AMERICAN INDIAN CULTURE AND RESEARCH JOURNAL 13:3 & 4 (1989) 21-31

AIDS—Tribal Nations Face the Newest Communicable Disease: An Aberdeen Area Perspective

BETTY J. CLAYMORE and MARIAN A. TAYLOR

> The uniqueness of man comes from the fact that he does not live only in the present; he still carries the past in his body and in his mind, and he is concerned with the future. To be really relevant to the human condition, the concept of adaptability must incorporate not only the needs of the present, but also the limitations imposed by the past, and the anticipations of the future.
>
> René Dubos, *Man Adapting*, 1965

Until the arrival of foreigners on the shores of the "new continent," it appears that Indians were relatively free of infectious diseases, with the exception of tuberculosis. This situation left bands and tribes without any acquired immunity, and they fell appallingly easy victims to diseases brought in by outsiders.[1] Unfortunately, there is a paucity of detailed information available concerning American Indians and Alaska Natives, and the importation of diseases that decimated or annihilated whole populations and tribes.

Betty J. Claymore, Ph.D., is Area Mental Health Consultant for the Nashville Area Office of Indian Health Service, Nashville, Tennessee. Marian A. Taylor, MSW, is a retired Area Social Work Consultant for the Aberdeen Area Bureau of Indian Affairs. She is of Sac and Fox ancestry.

BRIEF HISTORIES OF PAST DISEASES AND THEIR IMPACT UPON INDIAN AMERICANS (UNITED STATES)

Smallpox

Smallpox, syphilis, gonorrhea, and other infectious diseases were brought to Indians by the adventurers, explorers, and colonists who came to the shores of the New World. Around Newfoundland, Indians were quickly decimated by diseases brought to them by sailors plying the lucrative cod harvests.[2] Smallpox, one of the earliest and deadliest diseases, first came to the islands called Hispaniola in 1518 and within a few years had reached the Aztecs and Incas to the south, ruining two mighty civilizations.

On the northeastern coast of the United States, the colonists brought their diseases to resident tribes. By 1730, the Cherokees had suffered a loss of fully half their members from smallpox.[3] As the colonists pushed ever inland with their own brand of "civilization," it became apparent that disease, rather than fighting, weakened the Indians, leaving them unable to defend their territories or care for their people. Smallpox broke out in Indian populations approximately every 20 years.

By 1837, with the arrival of the American Fur Company, smallpox attacked the Plains tribes and those on the upper Missouri, diminishing the Mandan population from 1,600 to 31. The Plains tribes, including the Sioux, were said to have lost 10,000 in just a few weeks; the Assiniboines lost whole villages; the Crows lost one-third of their population.[4] The Blackfeet fled to the mountains to avoid smallpox, but still suffered many deaths that year and again in an outbreak in 1870.[5] It is said that when the late summer epidemic had run its course, 17,000 Indians had perished along the upper Missouri Valley.[6]

In 1839–1840, the Kiowas suffered a similar epidemic.[7] A form of vaccination for smallpox was developed in 1799 and authorized by Congress for large-scale vaccination of Indians in 1832,[8] but it took many more years to reach Indian tribes in great numbers and to prevent the spread of disease.[9]

Cholera

Cholera (AKA Asiatic cholera), a gastrointestinal disease, was responsible for a grim winter count in 1849 among the Oglala

Sioux. The disease lingered among the western Sioux for over a year and then was followed by epidemics of smallpox and measles, severely weakening the population and increasing hostility toward white settlers. Cholera is believed to have been brought up the Missouri River by settlers moving westward in search of new lands and gold, and it was spread to the Indians along the Platte River.[10]

Tuberculosis

Rapid social change, stress and anxiety were some of the contributing factors to a tuberculosis epidemic among the laboring classes of the continental United States during the nation's early history. This disease spread among the Indians as they came into contact with the Europeans.

