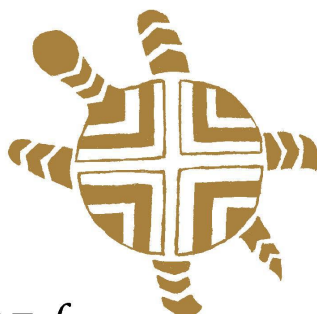


**Research on HIV/AIDS
in Aboriginal People
A Background Paper[©]**

by

**Northern Health Research Unit
University of Manitoba**



CENTRE *for*
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1.0 Methodology for Review of Aboriginal HIV/AIDS Research

This review of Aboriginal HIV/AIDS research in Canada was undertaken by the Northern Health Research Unit (NHRU) at the University of Manitoba under contract to Health Canada. The timeframe of the review was extremely short. The contract was issued in late April 1998 with a draft Report by May 20, 1998 and a Final Report by August 15, 1998.. Dr. John O’Neil, Director of the NHRU, undertook the review. A Research Advisory Committee was established and this Committee met weekly to assist in identifying research directions and gaps, and to review drafts of this document. The Committee consisted of Dr. Judy Bartlett, Mr. Daniel Paul Bork, Dr. Lawrence Elliot, Ms. Audrey Leader, Mr. Albert McLeod, Dr. Stephen Moses, Dr. Pam Orr, Dr. Alan Ronald, Ms. Marilyn Tanner-Spence, Ms. Pauline Wood-Steiman, and Dr. Kue Young. Ms. Anne Katz and Ms. Brenda Elias provided research assistance to the Review. The Draft Report was presented at the 3rd Annual Aboriginal HIV/AIDS Research and Surveillance Meeting. Participants provided critical feedback to the author, which has been incorporated into the Final Report. We would like to thank all those who commented and particularly Marcel DuBois (MSB, Health Canada) and Mai Nguyen (LCDC) who provided extensive editorial advice. Any remaining errors or omissions remain the responsibility of the author.

Given the time frame, this review focused on sources that describe Aboriginal HIV/AIDS research in Canada only. A broader review of literature describing groups at risk, social determinants, and relevant international literature remains to be done.

The term “Aboriginal” includes First Nations, Metis, Inuit, and non-status Indians, groups which share a common indigenous heritage but which differ in terms of program entitlements and jurisdictional responsibilities. Only First Nations and Inuit in Labrador (less than one half the total Aboriginal population) are a federal responsibility in the area of health care. Categorization of Aboriginal AIDS/HIV data on a national level is problematic due to reporting variability between regions and is a sensitive and potentially controversial issue (McLeod 1997).

To present an overview of Aboriginal HIV/AIDS research undertaken in Canada over the past decade, a variety of sources were reviewed. A literature search was undertaken in MEDLINE, CINAHL, Psychlit, Sociofile and Healthstar using the keywords HIV, AIDS, First Nations, Aboriginal, North American Indian, safer sex, injections drug use, street youth. Proceedings of meetings and symposia were reviewed. A list of all sources consulted is presented in the bibliography. A number of individuals in the research community were asked about their ongoing projects that have not been completed or published. Individuals working in Aboriginal AIDS Service Organizations that provide services to Aboriginal people were contacted. “Research” is interpreted somewhat broadly for this paper, in keeping with the focus on participatory methodologies. Participatory, community-based research is less-often published in scientific journals and is more frequently reported at conferences or in discussion papers. Much

of the Aboriginal AIDS research literature is represented in this way. This paper asks the question “What do we know about HIV/AIDS in the Aboriginal community?” as the key to identifying relevant literature.

The review is organized in three sections: (1) Burden of illness (2) Determinants and Risk Factors, and (3) Interventions. Each section identifies research that has been undertaken in this area, the impact of those studies if any, gaps where further research is required, and recommendations for the development of a new Aboriginal HIV/AIDS research agenda. In two sections, a selection of key publications is presented in annotated format. Given the scarcity and limitations of literature in this area, we decided to maintain this format in the Final Report for several reasons. First, the literature is insufficiently mature to be able to draw general conclusions. Second, this document is intended to be a work-in-progress; it will be up-dated periodically to reflect further research developments. We felt the annotated format might be more useful to a reader interested in the state-of-the-field until such time as general conclusions can be drawn from the cumulative body of work. Finally, recommendations for a new research agenda are not intended to be programmatic; we expect the National Aboriginal HIV/AIDS Working Group will develop a new focus for research in this area. This paper is intended to assist that process.

2.0 HIV/AIDS Burden of Illness Among Aboriginal Peoples in Canada:

According to the Bureau of HIV/AIDS, STD and TB, as of December 31, 1997, a cumulative of 15,528 AIDS cases were reported in Canada and of these, 255 were indicated as Aboriginal. Adjusting for reporting delay, the number of Aboriginal AIDS cases was estimated at 332 by the end of 1997. The proportion of AIDS cases attributed to Aboriginal persons has increased from 2% before 1989 to more than 10% in 1996/97 (HIV/AIDS Epi Update, May 1998). Anecdotal information from Aboriginal AIDS Service Organizations (AASO's) suggests that there were as many as 395 Aboriginal AIDS cases by the end of 1997 (McLeod, 1997).

