22.6 compared with 30.0 for the total U.S. population (U.S. Census Bureau, 1984). In 1990, 33 percent of American Indians were younger than 15, compared with 22 percent of the U.S. population generally. Only 6 percent of American Indians were older than 64, compared with 13 percent of the general population (U.S. Census Bureau, 1992).

These data reflect the fact that American Indians are a young population. Because the prevalence of many cancers increases with age, the age distribution of Indians may be one factor contributing to the generally lower number of cancer cases in this population.

Life expectancy rates for American Indian women continue to lag behind those of other women in the United States. Rates for the period 1992 through 1994 show that life expectancy for calendar year 1993 was 71.1 for American Indians, compared with 75.3 for U.S. Whites (IHS, 1997). Generally, American Indian women have a longer life expectancy than the men, whose average life expectancy in 1988 was 67.3 years, compared with 75.9 for the women (IHS, 1993a). Accidents (especially automobile

accidents), often associated with alcohol abuse, take a high toll on the lives of young American Indian men.

According to year 2000 projections (made in 1995), 74 percent of American Indian households are family households. Of these, 65 percent are headed by married couples and 26 percent are single female-headed households. The typical American Indian family has 3.57 people—more than the average 3.12 people for families of all races in the United States (U.S. Census Bureau, 2001).

Economic Status

Because of the high mortality rates for American Indian men, many of the women are single parents or heads of households. Poverty is common—many of the women are on public assistance, and those who are employed are usually unskilled workers earning low wages.

American Indians are among the most impoverished ethnic groups in the United States. Based on a 3-year average (1997 to 1999), the poverty rate for American Indians was 25.9 percent. This was higher than poverty rates for non-Hispanic Whites (8.2 percent) and Asian Americans and other Pacific Islanders (12.4 percent), but not statistically different from the rates for African Americans (25.4 percent) or Hispanics (25.1 percent) (U.S. Census Bureau, 2001). The median household income of American Indians is just under \$31,000, which is lower than that for non-Hispanic Whites (\$43,300) and Asian Americans/Pacific Islanders (\$48,600), but higher than for African Americans (\$26,608) and not statistically different from Hispanics (\$29,100) (U.S. Census Bureau, 2001). In 1990, 31.7 percent of the American Indians and Alaska Natives living on rural reservations or in villages had incomes below the poverty level. For the rest of the U.S. population, the overall percentage living below the poverty level at that time was 13.3 (U.S. Census Bureau, 1992).

Amott and Matthaei (1991) noted that nearly three quarters of employed American Indian women have been and continue to be in the secondary labor market (unskilled or semiskilled labor). Family responsibilities, limited access to jobs, and inadequate education affect the income potential and occupational status of Indian women. For example, one quarter of all American Indian women of employable age in 1980 had not completed high school, compared with 16 percent of White women of the same age group (Amott and Matthaei, 1991).

Therefore, poverty rates remain high despite the increasing numbers of American Indian women who have been entering the work force since the turn of the century. In 1900, 1 percent of employed American Indian women were in low-paying clerical positions. By 1970, 25.9 percent were employed in these positions. Similarly, there was an increase in the number of American Indian women in various

service occupations—25.9 percent in 1970 compared with 12.1 percent in 1900. Overall, participation of women in the work force rose from 35 percent in 1970 to 48 percent in 1980 (Amott and Matthaiei, 1991). On the other hand, according to the 1990 Census, 13.5 percent of American Indian women older than age 16 and living on reservations (compared with 6.2 percent of all U.S. women) were unemployed in 1989 (U.S. Census Bureau, 1992). In 1990, 13.4 percent of the women were unemployed compared to 6.2 percent for all U.S. races (IHS, 1997).

Many American Indians leave the reservations in search of jobs. For those who move to the cities, the rise and fall of job opportunities determines how long they stay there. When employment situations become bleak, the family often migrates back to the reservation. At the same time, significant numbers of American Indians have settled permanently in cities and the suburbs, especially those who were raised in cities or who married non-Indians. In 1980, the last year for which these census data were collected, 54 percent of American Indian women were reported to be married to non-Indians, and most of these women and their families lived in off-reservation communities (Office of Technology Assessment, 1986).

Educational Attainment

Although more American Indian females than males complete high school, both groups are less likely than other minority youths to graduate from high school. The 1990 Census provided data to allow for comparisons of the percentages of high school and college graduates from different minority groups. Individuals with Hispanic, African American, and American Indian or Alaska Native backgrounds do not do as well in completing school as those from White or Asian American backgrounds. Sixty-five percent of American Indian women had completed high school and 9.3 percent had at least a bachelor's degree, compared to 77.9 percent high school graduates and 21.5 percent college graduates among Whites and 20.3 percent college graduates across all races (U.S. Census Bureau, 1992). Although the number of female American Indian college graduates is increasing, many barriers remain, especially for those living in remote rural communities.

Health

The National Center for Health Statistics reported that of all minority groups in the United States, African American and American Indian women younger than age 45 have the highest mortality rates (Fingerhut and Makuc, 1992). The leading causes of death for American Indian women from 1992 to 1994 were heart disease (20.8 percent), cancer (17.2 percent), and accidents (9.5 percent), as well as diabetes, cerebrovascular diseases, chronic liver diseases, and cirrhosis (IHS, 1997). In deaths resulting from accidents, chronic liver disease, and cirrhosis, alcohol plays a role. For heart disease and cancer, smoking and other tobacco use contribute to major causes of death. Despite various interventions, the leading causes of death for American Indian and Alaska Native women, as depicted in Table 1, were

relatively unchanged during the 1990s. Cancer deaths rose from 14.4 percent between 1981 and 1983 to 18.5 percent between 1996 and 1998.

As single heads of households, some American Indian women do not invest time in seeking preventive health care. Instead, they wait until symptoms of ill health become unbearable or severely debilitating. Even if some women suspect the symptoms might be cancerous, they often do not have time to worry about their condition or may not wish to confirm their fears.