Estimates of Indian population in pre-Columbian times have been studied and formulated by hypotheses, but vary widely, from 8,500,000 to 90,000,000 people in the Americas.[11] In *A History of Indian Policy*, Tyler uses a figure of 1,000,000 Indians in what is now the United States, excluding Alaska.[12] After contact with Europeans, the Indian population rapidly declined as a result of wars, famine, loss of homes and lands, and epidemic diseases. Tuberculosis was a major factor in the decline of the Indian population to a nadir of 250,000 by 1890.[13] With the settlement of Indians upon reservations and the advent of better health care, the population of American Indians has increased to approximately 1,000,000, according to the United States Department of Health, Education, and Welfare (1978).[14]

Paleopathological evidence has demonstrated that there was tuberculosis in the Americas in pre-Columbian times, but increased incidence of illness and death from tuberculosis was attributed to growing contact with non-Indian populations during the last century. Because Indians suffered inadequate food, poor living conditions, poor housing, and cultural disintegration when forced from nomadic life to reservations, they were most vulnerable to the disease. By 1931, Canadian Indians had a tuberculosis death rate of 547 per 100,000.[15] When national tuberculosis reporting in the United States began in 1953, it was found that Native Americans and other minorities accounted for disproportionate numbers of the cases. In 1985, the tuberculosis rate for American Indians and Alaska Natives was 4.4 times the rate for

the white population.[16] This disease still lingers in pocket areas. Although for a while it appeared almost eradicated through improved living conditions, modern drugs, and health education, it increased again in 1986, with 62 percent of all reported cases occurring among racial and ethnic minorities.[17] Aberdeen (South Dakota) Area Reservation Indians comprised 28.6 percent (30 cases) of the 106 area cases.[18]

According to the National Center for Disease Control, Atlanta, Georgia, there is evidence that an individual who has a positive skin test for tuberculosis and also an HIV infection has an increased risk for full-blown tuberculosis. The reasoning is that the immunosuppression resulting from the HIV infection may allow latent tuberculosis infection to progress.[19]

Other Diseases

In 1917–1918, the influenza epidemic that killed one-half million Americans caused many deaths on Indian reservations. Poliomyelitis, a more recent disease, killed 22,000 Americans out of 400,000 who were infected between 1943 and 1956. The impact of these diseases on new populations was tragic. Polio, striking the Eskimo population at Hudson Bay in 1948, killed 14 percent of the population and left over 40 percent with paralytic disease. In 1952, over 99 percent of the Eskimo population of Ungava Bay was affected by measles, with a 7 percent mortality rate.[20] Through constant intensive immunizations, education, and follow-up, childhood diseases such as polio, measles, rubella, and mumps are now better controlled.

AIDS

AIDS, first diagnosed in 1981, empirically named Acquired Immune Deficiency Syndrome by the Center for Disease Control (CDC) in 1982, is the newest communicable disease to threaten the well-being of Native Americans. This deadly disease has spread globally, with 125 countries reporting cases to the World Health Organization by December 1987. As of April 1988, the CDC advised that there have been 59,287 AIDS cases in the United States, with 33,060 deaths already recorded. It is predicted

that by 1991 there will be more than 270,000 cases of AIDS, with a death toll of 179,000.[21]

AIDS/HIV Cause and Symptoms

AIDS is caused by a tiny human T-cell lymphotropic retrovirus that defied international efforts at detection for several years. By attacking the T-cells, the AIDS virus allows opportunistic infections to invade the body. HIV (human immunodeficiency virus), the causative agent of AIDS, is estimated currently to infect 1.5 million Americans, who continue to be capable of infecting others.

Early AIDS-related complex (ARC) symptoms experienced by patients may include extreme fatigue, fever and night sweats, rapid and unexplained weight loss, enlarged lymph glands in the neck, armpits, and groin, and chronic diarrhea. With the weakening of the body's defense system, virulent death-dealing diseases such as pneumocystis carinii and Kaposi's sarcoma may develop. Other deterioration may include loss of concentration, reduced thinking ability, deteriorating eyesight, and failing muscular ability. The definition of AIDS was expanded in 1987 to include cases of emaciation, tuberculosis, dementia, and other problems of patients whose physicians presumed they had AIDS, but whose symptoms did not fit classic definitions. Drugs that might ordinarily be expected to help patients with AIDS symptoms do not work, and although many new drugs, such as AZT, are being tested to assist the body's immune system, there is still no known cure for AIDS.[22]

AIDS Transmission

Transmission of the disease in the United States was first noted to be associated with homosexual behaviors primarily in the gay communities of San Francisco and New York. One man, Gaeton Dugas, called "patient zero" by the CDC, was believed solely responsible for some 40 of the first AIDS cases in the United States.[23] AIDS was next linked to IV drug usage and sharing of needles. Eventually, AIDS became linked to blood transfusions and to treatment of hemophilia with infected blood products.