Exposure categories for 213 male Aboriginal AIDS cases were: men who have sex with men (MSM) 59.2%, intravenous drug users (IDUs) 18.8%, MSM/IDU 13.6%, heterosexual contact 4.2%, receiving blood/clotting factors 0.9%, and perinatal transmission 0.9%. Exposure categories for 42 female Aboriginal AIDS cases were: IDUs 47.6%, heterosexual contact 35.7%, receiving blood/clotting factors 9.5%, and perinatal transmission 4.8%. It is also observed that Adult Aboriginal AIDS cases are more likely than adult non-Aboriginal AIDS cases to have their exposure category attributed to injection drug use (19.0% vs 3.2% for men, 50.0% vs 17.4% for women).

AIDS data provide information on HIV infection occurring with a median of 10 years in the past. Data on HIV better reflect better the current trends of HIV infection. Of the nine HIV seroprevalence studies done among Aboriginal people or in sub-populations with Aboriginal

identifiers, prevalence rates in a variety of settings were 0.4%-2.5% in Vancouver (Native alcohol and drug treatment centres, inmates, and needle exchange centres), 2.1% in Alberta STD clinics, and 7.9% in Ontario reserves (self-report by those who had been tested for HIV). Overall, these prevalence rates are similar to those of corresponding non-Aboriginal groups, but the relatively small amount of data cannot rule out the possibility that rates are in fact higher among Aboriginal people. For more information, please refer to Table 1 (Source: Inventory of HIV Incidence and Prevalence Studies in Canada, April 1998, Bureau of HIV/AIDS, STD and TB, Laboratory Centre for Disease Control, Health Canada).

Recent HIV testing data (1993-97) from B.C., Alberta, and Saskatchewan show that Aboriginal people account for 15%, 26%, and 43% of newly diagnosed HIV-positive cases respectively, and that IDU and heterosexual behaviours were the most significant risk factors. For example, the proportion of new HIV-positive tests among Aboriginal persons attributed to IDU and heterosexual groups were 73% and 12.8% in BC, and 60% and 13% in Alberta, respectively. It has also been observed that in Saskatchewan, 28% (481/1,742) of individuals who tested at anonymous HIV testing programs in 1996 were Aboriginal.

Aboriginal populations are at increased risk for HIV infection for several reasons. Transmission of HIV within this group is facilitated by the high rates of STD's (5-10 times the national average); high rates of substance abuse including injection drug use and other health, social issues. These risks are compounded by the over-representation of Aboriginal persons in prisons (14%-40% of federal/provincial inmates) and inner-city services such as needle exchange and counseling referral sites (11-75% of clientele), clinics caring for HIV-infected pregnant women (41% of women under care in a clinic in BC). In addition, high transient movement of Aboriginal persons between inner cities and rural or reserve communities brings the risk of HIV to even the most remote Aboriginal communities. HIV testing and AIDS data show a clear increase of Aboriginal cases although HIV prevalence in the Aboriginal population is comparable to the non-Aboriginal population.

2.1 Gaps in Knowledge

Aboriginal AIDS cases are under-reported because of delays in reporting and variation in the completeness of reporting ethnic status between provinces. Interpretation of AIDS data among Aboriginal people is difficult because ethnic information is lacking for many reported AIDS cases. This may lead to bias if the proportion of Aboriginal people in the unrecorded group is different to that in the recorded group.

With respect to HIV data, HIV testing and clinical data are available only for those who volunteer for testing and/or treatment; thus they do not represent the total number of Aboriginal people infected with HIV. Furthermore, relatively scant information collected by anonymous HIV testing programs makes it difficult to rule out duplicates and to further interpret the characteristics of Aboriginal HIV-positive tests reports.

Regarding HIV prevalence data, most studies have been done specifically in Aboriginal populations living in urban areas or in mixed populations where Aboriginal status is identified. Therefore, generalizability of these results to the general Aboriginal population or populations living on reserve is limited. In addition, seroprevalence studies among Aboriginal communities provide only a “snapshot” that does not capture those individuals who migrate between the community and urban centres.

Several anonymous unlinked (“blind”) seroprevalence studies (HIV testing on blood specimens drawn for another purpose) have been conducted among Aboriginal STD clientele or pregnant women representing the general Aboriginal population. Although such studies can provide accurate information on the extent (prevalence and incidence) and trends of HIV infection in Aboriginal populations, this type of study has generated concerns in some Aboriginal groups. O’Neil, Reading and Leader (1998) discuss the potentially dangerous consequences of epidemiological research which usually emphasizes the negative aspects of health in Aboriginal communities. Blind HIV testing is recognized to potentially cause harm to groups or individuals through stigmatization or discrimination and ethical guidelines have been developed in an attempt to minimize this effect (Federal Centre on AIDS Working Group on Anonymous Unlinked HIV Seroprevalence 1990). Although Canadian authorities generally support blind seroprevalence studies for broad epidemiological purposes (i.e., to control for selection bias in voluntary testing), this is not the case in some other Western countries where the topic has generated much controversy and in some instances “blind” seroprevalence studies have been banned (Bayer, Lumey and Wan 1990).

