The Epidemiology of HIV/AIDS in Aboriginal¹ Communities: An Anthropological Perspective

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Abstract: Historically, Aboriginal people have been dramatically affected by epidemics of infectious disease. Today, levels of morbidity and mortality from such illnesses are much higher than in the broader Canadian population. This paper presents an anthropological investigation into the factors which put Aboriginal people and their communities at risk for the AIDS epidemic, and explores some of the many approaches Aboriginal people have chosen to respond to this crisis.

Introduction

At a time of staggering biomedical advances, with most Canadians enjoying the benefits of a sophisticated health care system, statistics indicate high levels of illness such as infectious disease, injuries, substance abuse and mental health disorders in First Nations communities.

Loss of Aboriginal identity, language and nurturing ways are some of the multiple, multi-generational losses which have contributed to erosion of Aboriginal self-reliance and collective responsibility for health. These losses are results of the assimilation policies and practices, removal of children through residential schools and adoptions, and the implementation of the *Indian Act*. It is also acknowledged that inequities in education, employment, incarceration, housing and infrastructure have had a negative impact on Aboriginal health. (*Ontario 1994:2*)

The preceding quote from the New Directions. Aboriginal Health Policy of Ontario (1994) provides us with a glimpse of the complex interaction of social, economic and political factors which have contributed to the poor health status of Aboriginal people in Canada today. Although Aboriginal people are diverse and local circumstances differ within each of their communities, it is evident that a deeper understanding of Aboriginal health and its improvement can only be attained through an awareness of the historical context of colonialization which has led to the current health conditions. At the same time, it is important not to perpetuate an image of Aboriginal people as passive victims of oppression, but rather to acknowledge their active response to colonial situations (Waldram et al. 1995:270).

Historically, Aboriginal people suffered dramatically from epidemics of infectious disease, such as measles, influenza and tuberculosis. Important contributing factors have been the social circumstances surrounding the encounter with infectious agents (Waldram *et al.* 1995:43-64). Statistics consistently show

that many Aboriginal people are socio-economically disadvantaged, and that high rates of unemployment, inadequate housing and poor sanitation are common in many communities. Considering the effect of past epidemics and the fact that the emerging AIDS population in the 1990s are people of poor health and low socio-economic status (Wortman 1992:5), a pressing need arises to research what the effect of the AIDS epidemic may be for Aboriginal peoples.

Recognition of AIDS within the Biomedical Community

Soon after the identification of the acquired immune deficiency syndrome (AIDS) as a clinical syndrome by the United States Centres for Disease Control in June 1981, AIDS was recognised as an infectious disease with global public health risks. The pandemic proportions of the disease became apparent as further cases were diagnosed almost simultaneously in Europe, Central Africa and the Caribbean. The first case of AIDS in Canada was reported in 1982 (Canada 1995:9).

During the following years, the Human Immunodeficiency Virus (HIV) was isolated and HIV antibody tests were developed. The conviction that AIDS could be contained and a vaccine developed was held in the medical community as late as 1984 (Feldman 1986:37). This optimism reflected the attitude of complacency towards infectious diseases held by the biomedical community of the developed world in an era when molecular biology and anti-microbial agents represented a potential for cure.

The understanding of AIDS has now shifted towards an awareness of the chronic and progressive nature of this disease and its life-threatening consequences. The HIV disease primarily results in the dysfunction of the immune and nervous systems. The symptomatic period of the disease occurs in the later stages of HIV infection. AIDS is diagnosed in an HIV positive individual when an AIDS-defining secondary infection, cancer, or illness occurs.

Without a biomedical cure or vaccine on the horizon and considering the moderate capacity for success in the treatment and management of the disease at this point in time, a special need has arisen for contributions to HIV/AIDS research by social scientists. It is necessary to focus attention on studies concerning appropriate health care delivery, culture-bound variances in HIV epidemiology, as well as sociocultural responses to the HIV/AIDS epidemic.

The Anthropology of AIDS

An anthropological approach to the understanding of AIDS is particularly important as it has the potential to play an important role in alleviating human suffering. Three basic areas of HIV/AIDS research which require anthropological investigation have emerged (Feldman, 1986:38; Gorman 1986:31-32). First, an anthropological approach is essential for discovering the cross-cultural variability in patterns of transmission and prevalence of HIV/AIDS, in order to gain insight into the social epidemiology of this disease. Studies in this field are not limited to identifying behaviours of members of high risk subcultures, such as IV drug users or homosexual men. Rather, research must be aimed at the identification of potential

groups in danger of engaging in high risk behaviour. Second, analyses of the sociocultural impact of HIV/AIDS fall within the realm of medical anthropology and include the study of cultural change in high risk and mainstream populations in response to the disease. Lastly, applied anthropological research is needed for the development and delivery of culturally appropriate prevention programs and health care. In practice these areas very much overlap; the common thread that ties them together is the attempt to approach research in health and disease in a holistic manner.