Anxiety is growing among the general public as additional

cases surface in heterosexuals who apparently acquired the disease through sexual contact with bisexuals, and in fetuses or babies to whom AIDS was transmitted by infected mothers. While spread of the virus is commonly by either anal or vaginal intercourse, or by the introduction of infected blood or blood products into the bloodstream, there continues to be public concern regarding the possibilities of exchange through other body fluids. Some cases recorded by the CDC have undetermined risk factors related to transmission. Regional complacency has been shaken by the recent discovery of a 1969 AIDS victim from St. Louis who claimed he had never left the Midwest.[24] In December 1987, a new strain of AIDS virus called HIV-2 was reported on the East Coast. Although new to the United States, this virus is endemic to West Africa.[25]

Native American Incidence

By June 1988, 65 cases of AIDS were reported among Indians in the United States. Seventy-three percent of the cases have been diagnosed since January 1986. The majority of these cases were diagnosed with pneumocystis carinii pneumonia. The average age of victims was 33.6, and they were predominantly male. There were 4 cases of children under thirteen years of age. Of the 59 adult cases, 53 percent (31 cases) were homosexual/bisexual; 17 percent (10 cases) were heterosexual/IV users; 15 percent (9 cases) were homosexual/bisexual/IV users; 5 percent (3 cases) were hemophiliacs; 3 percent (2 cases) were heterosexual partners of high risk individuals; 2 percent (1 case) were the result of blood transfusion, and 5 percent (3 cases) were undetermined. The 4 children acquired the disease either perinatally or from contaminated blood components.

Current rates of AIDS cases among Native Americans are at 43.3 per million, a lower rate than for other minority populations.[26] The CDC has estimated that out of 2,000 Native Americans who would test positive nationally, there would be 25 cases among the Aberdeen Area Native American population served by the Indian Health Service.[27] This four-state area encompasses reservations located within North Dakota, South Dakota, Nebraska, and Iowa, and includes 79,964 Native Americans. General population cases reported by states as of June 1988 include

62 cases for Nebraska, 9 cases for South Dakota, 7 cases for North Dakota, and 76 cases reported by Iowa. Two cases have been specified as Native American.

The incidence of AIDS among Native Americans and non-Indians living in the Midwest is low compared to other parts of the country, but this figure probably will increase rapidly with the geographic mobility of the population. Also, some researchers believe that the cases of HIV infection may be underreported.

Native American Risk Factors

Native American populations are young, with a median age of 18. The sexually active young people living on the seventeen reservations within the Aberdeen Area and those who reside in off-reservation urban communities may find it difficult to receive adequate medical care. Resources may be limited for dealing with AIDS or HIV through an already strained-to-the-limit Indian Health Service, where other diseases and illnesses are prioritized. Limitations on medical staff and budget, coupled with lack of community support and understanding of the disease itself, may possibly contribute to the spread of AIDS. According to CDC researchers, the social behavior common in some Indian communities—where high unemployment, lack of individual goals, and low self-esteem may lead to alcoholism, drugs, multiple sexual partners, and social diseases—can result in a higher risk of developing AIDS. A general population study in North Dakota found that 71.5 percent of the population surveyed did not use "safe sex" protection such as condoms.[28] In 1986, American Indians accounted for 35 percent (121) of the cases of gonorrhea reported in North Dakota. In the same year in South Dakota, Native Americans had 41 percent (331) of reported gonorrhea cases and 61 percent (812) of the chlamydia cases.[29] While there is low intravenous drug usage among Indians, and homosexuality is generally still "closeted," public health officials are concerned about bisexual behaviors that could facilitate transmission.