CANCER STATISTICS

According to NCI's SEER Program data and IHS data, American Indians have lower rates than the general population for all cancers combined, and for cancers of the lung, breast, and colon (Miller et al., 1996; NCI/SEER, 2000). However, they have higher rates for cancers of the stomach, gallbladder, and pancreas (NCI/SEER, 2000). Table 2 shows age-adjusted cancer incidence and mortality for Native American versus White women from 1992 to 1998 and survival data from 1988 to 1997.

Data on cancer among American Indians remain troublesome for a number of reasons, some of them related to matters of ethnic/racial definition, diversity across tribes and regions, and the numbers of American Indians living in various areas. For example, Alaska Natives often are combined with American Indians in reporting statistics (Baquet, 1996), though their cancer profiles may be quite different. Also, not all American Indian communities are a part of cancer registries, and available data often represent small numbers with large confidence intervals (Horner, 1990; Justice, 1990; Hampton, 1989; Valway et al., 1992).

Because cancer patients often are treated in non-IHS facilities, there are few critical data on incidence, treatment modalities, follow-up outcomes, complications, and compliance. Moreover, what is known about cancer and cancer risks for American Indians is frequently limited by the types of cancers and the number of tribes studied (Mahoney and Michalek, 1991; Justice, 1988). These systematic limitations exist in the best available cancer statistics, such as those from SEER registries, as well as for much of the published literature discussed in this chapter.

In addition, because the majority of American Indian reservations are in states that do not have state or regional cancer registries, data from the New Mexico Tumor Registry or SEER have served as the national benchmarks for evaluating cancer patterns among American Indians (Samet et al., 1987; Miller et al., 1996). Therefore, these data only reflected Indian tribes in the Southwest, not the Indian population nationwide. Other SEER sites including Seattle/Puget Sound, Connecticut, Iowa, and Utah, as

well as Arizona (a Supplemental SEER Registry), also cover areas where many American Indians reside. Nevertheless, the enormous variation across tribes and locations imposes an important limitation on drawing conclusive inferences from currently available cancer statistics data.

Despite improvements, some data sources remain problematic. For example, cancer data for American Indians and Alaska Natives in urban or off-reservation communities may not be a part of statistical profiles. The problem of missing data is further complicated by frequent problems of ethnic misclassification in hospital cancer care records (Frost et al., 1992).

Cancer Sites and Mortality

Hampton (1992) considered cancer a growing epidemic among American Indian communities, because it was so uncommon in the past. Mortality and morbidity reports confirm this observation. Cancer is the second leading cause of death for American Indian women and the third leading cause of death for both sexes. Moreover, the 5-year cancer survival rate for American Indians is below that of other minority populations (IHS, 1997; Boss, 1986).

As Table 2 shows, American Indian women had lower overall cancer mortality rates than Whites (87.7 versus 138.0 per 100,000, respectively) through the late 1990s. They had higher mortality rates than Whites for cancers of the stomach, gallbladder and cervix. For all cancers, American Indian women were less likely to survive than were White women (49.6 percent versus 62.2 percent). Further, as shown in Table 3, American Indian women showed increases in cancer mortality during this period for most cancer sites, and in particular for esophageal cancer. Furthermore, the increases were more elevated than mortality experienced by White women who experienced declines in mortality.

Data compiled by NCI for the years 1977 to 1983 illustrated the cancer problem for American Indians in comparison with other minority populations in the United States. While Alaska Natives had higher cancer mortality rates than American Indians for all site-specific cancers covered, American Indians had relatively lower cancer rates for all sites but cancers of the cervix and kidney. However, as noted above, these rates have changed in many ways over the 15 years since these data were reported (Horm, 1991; Horm and Burhansstipanov, 1992).

Table 4 summarizes the leading causes of cancer mortality, broken out by cancer site, IHS Area, and sex, between 1984 and 1988. The table illustrates the significance of smoking and lung cancer for both American Indian men and women. Of particular note is that oral cancer, presumably resulting from the use of smokeless tobacco, is the fifth leading cause of cancer mortality among males in the Great Lakes IHS Area. Thus, tobacco is associated with 55 percent of cancer mortality in this particular group. These

data should be interpreted with caution because of the small numbers of total cancer deaths per area and because they are not age adjusted. Nonetheless, they illustrate the variation in priority cancer concerns for American Indian women and men living in different regions of the country.

Survival Rates

The 5-year cancer survival rate for American Indian women, both overall and for various site-specific cancers, is significantly lower than that for White women of comparable ages. Table 2 provides some comparisons for the years 1988 through 1997. American Indians have disproportionately low 5-year survival rates for lung, stomach, and other cancers. Although survival rates for cervical cancer (70 percent) and breast cancer (73 percent) are significantly higher than for some other cancers, they are still well below the rates for White women, of 78 and 86 percent, respectively (NCI/SEER, 2000).

Causes for the lower cancer survival rates among American Indians are not clear, but most observers link the poor outcomes to late detection, inadequate access to health care, poverty, and various social and cultural barriers. Unfortunately, little detailed information is available about some of these barriers, including overall knowledge and attitudes of Native Americans about cancer.

SELECTED CANCER SITES

Cancer incidence and survival data for American Indian women are available for only a few tribes. Table 5 summarizes age-adjusted cancer incidence rates for American Indian women from selected tribes in the Southwest between 1982 and 1987. Table 6 shows age-adjusted cancer mortality between 1992 and 1998 for American Indian women from selected IHS Areas and for women of all races in the United States. These data illustrate the great variability across tribes and geographical areas. While the incidence data are the most recently available data for American Indian women, they should be interpreted with caution because they are now 10 to 20 years old. Also, it must be noted that mortality rates are shown for both American Indian and Alaska Native women as a single population, without separate data for American Indian women.