This paper represents an anthropological investigation into the factors which put Aboriginal peoples and their communities in Canada at risk in the AIDS epidemic. Various aspects of the above-mentioned anthropological approaches to HIV/AIDS research within this context will be explored and discussed.

Infectious Disease and Aboriginal People in Canada

Current research shows that there is no single, simple explanation to account for the patterns of disease and illness among Aboriginal people in Canada. Health problems experienced by Aboriginal people today are inextricably linked to the historical process of colonialization which has resulted in the marginalization and economic underdevelopment of their communities (Warry 1990:207). The current health status of Aboriginal people can only be understood within the broader context of the complex interweaving of health with socio-economic and political conditions, as well as historical and local circumstances (Waldram *et al.* 1995:269).

Extensive documentation (Muir 1991; Warry 1991; Waldram et al. 1995) shows that the incidence of infectious disease in Aboriginal communities is extremely high compared with the Canadian national average, and closely associated with conditions of poverty. Immunization programs and improved health care services have managed to narrow this gap and have resulted in a dramatic decline of infectious disease in the second half of this century (Young 1988:46-47), but Aboriginal people are still five times more likely to die from infectious diseases than the average Canadian (Young 1988:51). Although non-infectious health problems such as heart disease, diabetes, and trauma are currently emerging as significant causes of morbidity and mortality for Aboriginal people (Waldram et al. 1995:65), the future impact of infectious disease must not be underestimated, especially in light of the current AIDS pandemic. Since HIV compromises the immune system and infected individuals are highly susceptible to secondary infections, high levels of infectious diseases on reserves not only pose a significant health risk for people living with HIV/AIDS (PHAs), but some diseases may facilitate the transmisson of HIV or act as co-factors.

The most consequential infectious diseases of high prevalence among Aboriginal people are tuberculosis and sexually transmitted diseases. In some Aboriginal communities the incidence of tuberculosis has been reported to be as high as ten times the national average (Waldram *et al.* 1995:77). Since people infected with HIV become highly susceptible to clinical tuberculosis and the number of patients with dual infection are rising (Canada 1995:14), there is the added high risk of dual infection with

HIV and tuberculosis spreading rapidly in these communities once HIV is introduced (Canada 1995:14).

Sexually transmitted diseases (STDs) have been established as an important co-factor in the transmission of HIV for several reasons. A high incidence of STDs are a sign of the prevalence of high risk sexual behaviour, which increases the chance of exposure to the virus. STDs also weaken the immune system resulting in a higher risk of infection should exposure to HIV occur. Skin disruptions, caused by genital sores or ulcerations associated with STDs can significantly enhance transmission of the virus by acting as a susceptible point of entry (Piot *et al.* 1988;575).

Some cause for concern is signalled by the fact that the rate of STDs in Aboriginal communities is estimated to be four times higher than the Canadian average and, in parts of northern Ontario, the rates are even higher. The incidence of gonorrhea in the Sioux Lookout Zone, for example, is reported to be ten times the national average (Ontario 1995:15). Once HIV is introduced into a community with a high rate of STDs, there is the danger of relatively rapid spread, since the transmission of HIV is enhanced and unsafe sexual practices are more firmly established.

HIV/AIDS in Aboriginal Communities

Comprehensive seroprevalence studies of HIV have not been undertaken in Aboriginal populations and, prior to 1988, the ethnicity of tested individuals was not recorded by physicians. The Laboratory Centre for Disease Control reported 9511 cases of AIDS in Canada as of April 1994 (Canada 1994). According to these statistics, 97 cases were reported among Aboriginal people, accounting for 1.1 percent of the total cases, whereas as of October 1991, only 33 cases were reported among Aboriginal peoples, representing 0.6 percent of all AIDS cases in Canada.

When considering the statistical percentage of Aboriginal people who are infected with HIV, it may initially appear that they represent a low risk group, since only four percent of the Canadian population consider themselves to be of Aboriginal ancestry. But statistics on HIV/AIDS are obscured by several factors, in particular the fact that ethnicity is recorded by self-identification. Many indicators also suggest that cases of HIV/AIDS among Aboriginal people are severely underreported (Canada 1994:2), in part due to a general feeling of distrust toward medical practitioners. According to the Centre for Disease Control, reported cases of Aboriginal people with AIDS doubled from 1990 to 1991 and tripled by 1993. These figures represent an increase of reported HIV/AIDS cases which is on par with the rapid increase of this disease in the male homosexual community in the early 1980s (Ontario 1995:11). These facts lead AIDS workers and researchers to believe that the statistical estimates seriously underestimate the actual number of infected individuals.