HIV positive individuals are at risk from something other than AIDS: positive tests have been shown to be related to suicides.[30] The Aberdeen Area already ranks third among twelve IHS areas in suicidal behavior. In addition, there are concerns about the

high rate of AIDS-related tuberculosis among Indians, since tuberculosis mortality increases have been linked to AIDS in Florida, New York City, and Newark, New Jersey.[31]

The Urgency of AIDS Education

Health education directed towards reducing risk behaviors among tribal peoples may prevent many cases of AIDS among American Indians and Alaska Natives. But time is running out. It is estimated that victims may carry HIV for as long as nine years before developing AIDS, so that many more Native Americans may be transmitting the disease unknowingly to other members of their tribe. (Gay American Indians were part of the "coming out" movement and marched in the 1980 San Francisco Gay Freedom Day Parade.)[32]

To maintain contact with family and culture, many urban Indians return to the reservation annually for their tribal celebrations and ceremonies. For the Plains Indian, this may include participation in a Sun Dance. The Sun Dance, directed by tribal medicine men, is a spiritual ceremony consisting of a number of days of fasting and dancing, during which a participant will demonstrate his ability to endure pain and suffering. Total concentration of mind, body, and soul is required as the dancer seeks purification and healing and becomes spiritually aligned with the earth, the sky, and all nature around him.[33]

Native Americans often use both modern medicine and native medicine. It is customary for them to return to ways of spirituality for healing purposes.[34] Unfortunately, the piercing of the flesh and insertion of skewers as part of the healing ritual of the Sun Dance can be a danger if disposable or sterilized knives are not used by the medicine man after each cutting. Plains Indians also travel frequently to other tribes to participate in healing and cultural activities. Suspected HIV-infected individuals have participated in piercing related to tribal Sun Dance ceremonies within the area, causing great consternation among the other participants.

Native American AIDS victims have returned home to their reservations to die. Tribal police and health care providers have already experienced conflict with some HIV-infected patients. These patients, who feel rejected and victimized, lashed out towards those public servants who were responsible for serving

them. Local health care providers, 75 percent of whom are also Native Americans,[35] have expressed a need for more information about protecting themselves from transmission when handling AIDS patients.

Preliminary findings from an AIDS attitude and information survey administered to 500 Native American students at tribally controlled, reservation-based community colleges indicate that most students are currently in the beginning stage of forming attitudes about AIDS. Tribal attitudes, or "groupthink," have not yet solidified. Students strongly respond that AIDS education should be provided in public schools, but they appear only moderately concerned that AIDS will affect their lives. They are generally aware of those basic ways in which AIDS is transmitted, but tend also to believe it is transmitted by toilet seats, drinking fountains, and saliva.

Implications for health education are that students are willing to be educated about AIDS and are open to new information. They are not alarmists and could best be described as curious. One might expect that as their involvement with AIDS victims becomes more personal, moving from a national and state level to a tribal, friend and relative level, their personal anxiety and concerns will increase. Therefore, now is a good time to present material to them that can be accepted in an objective manner.

Other Tribal Implications

Legal and ethical issues are beginning to face tribes as HIV-positive and AIDS cases slowly become known. Tribal responses have varied from sending infected tribal members back to their previous urban residences, to demonstrations of great empathy and assistance to the terminally ill. Concerned members have been heard to say ominously that "something will happen to people who come back and infect others."

Tribal resolutions have been proposed and policies established relating to AIDS testing. It is important for tribes to search within their own values for the answers to the complex issues raised by AIDS. Confidentiality and individual rights may have to be moderated in the tribal context. There is increasing need for tribes to develop their own ethics committees to study and define their positions.

CONCLUSION

History has shown that Native Americans were ill prepared for and consequently suffered severe losses from previous epidemics. Despite the current low incidence rates of HIV infection among reservation populations, there are many factors which will make this population especially vulnerable once they are exposed. We feel it is inevitable that the disease will continue its spread to Indian country. Tribal governments, with their traditional beliefs, and public health agencies, with modern medical technology, must work in harmony to educate those they mutually serve. New health education information must be adjusted to old frames of reference. Native Americans must respond not from a sense of fear, but from love of family and tribal community, in addressing and preventing the spread of AIDS, the newest communicable disease to threaten mankind.[36]