Breast Cancer

The American Cancer Society reports that an estimated 40,800 women in the United States died from breast cancer in 2000 (American Cancer Society, 2000). With early diagnosis and treatment, breast cancer is curable. For example, the 5-year survival rate for nonlocalized breast cancer is 60 percent, but the survival rate increases to 91 percent if the cancer is detected and treated while in the localized stage. Survival rates approach 100 percent if in situ breast cancer is detected and treated early (American Cancer Society, 1991).

The incidence of breast cancer in general for all American Indian women is less than that for Whites. Statistics have indicated that breast cancer incidence for American Indian women was increasing through the 1980s (Funk, 1986; Mostow and Lanier, 1989; IHS, 1990a,b; Samet et al., 1987), but during the 1990s the incidence of breast cancer in Native American women decreased by 12.9 percent, or an estimated annual percentage decline of 5.3 percent (NCI/SEER, 2000) (see Table 3).

The rates and trends for breast cancer vary from tribe to tribe. For example, one report (IHS, 1990a) revealed that breast cancer mortality is higher among Great Plains American Indian women than among women in the general U.S. population and among tribes in the Southwest. The report also noted that rates of cervical cancer may equal or exceed the rates of breast cancer in some IHS Areas (IHS, 1990a).

Because breast cancer detection often comes late for American Indian women, breast cancer survival for this population is relatively poor (see Table 2). The 5-year survival rate for breast cancer (all stages) among American Indian women is 72.6 percent, compared with 86 percent for White women (NCI/SEER, 2000). In an analysis of staging of breast cancer among 84 Southwestern American Indian women, IHS data show that only 26 percent were diagnosed at a localized stage, 45 percent were diagnosed at a regional stage, and 29 percent were diagnosed at distant or unknown stages (IHS, 1990a).

Data on 76 of the 84 women in the above sample indicated that 66 percent of them discovered a lump during a self-examination, and only 4 percent of cases were diagnosed by mammography. The rest of the cases, 30 percent, were discovered by a physician during examination (IHS, 1990a). A further analysis summarized the age at diagnosis and the time interval between detection of the mass and clinical presentation, by stages of cancer, for 26 of the women. The interval from detection of a mass to clinical presentation for the early-stage cancers was 1.8 months, regardless of the woman's age, but the interval from detection to clinical presentation for late-stage diagnoses averaged 12.7 months, and was much longer (averaging 21.1 months) for women aged 51 or older. Unfortunately, these types of data are not available for the rest of the American Indian women nationally who are diagnosed with breast cancer, which highlights the need to develop and maintain better information on cancer patterns among this population.

Mammography service is relatively new in most IHS health programs. Many IHS facilities do not have mammography equipment, so women may be referred to other facilities for mammograms. In 1991, a national survey revealed that IHS had only four in-house mammography units (within IHS facilities) and was expecting to acquire seven more units in 1992 (Gwilt, 1992). Because IHS has yet to equip all of its health facilities to perform mammography, most women older than age 40 who do not have any

symptoms do not have routine mammograms (Giroux et al., 2000). American Indian women who desire a mammogram often go without, or those who can afford the cost seek that service in non-IHS facilities.

There is an additional problem when an American Indian woman must seek health care services outside the IHS system. Follow-up on abnormal results may not occur, or valuable time may be lost if IHS requires that tests be repeated before further diagnostic tests or treatment can be approved. Where IHS has in-house mammography services, baseline mammograms are a part of the health care offered and are accepted by most American Indian women. For example, in 1991, the IHS Cancer Prevention and Control Program reported that approximately 10,500 mammograms were performed (Gwilt, 1992). The data unfortunately do not indicate how many of these were baseline mammograms for women older than age 50.

Cervical Cancer

In a discussion of results from a 9-year cytologic cancer detection program, Jordan and Key (1981) noted that cervical cancer was found more frequently among young American Indian women (younger than 35 years old) than among Hispanic or White women in the same age group. In the postmenopausal age group, cervical cancer detected among older American Indian women tended to be in advanced stages, and many of the women reported that they had never had cytologic screening prior to the examination by the project staff (Jordan and Key, 1981).

In the 1980s, it was reported that the incidence rate of cervical cancer for Native American women was more than twice that of the U.S. female population overall (IHS, 1990b; Hampton, 1989). These figures included Alaska Natives, who have a particularly high rate of cervical cancer. Also, the incidence of uterine cancer, as with other kinds of cancer, varies by area. For example, between 1978 and 1981, cervical cancer ranked second to breast cancer among American Indian women living in New Mexico (IHS, 1993a). More recent data show a lower rate of cervical cancer for Native American women than for White women—6.2 percent and 8.1 percent, respectively (NCI/SEER, 2000) (see Table 2).

American Indian women still have poor survival rates for cervical cancer compared with White women (Joe and Young, 1993; NCI/SEER, 2000). Among the Northern Plains tribes, where lung cancer is among the leading causes of death for both men and women, cervical cancer exceeded U.S. rates for all races (Welty, 1992). Similarly, Becker and colleagues (1993), who noted high rates of cervical cancer and dysplasia among Southwestern American Indian women, pointed to possible risk factors associated

with dysplasia, such as cigarette smoking, human papillomavirus infection, use of contraceptives, parity, multiple sex partners, and others.

Although a majority of American Indian women participate in cervical cancer screening programs (Risendahl et al., 1999b), many do not respond when notified for a follow-up visit because of positive or questionable results. To improve follow-up, several clinics have increased their efforts to identify such patients. In addition, some of the clinics now routinely review each patient's chart during an outpatient visit or hospitalization to determine if there is a need for a Pap test.

A lack of contact with health facilities is not the primary reason for the low rate of cervical cancer screening and follow-up (IHS, 1990a). In 1989, health care providers on the Tohono O'odham Reservation examined this issue among a sample of women. They found that although women needing a Pap test were reminded of this when they came to the clinic for other kinds of medical care, few made appointments to have the test done. Some of these women were later interviewed and they reported that they did not make the necessary appointment because it would require arranging another trip to the clinic, a situation that often was too time-consuming, especially when they felt well (IHS, 1990a).