It is evident that established reporting procedures fail to provide a clear picture of the epidemiology of HIV/AIDS in First Nations communities. In the most extensive study to date on AIDS and healthy lifestyles, Myers and co-workers (1993:61) estimate from their survey of eleven Ontario First Nations communities that 212 people living on-reserve in Ontario are infected with HIV, yet front-line health care workers estimate that a much larger number of Aboriginal people are infected.

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Risk Factors in Aboriginal Communities

Preliminary findings by Health and Welfare Canada (Canada 1990a) recognized that Aboriginal people may be at particular risk of HIV infection due to poor health status, high rates of STDs and reduced access to medical facilities and health care. Subsequent research identified further risk factors, which are of particular importance to Aboriginal people. A brief summary of these issues follows.

Aboriginal women represent 11 percent of the total reported Aboriginal AIDS cases, twice the Canadian average of incidence of AIDs in women (Waldram et al. 1995:80). According to a survey by the Ontario Native Women's Association, Aboriginal women are between five to eight times more likely to become victims of sexual assault compared with women within the Canadian population (Ontario 1995:15). HIV infection as a result of sexual violence is therefore a threat to Aboriginal women in particular. In addition, many Aboriginal women suffer from low self-esteem as a result of racism, abuse and poverty. This may translate into unassertive behaviour in sexual relations and sufficient individual disempowerment which may prevent women from insisting on the use of condoms during sexual intercourse (Ontario 1995:15).

Although research of the prevalence of HIV among urban Aboriginal people is presently lacking, evidence suggests that this population may be at an even greater risk than the rural or on-reserve population. Aboriginal youth moving from rural areas to urban centres may be at a particularly high risk, due to the overrepresentation of Aboriginal youth in inner cities and the high risk behaviour of prostitution and drug use associated with street-living (Holmes 1992:15). The Vancouver Sun reported that an estimated 70 percent of the youth involved in prostitution on the streets of Vancouver are Aboriginal children (Vancouver Sun October 24, 1988). A seroprevalence study of Vancouver street youth showed that Aboriginal youth had a 30 percent higher rate of infection than any other ethnic group (Rekart et al. 1990;. Myers et al. 1993). The high rate of mobility of significant proportions of Aboriginal people between urban centres and rural reserve communities represents an added risk to the population. High risk activities in cities can lead to HIV infection, which in turn may be later introduced into the small rural communities.

Due to the proportional overrepresentation of Aboriginal men and women in correctional facilities, HIV infection in prisons is of great concern. High risk activities, such as unsafe sexual practices and the sharing of needles for IV drug use and tattooing, are relatively common practices amongst inmates of correctional facilities. A recent study indicated that needle use was four times more common among Aboriginal inmates compared with the wider prison population (Ontario 1995:17). Voluntary HIV testing in Quebec institutions found that 4.7 percent of men and 7.2 percent of women tested positive. Although it is not possible to estimate the actual rate of HIV infection in prison populations from these statistics, they nevertheless point to the fact that it is a potentially serious problem for inmates. High rates of tuberculosis in prisons adds the threat of double infection with tuberculosis and HIV. A further consequence of incarceration is that released inmates may unknowingly introduce HIV into their home communities (Canada 1990b:43).

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These risk factors must not be perceived to be rooted within cultural differences of an 'ethnic' minority in a larger pluralistic society. Rather, they must be viewed against the backdrop of colonial processes and the consequent assimilation policies and practices that have resulted in the erosion of Aboriginal identity and self-esteem. In addition, social, economic and political inequities have resulted in unemployment and poverty among Aboriginal people. These social problems ultimately form the basis for most of the identified risk behaviour associated with HIV.

Attitudes and Beliefs about HIV/AIDS in Aboriginal Communities

Myers and co-workers found that knowledge about the transmission of HIV was generally high among members of the eleven Ontario First Nation communities that they surveyed (1993:60). Regional differences indicated that southern communities, which are located closer to the centre of the Ontario AIDS epidemic, are at an advantage in this respect. Despite the high level of awareness, 80 percent of all age groups continue to engage in unprotected sexual intercourse at least some of the time (Myers et al. 1993:61).