NOTES

1. René Dubos, *Man Adapting* (London/New Haven: Yale University Press, 1965), 172-73.
2. Ruth M. Underhill, *Red Man's America* (Chicago: University of Chicago Press, 1953), 71-72.
3. Peter H. Wood, "The Impact of Smallpox on the Native Population of the Eighteenth Century South," *The New York State Journal of Medicine* (January 1987), 35-36.
4. Dubos, *Man Adapting*, 172-73.
5. Kit Carson, *Kit Carson's Autobiography*, ed. M. M. Quaife (Chicago: Lakeside Press, 1935), 48-49, 162.
6. Bruce Nelson, *Land of the Dacotahs*, 2nd ed. (Lincoln, NE: University of Nebraska Press, 1946), 108-109. (Smallpox is described as starting from the American Fur Company's steamboat penetrating the upper Missouri with several cases of smallpox on board, and a fort commander who then attempted to vaccinate Indians. The disease spread to many tribes, with deadly results.)
7. David Lavender, *Bent's Fort*, 2nd ed. (Lincoln, NE: University of Nebraska Press, 1954), 147-48.
8. Wood, *The Impact of Smallpox*, 30-36.
9. *Ibid.*
10. G. E. Hyde, *Red Cloud's Folk*, 2nd ed. (Norman, OK: University of Oklahoma Press, 1937), 63-64.
11. H. F. Dobyns and H. P. Thompson, et al., "Estimating Aboriginal American Population," *Current Anthropology* (1966), 395-449.
12. S. Lyman Tyler, *A History of Indian Policy* (Washington, D.C.: Government Printing Office, 1973), 18.
13. Dubos, *Man Adapting*, 172-73.

14. Alan Parker, Jerry Flute, Michael Cox and Patricia Zell, *Report on Tribal Government Task Force 2* (Washington, D.C.: U.S. Government Printing Office, 1976), Appendix XVII.

15. Don Jenkins, "Tuberculosis: The Native Viewpoint on Its Prevention, Diagnosis, and Treatment" (Unpublished paper, University of British Columbia, Vancouver, B.C., 1977), 543-55.

16. Massachusetts Medical Society, "Tuberculosis Among American Indians and Alaska Natives—United States," *Morbidity and Mortality Weekly Report* 36:30 (7 August 1987):494-95.

17. Center for Disease Control, Division of Tuberculosis Control, "Tuberculosis as Related to AIDS and HIV Infection Among Minorities" (Paper presented at National Conference on AIDS in Minority Populations in the United States, Atlanta, GA, 1987), 1-4.

18. Aberdeen Area Epidemiology Program, Indian Health Service, "Tuberculosis Morbidity Rates" (Report, 1986).

19. Center for Disease Control, "Tuberculosis as Related to AIDS," 1-4.

20. Dubos, *Man Adapting*, 174.

21. National Academy of Sciences, Institute of Medicine, *Confronting AIDS, Directions for Public Health, Health Care, and Research* (Washington, D.C.: National Academy Press, 1986), 8.

22. National Academy of Sciences, *Confronting AIDS*, 5-8.

23. Randy Shilts, *And the Band Played On* (New York: St. Marten's Press, 1987), 21-23, 146-47, 439.

24. "AIDS Virus Believed Present in 1969 Victim," *Omaha World Herald*, 25 October 1987.

25. Massachusetts Medical Society, "AIDS Due to HIV-2 Infection—New Jersey," *Morbidity and Mortality Weekly Report* 37:3 (29 January 1988):34-35.

26. P. E. Johannes, conversation and raw data, Center for Disease Control, AIDS Program, 22 June 1988.

27. R. Follas, oral presentation by public health advisor, to Indian Health Service Unit Directors' Meeting, Rapid City, SD, 20-21 October 1987.

28. North Dakota State Department of Health, Division of Disease Control, "Report: North Dakota Public Knowledge, Opinion and Behavior Survey on AIDS" (Bismarck, ND, September 1987).

29. T. Welty and R. Follas, letter from Area Office of Epidemiology to Director, Black Hills Training Center, Rapid City, SD, 6 July 1987.

30. C. Pierce, "Suicides Underscore Urgency of HIV Test Counseling," *Clinical Psychiatry News* 15(10): 1, 29.

31. Center for Disease Control, "Tuberculosis as Related to AIDS," 1-4.

32. Shilts, *And the Band Played On*, 14.

33. R. and G. Laubin, *Indian Dances of North America* (Norman: University of Oklahoma Press, 1977).

34. M. Primeaux, "Caring for the American Indian Patient," *American Journal of Nursing* 77(1): 91-94.

35. J. Weber, Aberdeen Area Indian Health Service, EEO raw data regarding service unit staff.

36. Aarow Sciences Division of Mandex, "Profile of the Community-based Diffusion Model for Transferring Health Information, and Innovations to Culturally Diverse Communities" (Report prepared under National Institute of Health Contract NO1 + D-2-7003, Bethesda, MD, 1980-1983).