Sometimes follow-up is hampered by misinformation. For example, Campos-Outcalt and colleagues (1992) found that Yaqui American Indian women often had difficulty understanding the difference between a pelvic examination and a Pap test. Thus, a number of these women indicated that they had had a Pap test when they may have had just a pelvic examination.

American Indian women of childbearing age are more likely to have a routine Pap test as a part of their prenatal care. However, once past the childbearing age, most Indian women are not tested (Risendahl et al., 1999b). When asked, many associated the Pap test with prenatal care. Thus, most Indian women who are past childbearing age are not likely to avail themselves of Pap screening.

Modesty is another barrier. Most American Indian women prefer to be examined by female physicians or nurse practitioners. However, very few health facilities in Indian communities are staffed by female physicians and nurse practitioners.

Health care providers frequently cite several barriers that prevent them from doing cervical and breast cancer screening, such as limited clinical space, time constraints, and lack of provider interest. Table 7 lists the main reasons given by a sample of 294 IHS health care providers who were surveyed in 1989. Inadequate clinic space, lack of time, and inadequate reminders are significant barriers to routinely performing cancer screening, especially for asymptomatic patients. Lack of follow-up on abnormal

cervical test results also has been a barrier, especially because of the lack of resources or trained providers to do colposcopies. This situation, however, is slowly changing as more IHS physicians are trained to do colposcopies (Daniels and Percy, 1993).

Lung Cancer

Lung cancer is a growing problem for American Indians of both sexes. The 5-year survival rate for American Indian women who develop lung cancer is 13 percent, lower than the survival rates of other U.S. population groups for this cancer (NCI/SEER, 2000; Baquet and Ringen, 1986; Welty et al., 1987; IHS, 1990a; Samet et al., 1980; Becker, 1991) (see Table 2).

As with other kinds of cancer, the incidence of lung cancer varies by tribe and geographical region (Mahoney et al., 1989; Horner, 1990). Although there is inadequate documentation of smoking patterns among most American Indian tribes, Baquet (1987) and other researchers predicted that tobacco-related cancers would rise due to heavy smoking and use of smokeless tobacco among American Indian youth (Schinke et al., 1989a, 1990; Beauvais and LaBoueff, 1985). In addition, National Center for Health Statistics data indicate that Indian youth have the highest smoking rates of all ethnic groups (Baquet, 1987).

According to Hampton (1989, p. 48), lung cancer is the most common cause of cancer mortality for American Indians and Alaska Natives, by "a factor of more than two." Again, there are significant regional differences. For example, Welty (1989) compared lung cancer deaths of Northern Plains tribes with those of Southwestern tribes. The age-adjusted lung cancer mortality rates for the Northern Plains and Great Lakes IHS Areas were reported per 100,000 as follows: Aberdeen, 147.8; Bemidji, 154.4; and Billings, 150.1. These rates are considerably higher (per 100,000) than for the Southwest IHS Areas: Phoenix, 12.4; Albuquerque, 6.6; Navajo, 3.9; and Tucson, 3.3. The high prevalence of cigarette smoking in the Great Plains tribes and the lower rates of smoking in the Southwest are seen as a major factor in this difference (Welty, 1992; Hampton, 1992).

Stomach and Gallbladder Cancer

According to Horm and Burhansstipanov (1992), the only cancer site for which American Indians of both sexes combined had higher incidence rates than Whites through the 1980s was the stomach (15.1 cases per 100,000 compared with 5.8 cases per 100,000, respectively). This observation was also supported by data from the New Mexico Tumor Registry (a 1979 computer printout) and Justice (1988).

Table 8 indicates that incidence rates for cancer of the stomach and biliary tract vary from tribe to tribe, and are generally much higher for men than for women. Although a high incidence of stomach cancer

has been noted for some tribes, Justice (1990, p. 14) indicated that “no studies about stomach cancer [among American Indians and Alaska Natives] have attempted to ascertain correlations with any known risk factors by detailed comparison of cases and controls, or even by a correlation of grouped characteristics.” In fact, the calculation of age-adjusted rates for these tribes must be interpreted cautiously because of the relatively small numbers of cases, as well as the small denominators.

Although certain risk factors, such as age, sex, race, occupation, genetic factors, diet, environment, lifestyle, and exposure to toxic substances, have been identified for other groups, comparable studies among American Indians are lacking. It is known, however, that the survival rate for stomach cancer among American Indians was only 9 percent in the 1980s (Baquet and Ringen, 1986), though it improved to 11 percent in the 1990s (NCI/SEER, 2000). Also of note, the age-adjusted incidence of stomach cancer for Native American women is now only slightly higher than for White women (4.3 versus 4.0 per 100,000, respectively) (NCI/SEER, 2000).

The survival rate for those with gallbladder cancer in the 1970s was less than 5 percent (Morris et al., 1978; Justice, 1981). Horm and Burhansstipanov (1992) reported that the age-adjusted gallbladder cancer mortality rate (per 100,000) was 2.6 for American Indians, 0.7 for African Americans, 1.1 for Japanese Americans, and 0.9 for Whites.

RISK FACTORS AND BEHAVIORS

A better understanding of the cancer problems of American Indian women can be achieved by examining the prevalence of behavioral and other risk factors related to the most common cancers, including suboptimal screening practices which may lead to later-stage diagnoses. Although there is limited information on specific health risk behaviors across the American Indian population, cancer and the other leading causes of death among American Indians are usually linked to unhealthy lifestyles, including such factors as smoking and smokeless tobacco use, unhealthy diets, obesity, lack of physical activity, and alcoholism (Pearce, 1990). Knowledge and attitudes, environmental concerns, and toxic wastes also are potential considerations related to both cancer risks and cancer prevention among American Indian women.