Myers *et al.* (1993:29) conclude that the consumption of drugs and alcohol is not related to increased sexual high risk activities, since survey respondents claimed that intoxication did not influence their sexual risk behaviour. Yet, it is misleading to assume that alcohol and drug use are not risk factors *per se*. Aboriginal people living with HIV/AIDS (PHAs) identify alcohol and drug use as a major contributing factor to a social milieu of high risk behaviour in urban environments. This social environment often includes high risk practices such as the sharing of needles, unprotected sex, and prostitution (Larmondin 1994:9). Furthermore, socially deviant behaviour such as sexual assault, sexual abuse and incest are often associated with a social environment of high alcohol consumption and alcoholism.

Myers and co-workers (1993:61) report low tolerance and acceptance of alternative sexual life styles and PHAs among members of the surveyed communities. Homophobia represents a significant barrier to HIV/AIDS education and prevention. and affects the broader Canadian society (Canadian AIDS Society 1991). Homophobia and AIDS are firmly linked; many people's responses to PHAs is inseparable from their attitude towards homosexuality. Homophobia also leads to the social stigmatization of AIDS and affects many aspects of this disease, such as transmission, prevention, program planning and access to services for PHAs. Initially termed "gay related immune deficiency" by the medical profession, AIDS is typically conceptualized as a disease of "other people" (Helman 1990:100). As a result of this stigma, many individuals outside certain social categories falsely believe that they are not at risk for HIV infection. The Canadian AIDS society has chosen to address the issue of homophobia in their 1995 AIDS Awareness Campaign. Using this timely issue as a starting point, I intend to show the emerging and vital role of the recovery of traditional Aboriginal cultural values in local initiatives of HIV/AIDS in prevention and education.

Recovery of Traditional Values

Initiatives taken in Aboriginal communities in response to HIV/AIDS are varied. Many communities are planning AIDS workshops and making condoms available free of charge at the community health centres as ongoing methods of AIDS prevention. It has been suggested that "the manner in which condoms are discussed and made available is a reasonably reliable litmus test of societal openness about HIV and AIDS" (Mann and Carballo 1989:S222). Yet, successful prevention programs need to emphasize a holistic approach to health, including the physical, mental, emotional and spiritual aspects of life. The James Bay Cree, for example, have used culturally appropriate and community-specific approaches and have experienced a tremendous turnaround in community support of HIV/AIDS prevention programs (Valverde 1992:9-11).

A significant step towards reducing barriers to HIV/AIDS prevention is the effort of the 2-spirited people of the First Nations. According to Chris Bergeron, Aboriginal bundle carrier and HIV/AIDS education co-ordinator of the 2-spirited people of the First Nations, the term "2-spirited people" is a more culturally relevant way to describe Aboriginal people who identify themselves as gay or lesbian (pers. comm.). During a recent interview, Mr. Bergeron pointed out that homophobia is not indigenous to the traditional beliefs of Aboriginal people, but is an attitude adopted during the process of Christianization. Beaver describes the role of the 2-spirited people in the following way:

[The 2-spirited people] were respected and vital parts of our societies. We were medicine people, warriors, healers and visionaries. It is said that 2-spirited people will walk where everyone else is afraid to and we will go where no one else will... As an organization and as individuals we have gained strength from knowing that we once held a sacred and special place in the spiritual and political life of our nations. We intend to honour that tradition and reclaim that place in society. (1993:5)

Mr. Bergeron identifies the often held notion that 2-spirited people are 'deviant' as one of the most critical issues which impede HIV/AIDS education. This commonly encountered attitude also prevents PHAs from returning to their home communities, feeling that it is not safe to do so. One of the many aspects of his work involves dispelling this myth through HIV/AIDS education workshops in various Aboriginal communities. Recovering the traditional role of the 2-spirited people will thus not only lead to their empowerment, but may also have the potential to reduce homophobia and, as such, help to prevent the spread of HIV/AIDS in Aboriginal communities.

The work that is accomplished by the 2-spirited people in recovering traditional Aboriginal values, while at the same time fighting homophobia and educating their communities about HIV/AIDS, is a dramatic example of the way in which Aboriginal people have chosen to actively respond to the legacy of a colonial past. While their efforts which are based on First Nations' traditions, represent an important response to the HIV/AIDS epidemic, similar initiatives at the community level will be needed to make prevention programs acceptable and feasible in other Aboriginal communities.

Notes

The term "Aboriginal" is used throughout this paper in agreement with the usage
of this term in the Constitution of Canada and includes all people of Indian and
Inuit descent, including Metis and non-status Indians.

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