Smoking and Smokeless Tobacco Use

There appears to be wide variation among tribes and regions in the extent of tobacco use, as reflected in lung cancer incidence and mortality. When Welty (1989) compared lung cancer deaths of Northern Plains tribes with those of Southwestern tribes, he found very high age-adjusted lung cancer mortality rates for the Northern Plains and Great Lakes IHS Areas, between 147.8 and 154.4 per 100,000. Yet the rates for the Southwest IHS Areas were quite low, between 3.3 and 12.4 per 100,000. It is believed that the high prevalence of cigarette smoking among the Great Plains tribes and the lower rates of smoking in the Southwest are the major reasons for this difference (Welty, 1992; Hampton, 1992).

Although not much is known about smoking patterns and smoking-related cultural attitudes among American Indian women, a survey of smoking patterns among 592 Indian patients in four urban Indian clinics revealed a median consumption of 11 cigarettes per day, compared with 20 per day in the general U.S. smoking population (Lando et al., 1992). In this sample, 65 percent of respondents were women. Although many respondents said they wanted to quit, most who had quit started smoking again for various reasons, including cravings to smoke, social situations, stress, nervousness, habit, or having “no reason not to” (Lando et al., 1992). Unfortunately, there are no data on the impact of cultural factors on smoking prevalence among urban and reservation Indians, nor are there data on intergenerational differences in smoking patterns among American Indian youths and parents.

Three recent reports provide estimates of the extent of smoking among American Indian women in different parts of the country, again revealing widely divergent tobacco use patterns. The Navajo Health and Nutrition Survey studied 566 Navajo women on reservations in eight Navajo Service Areas, and found that only 4 percent were current smokers, though 10 percent reported using smokeless tobacco (Strauss et al., 1997). Risendahl and others (1999a) conducted a survey of 519 adult Indian women in urban Phoenix and found 20.2 percent to be smokers. Yet much higher tobacco use rates were found in a survey of Indian women in California. In a survey of 847 California women, 37.2 percent were current smokers and another 27.1 percent said that they were former smokers (Hodge and Casken, 1999). This study provided more detail about the women’s smoking patterns, as well—more than half the smokers smoked 10 or fewer cigarettes per day, with a mean of 13.6 cigarettes per day; 52 percent were not interested in or considering quitting smoking; and those who wanted to quit overwhelmingly preferred “cold turkey” as the quitting method (Hodge and Casken, 1999).

In addition to cigarette smoking and alcohol use, smokeless tobacco (chewing tobacco and snuff) is popular in many American Indian communities, especially among young people. Oral and nasopharyngeal cancers, which are closely associated with smokeless tobacco use, are much more common among males than among females (Horm and Burhansstipanov, 1992). Studies on American

Indian women's use of smokeless tobacco reported rates of 6.2 percent in California Indian women (Hodge and Casken, 1999) and 10 percent in Navajo women (Strauss et al., 1997). Both of these rates are much higher than rates in the overall U.S. female population.

For both men and women, the habit of smokeless tobacco use often begins during adolescence. According to Schinke and colleagues (1989a), adolescents who use smokeless tobacco daily tend to start before age 10. In other studies, Schinke and associates (1989b, 1987) found that 32 percent of the girls in a sample of 51 reported using chewing tobacco or snuff, although most of the subjects did not use it every day.

Diet and Obesity

Obesity, in particular, is an increasing problem for American Indian women (Jackson, 1994). Prior to European contact, American Indians followed a healthful diet because most of them lived in areas where the land offered both an abundance and variety of plants, as well as protein from a variety of meat sources. Vegetables and meat often were boiled or dried for future use (Jackson, 1994). The forced removal and confinement of people to reservations, however, diminished or prohibited their access to these traditional food sources. Diets on the early reservations were poor and limited to foods supplied and rationed by the federal government. The food rations often included poor-quality meat (often from diseased livestock), flour, coffee, and sugar (Smith, 1875). To make these foods edible, it became common practice to fry the meat and the bread with lard or other types of grease.

Today, the diet of most American Indian families is high in refined carbohydrates, fat, and sodium, and often is lacking in lean meat, dairy products, vegetables, and fruit (Kumanyika and Kellitzed, 1985). For example, Bass and Wakefield (1974) found high consumption of coffee, bologna, potato chips, and sodas on the Standing Rock Reservation at Fort Yates, North Dakota. Among some of the Southwest tribes, there also is a high consumption of such foods as bread, potatoes, and meat that have been fried (Kuhnlein, 1981). Such diets contribute to problems of obesity for women (Sugarman and Percy, 1989). In a study conducted between 1979 and 1980, Wolfe and Sanjur (1988) found that 63 percent of Navajo women weighed more than 120 percent of their ideal body weight.

Other recent studies confirm the disproportionately high rates of obesity and overweight among American Indian women, although specific rates vary. In their study of 519 American Indian women in urban Phoenix, Risendahl and others (1999a) found 69.6 percent of the women to be overweight, with 41.6 percent considered obese. The Navajo Health and Nutrition Survey reported a rate of 59 percent overweight among 566 Navajo women on reservations. And Hodge and Casken (1999) reported that 44.5 percent of the Indian women in California who they surveyed were overweight.

Strauss (1993) also reported that the mean body mass index for a sample of 9,464 American Indian children and youths (ages 5 to 18) exceeded that of children of the same age and sex in the general U.S. population. Therefore, obesity is becoming a major health risk factor for Indian youth; it has contributed to the increased number of American Indian youths who are being diagnosed with noninsulin-dependent diabetes mellitus, a disease that was previously found primarily in middle-aged adults. The prevalence of diabetes, especially type 2 diabetes, among American Indian populations averages 12.2 percent, or about twice that of the total U.S. population (American Diabetes Association, 2001). The prevalence of diabetes among Indians increased 29 percent between 1990 and 1997, and varies widely across tribes and regions—up to as much as 50 percent among members of the Pima American Indian tribe in Arizona (American Diabetes Association, 2001; Burrows et al., 2000).

Extent of Physical Activity

National data do not report gender-specific prevalence estimates for physical activity. American Indian men and women have higher rates of inactivity (33.8 to 46 percent report being inactive) than do Whites (26.5 to 38 percent report being inactive) (Macera and Pratt, 2000; U.S. Department of Health and Human Services [USDHHS], 2000). The percentage of American Indians accumulating 30 minutes of moderate-intensity physical activity at least 5 days a week (13 percent) or doing 20 minutes of moderate to vigorous physical activity at least 3 days of the week (25 percent) is also lower than for Whites (among Whites, 15 percent report doing 30 minutes 5 days a week, 32 percent report doing 20 minutes 3 days a week) (USDHHS, 2000). Finally, fewer American Indian men and women engage in vigorous physical activity than Whites (19 percent versus 24 percent, respectively) (USDHHS, 2000).

Substance Abuse and Other Behaviors as Risk Factors

For American Indians, poor health status combined with poverty is rooted in the history and complexity of the White/Indian relationship. One of the most critical factors has been the emergence of forced dependence on the federal government, caused by placement on nonproductive reservation lands. This dependence has fostered low self-esteem and the tendency to escape the pain and stress of everyday problems through the use of alcohol and other drugs. The adverse consequences of both alcohol and smoking contribute significantly to the five leading causes of death for American Indian men and women (IHS, 1993a).

Heavy drinking not only increases social problems but also has other serious consequences, such as suicide, homicide, and accidents, which contribute significantly to disability and early death. For American Indian women who drink during pregnancy, there is the additional risk of having babies with severe developmental disabilities—fetal alcohol syndrome or milder forms of disabilities associated with

fetal alcohol effects. The severity of these problems varies from one American Indian community to the next. For example, May and Hymbaugh (1983) noted that between 1968 and 1982, the rates of fetal alcohol syndrome were 1.4 per 1,000 among the Navajo Indians and 9.8 per 1,000 among the Plains Indians.

May (1991) indicated that although most children with fetal alcohol syndrome are born to a small number of Indian women, intervention programs often are not successful because these women are extremely difficult to reach. He states that “on the average, 22 to 25 percent of Indian women who have one alcohol-damaged baby will have a subsequent one” (May, 1991, p. 67).

Rates of alcohol use by women vary significantly across American Indian groups, according to recent publications. Among Indian women in California, alcohol use was much more common in urban (22.2 percent) than rural (12.8 percent) areas (Hodge and Casken, 1999). Approximately 12.1 percent of Indian women in urban Phoenix surveyed by Risendahl and colleagues (1999a) were classified as chronic drinkers.

The National Institute on Alcohol Abuse and Alcoholism (1990) noted also that chronic alcohol abuse exacts a greater physical toll on women; that is, the detrimental effects of alcohol on the liver (resulting in cirrhosis, for example) are more severe for women. Moreover, many women who drink also smoke, a combination that adds to health risks for cancer.

Environmental Concerns

On the Navajo Reservation during the 1960s and 1970s, more than 50 Navajos (mostly men) died of lung cancer. A majority of these men did not smoke but had worked in uranium mines, some for as long as 20 years. Their employers did not undertake any special safety precautions, and the miners were exposed to prolonged and excessive radon levels (Gottlieb and Husen, 1982). Not until 1967 were safety regulations imposed on mining companies by the federal government. However, 15,000 miners already had been working in these mines for some time. Easthouse (1993) notes that 20 percent of the miners were Navajos. Although this risk mostly affects American Indian men, related factors also cause problems for the women, as described below.

The average survival time for Navajo miners with lung cancer from the time of diagnosis was less than 1 year. Because of the number of people affected and because the antecedent strongly appeared to be related to high levels of radon exposure, this particular incident serves as one of the most frequently cited examples used to discuss work site safety as well as environmental safety and cancer for American Indians, although only one tribe (Navajo) was affected.

Uranium mining and the resultant exposure of miners to high radon levels also has been a problem elsewhere in the Southwest, especially in areas with extensive uranium development and weapons testings (mainly Nevada and Utah). Exposure to high radon levels has affected not only the health of the miners but also the health of their families and other community members who were exposed to varying levels of toxic wastes associated with nuclear weapons testing, uranium mining, and uranium waste. The Four Corners area (Arizona, New Mexico, Utah, and Colorado) of the Navajo reservation, a former uranium mining area, was found to have a high incidence of birth defects, and many women experienced reproductive complications (Calloway, 1981).

Moreover, Navajo children growing up in this area were 15 times more likely than the general population to develop ovarian and testicular cancers (Calloway, 1981). The rate of birth defects for Navajos residing in the Four Corners area was twice the national average (Calloway, 1981). Stanton (1982) also found high infant mortality among this group, and noted that learning disabilities occurred twice as frequently among families living in former uranium development areas than among families living outside the target area.

In 1990, Congress appropriated funding under the Radiation Exposure Compensation Act (Public Law 101-426) to provide compassionate payments for many American Indian families and others who live in the five Western States contaminated by various types of nuclear weapons development and who had prolonged exposure to high levels of radon. However, the compensation promised to the survivors, especially the wives and children of Navajo miners, was never fully realized. Several Navajo widows were denied eligibility because they could not provide the required documentation, such as marriage certificates, because many of the women and men were married in a traditional Navajo wedding ceremony (Easthouse, 1993).

Despite the detrimental consequences of exposure to nuclear waste, a number of Indian tribes recently have been courted by private corporations that want to establish toxic and hazardous waste plants on American Indian reservations (Taliman, 1993). A large amount of money was promised if the tribes agreed to participate.

The federal government is competing with the private sector to gain access to these tribal lands. Government representatives are requesting that various tribes consider setting aside plots of 450 acres for monitored retrievable storage sites, which would store approximately 10,000 tons of spent nuclear fuel rods generated by nuclear power plants (Taliman, 1993). One tribe in New Mexico completed a feasibility study for such a storage project, and supporters of the project forced a second election to get enough

votes to approve building the storage site. Tribal members who have supported the project emphasized the economic opportunities for the tribe. Opponents cited cultural and other reasons for their opposition, arguing, for example, that such a venture would be an affront to the sacredness of the land.

KNOWLEDGE AND ATTITUDES

A small 1990 survey on cancer knowledge was conducted in South Dakota among Sioux Indian women, who were asked to list the most important health problems in their communities. These women identified diabetes and substance abuse as major health problems; only 19 percent mentioned cancer (Madeiros, 1990). The ranking of the health problems by these women (mean age 57) is not surprising because, for some time, most Indian communities have had visible and aggressive prevention and intervention programs for diabetes and substance abuse but few programs for cancer prevention. Further, the disease burden and disability due to diabetes is much more immediate and visible, and the numbers of affected persons are higher than those affected by cancer.

Some of the few studies that have examined cancer knowledge and attitudes among American Indian women have found these beliefs to be positively associated with such cancer detection and prevention behaviors as obtaining breast cancer screening (Risendahl et al., 1999c) and successfully quitting smoking (Hodge and Casken, 1999).

Cancer Screening

There is concern that American Indian women are not obtaining appropriate screening for cervical and breast cancers, and that this contributes to elevated mortality and decreased survival for these diseases. As with many risk factors and behaviors, the rates of screening vary widely, but they generally have been found to be suboptimal. A chart audit of 1995 data from 12 IHS Areas found that, for women aged 50 to 69, screening rates were: Pap test within the last year, 26 to 69 percent; clinical breast exam in the last year, 28 to 70 percent; and ever having had a mammogram, 35 to 78 percent (Giroux et al., 2000).

Pap test screening rates in urban Phoenix were found to be 76 percent in the previous 3 years, but just 49.5 percent in the past year (Risendahl et al., 1999b). A particular concern was that women over age 50 who were not obtaining regular gynecologic services were significantly less likely to have had a Pap smear. The same survey revealed that only 53 percent of the women over age 50 had a clinical breast exam within the preceding year and 35.7 percent had a mammogram within the past two years (Risendahl et al., 1999c).

Cultural Factors

Cancer is one of the most dreaded diseases in mainstream society, and American Indians share this fear. However, the fear is often complicated by other sociocultural beliefs about wellness and unwellness. For example, many tribes believe that talking about an illness can bring about the illness. Thus, there may be strong taboos about discussing cancer because of a belief in the power of language. A desire to not “wish” cancer on anyone is one of the reasons why cancer may not be discussed publicly in many Indian communities.

In other instances, participation in cancer screening programs may be hampered by another unspoken taboo—the reluctance to “look for illness” when one is healthy. These cultural and personal perceptions of cancer often delay detection and slow adoption of strategies to prevent cancer.

To date, much of what is known about American Indians’ cultural beliefs about cancer has been anecdotal. For example, Bea Medicine, an anthropologist, has said that her tribe, the Sioux, view cancer as a “White man’s disease,” and therefore, cancer is viewed as a disease that has been inflicted on the Indian people by the Europeans (B. Medicine, personal communication, August 1990). Ellen Jackson, a Navajo nurse, states that to many of her tribal members, cancer is viewed as a fatal disease, and as a result, cancer patients and their families may not seek treatment or other interventions after diagnosis (E. Jackson, personal communication, December 1991). Ursula Wilson, a Navajo nurse practitioner and educator, has surmised that the fatalistic attitude toward cancer by the Navajos has influenced tribal health care priorities; that is, tribal health leaders fail to give priority to cancer prevention because they do not believe that “something can be done” about cancer (U. Wilson, personal communication, December 1991).

Most of the American Indian languages have no word for cancer, and translations may contribute to misunderstanding about the disease. For example, among the Navajos, cancer is referred to as “a sore that does not heal.” Focusing on only one of the symptoms of cancer sets the stage for a fatalistic prognosis. Also, because most cancers are not visible to the eye, the pathological process of cancer is not always comprehended and tends to fuel the fear of cancer. Not knowing or understanding what cancer does to the body can make understanding cancer treatment and cancer prevention a problem (Joe et al., 1992).

In addition to the poor understanding about the etiology and course of cancer, tribal members see that most members of their community who are diagnosed with cancer die. This observation perpetuates a fatalistic attitude. There is little awareness of contributing causes, such as late detection. Because cancer is a taboo subject in many American Indian communities, cancer survivors are not visible. The perceived absence of cancer survivors and fatalistic attitudes about cancer prevent the development of

much-needed support groups for cancer patients and their families, and of opportunities for cancer survivors to provide support and encouragement to persons newly diagnosed with cancer. Only in the late 1990s have some female American Indian cancer survivors become visible and begun vigorous education and anti-cancer advocacy for women in their tribes and communities.

PRIMARY AND SECONDARY PREVENTION PROJECTS

In recent years, cancer prevention research projects have been conducted with American Indian populations (Hampton et al., 1996). In particular, four of these focused on smoking cessation, and two targeted cervical cancer (Burhansstipanov, 1992; Glover and Hodge, 1999). Others involving youth have had a special focus on both tobacco use and diet (Glover and Hodge, 1999). All of these interventions involved working with existing tribal and reservation structures, and usually included Native staff and/or organizations (Hodge and Glover, 1999; LeMaster and Connell, 1994). Although the intervention strategies used a number of different theoretical models, they consistently emphasized cultural relevance—for example, having tribal members as part of the research team and using familiar tribal icons in the message or design of education materials.

Smoking Policies and Smoking Cessation

An intervention program working with Northwest Indian Tribes was developed to enhance tobacco control policies. The program included consultation interventions with tribal representatives, including a kick-off workshop, tobacco policy workbooks, follow-up visits, and telephone consultations (Lichtenstein and Lopez, 1999). The Indian Health Board was integral to the policy change approach, and it respected and focused on the political independence of the tribes. As a result of this endeavor, several tribes developed smoke-free workplaces and curtailed the sale of cigarettes in their communities. Based on qualitative findings, there were significant improvements in tobacco use policies as a result of this project (Lichtenstein and Lopez, 1999).

Hodge and Casken (1999) conducted a clinic-based intervention study designed to help American Indian adults in urban and rural communities in California to quit smoking. Using the physicians' "Quit for Life" smoking cessation model, the team modified some aspects of the intervention so that it could be more culturally relevant for use in this Indian population. The model included an Indian culture-oriented teaching guide and a video, in addition to follow-up and counseling by community health workers (trained paraprofessionals). It emphasized responsibility to family and tribe, and cultural respect for tobacco products. The evaluation showed that the cessation program was more effective than a "standard care" control, and that it achieved an overall 6.8 percent quit rate, with a higher rate of 7.2 percent in those who

were contemplating quitting before the cessation program was offered (Hodge and Casken, 1999).

Cervical Cancer Screening

Three intervention projects addressed prevention and treatment of cervical cancer in American Indian women. The American Indian Health Care Association developed a computer program to track cervical screening for women utilizing urban Indian clinics. This project targeted 9,333 women aged 15 and older from eight major metropolitan areas, and it included an assessment of cancer prevention knowledge, attitudes, and behavior.

The American Indian Women's Talking Circle project was a culturally appropriate intervention developed to promote cervical cancer screening among American Indian women in California. The format used traditional Indian stories as a vehicle for improved cancer education and screening. Preliminary results showed favorable responses to the culturally framed education project (Hodge et al., 1996).

In North Carolina, an intervention aimed to enhance cervical cancer screening and follow-up among Cherokee and Lumbee Indian women. The project developed culturally relevant education for these women that incorporated tribal beliefs about health, and various health education materials were developed to increase awareness of cancer prevention. Women from both tribes provided consultation, and some participated as members of the research team. The intervention used a lay health advisor who provided one-on-one education in homes, including verbal, print, and videotaped information (Bell et al., 1999). The intervention was effective in increasing knowledge and receipt of Pap tests in the group of Cherokee women (Dignan et al., 1996), as well as among the Lumbee women (Dignan et al., 1998). Among the Lumbee women, those who had had an annual physical exam were most likely to receive Pap tests (Dignan et al., 1998). Overall, the lay health advisor approach was successful, and there were both supports and barriers that were cultural and logistical (Messer et al., 1999).

Youth Interventions

The Pathways to Health program was conducted with over 500 American Indian children in grades 5 and 6 in New Mexico. The intent of the study was to prevent tobacco and smokeless tobacco use among the children and to develop an intervention strategy that would improve their nutrition. This intervention was a culturally relevant program that incorporated traditional values and lessons. The curriculum was compared with a family-supplemented intervention and with a control group. The early findings showed wide acceptance and use of the curriculum, and favorable changes in tobacco use and attitudes (Davis et al., 1999). Nutrition results are forthcoming.

Another youth intervention addressed tobacco use prevention and dietary modification among Indian youth from selected Northeastern tribes (Schinke et al., 1999). The program was carried out in collaboration with American Indian agencies, and promoted traditional dietary habits and an understanding of ceremonial tobacco use. Observing the connection between low self-esteem and smoking, the model utilized a social learning and skills intervention. The intervention sought to help the adolescents develop competency in problem solving, coping, and communication, and to improve their self-esteem. The findings suggested that knowledge and awareness were increased with the intervention, and that the combined diet plus tobacco prevention intervention seemed most effective in reducing smoking and promoting healthy eating (Schinke et al., 1999).

FUTURE DIRECTIONS

One of the principal goals of *Healthy People 2010* is to reduce health disparities among various groups of Americans (USDHHS, 2000). Recent studies in cancer prevention and intervention are some of the first systematic applied research studies to be conducted among American Indians. They hold great promise, not only for providing greater understanding about culturally sensitive approaches to the prevention and treatment of cancer, but also for providing vital baseline information on sociocultural perceptions of cancer and the factors affecting cancer incidence and mortality in Indian communities. Efforts such as these should help to delineate factors that contribute to disparities in cancer mortality, as well as provide information that will fill some of the major data gaps.

Recently, NCI and the Centers for Disease Control and Prevention began special initiatives to address breast and cervical cancer prevention in American Indian women. These initiatives can provide valuable information on cancer patterns among Indian women in more locations and in larger numbers, and will increase awareness of further research needs. In addition, these initiatives strengthen the new Cancer Control and Prevention Program established by IHS.

Various epidemiological data, including SEER and IHS data, indicate that there are substantial variations in cancer sites and cancer rates among American Indians, and that incidence and mortality rates for several cancer sites exceed the rates for the general population. While their cancer incidence and mortality rates are lower than the overall U.S. population, the 5-year cancer survival rates for some cancers remains lower than for the general population. The rates of decrease in incidence and mortality for most cancers are slower for American Indian women than for White women in the United States.

Data sources regarding cancer among American Indian women are limited and are often difficult to interpret because they combine diverse groups into overall figures. Therefore, more studies on cancer among American Indian women are needed to complete the picture. It would be extremely helpful to have national data sources, such as tumor registries, collect and maintain information that allows for key urban/rural and cross-tribal comparisons. Such information could support programs as well as research projects seeking to learn what kinds of cancer control models work best for this population.

Also essential to improving the current situations in terms of American Indian women and cancer: funding and services within IHS to better address early detection and treatment of cancers in this population. There also is a need for resources and efforts toward increasing the number of American Indian health professionals and cancer prevention and control researchers. Other research topics that require further exploration include the impact of cancer treatment and survival on American Indian women and their families.

CONCLUSION

Despite varying degrees of acculturation, cancer is still a taboo subject in many American Indian communities. Cancer prevention efforts, such as cancer screening, are hampered by misinformation and fear, as well as the lack of medical and other early detection resources in many rural Indian communities.

Although deaths caused by cancer are well remembered in most American Indian communities, cancer survivors are not visible. These and other sociocultural constraints affect the ability of Indian communities to embark on aggressive cancer prevention and control programs. Such endeavors will require substantial and active participation and support from the Indian communities if they are to be successful.