In order to investigate this issue, the Two Spirited People of the First Nations undertook a survey among an opportunistic sample of 83 Aboriginal persons across Canada. The majority of respondents in this survey indicated that seroprevalence studies are not acceptable, that such studies may do more harm than good in Aboriginal communities, that only individuals have the right to give consent for their specimen to be tested, and that Aboriginal leaders (Chiefs, Band Council, representatives from agencies) should not have the right to authorize HIV testing in communities (Two-Spirited People of the First Nations 1996).

2.2 Recommendations

Voluntary seroprevalence studies, wherever they are conducted, need to use ethnic identifiers to more accurately present the true picture of HIV prevalence among Aboriginal people. While seroprevalence studies are important to track the distribution of HIV in the population, they should be used as a basis for interventions so that the community derives some benefit. Blind seroprevalence studies that do not identify those infected and so do not provide individual benefits in terms of care and treatment for those infected should be approached with caution.

Seroprevalence studies that report low prevalence may cause a belief that HIV is not an issue for the Aboriginal community. It should be made very clear to the community that a seroprevalence study is a single snapshot at one point in time and not indicative of trends. The community needs to fully understand why the seroprevalence study is being done, how the study will proceed, who owns the data, and what happens to the results. Seroprevalence studies in the absence of additional data on risk behaviors may be counterproductive to the objective of raising awareness in the Aboriginal community about HIV/AIDS. On the other hand, if seroprevalence studies report high rates of HIV infection, dissemination of these results must be conducted according to previously agreed upon ethical protocols to protect Aboriginal communities and individuals from unwarranted discrimination.

3.0 Determinants and Risk Factors

The literature on risk factors associated with HIV/AIDS in the Aboriginal community is very small, although a broader literature related to high risk behavior generally has not been well integrated into the Aboriginal HIV/AIDS literature. Further, the literature is generally focused on individual risk behaviors, knowledge and attitudes, and rarely addresses broader social determinants such as poverty, discrimination, and marginalization. These latter forces impact particularly on Aboriginal youth (i.e., self-esteem and social identity) and may contribute directly to participation in high-risk activities such as the sex trade and intravenous drug use. There is virtually nothing in the literature linking general social trends such as migration between reserves and cities, changing employment opportunities, criminal activities, and housing availability to high-risk activities. Finally, no mention is made of the “re-spiritualization” process occurring throughout the Aboriginal community and its potential impact on HIV transmission. The few studies that have occurred are summarized briefly below. Most of these studies have been carried out in select populations that reflect the epidemiology of the high-risk groups such as women and prison populations.

1) Ontario First Nations AIDS and Healthy Lifestyle Survey (Myers et al 1993)

This study is a rare attempt to study knowledge, attitudes and behaviour related to HIV/AIDS in all First Nation communities in Ontario. The survey involved extensive participation of First Nations representatives at all stages of design, implementation and analysis. Six hundred and fifty-eight randomly selected individuals representing northern, central and southern regions of the province were interviewed (87% participation rate). The study found that knowledge about HIV transmission was generally high, particularly among the younger people. Older people require more accurate knowledge since many engage in high-risk behaviours. Multiple sex partners occurred relatively often but condom use appears to be relatively high with casual partners, particularly among youth. Alcohol consumption is primarily binge-drinking and probably not associated with increased risk. Anxiety and fear of the spread of HIV/AIDS is widespread. Somewhat surprisingly, respondents answered questions about sexuality openly.

Generally people were unsupportive of homosexuality but had little difficulty discussing previous sexual experiences.

- 2) *Differences in sexual risk-taking behavior with state of inebriation in an Aboriginal population in Ontario, Canada (Myers et al 1997).*

This paper analyses a subset of data from the Ontario First Nations AIDS and Healthy Lifestyle Survey. The findings suggest that alcohol and drug use may not be as strongly associated with high risk sexual activity in Aboriginal communities due to the binge-drinking context where sexual activity may be suppressed. This contradicts the generally held belief that people are more likely to engage in unsafe sex when inebriated.

- 3) *Condom use among First Nations people living on-reserve in Ontario (Burchell et al 1998).*

This paper is based of data on 400 individuals who had sexual intercourse in the past 12 months from the 1991 Ontario First Nations AIDS and Healthy Lifestyle Survey. Forty percent of males and 18% of females had more than one sex partner in the preceding 12 months. Of these 8 % always used condoms, 31 % sometimes and 61% never used condoms. Those who knew someone with HIV/AIDS or had good knowledge of AIDS were more likely to use condoms.

- 4) *HIV/AIDS and its impact on Aboriginal women in Canada (Aboriginal Nurses Association of Canada 1996).*

This is a 1992 survey of a voluntary sample of 582 women associated with Aboriginal organizations across Canada (19.4% response rate). Results indicate early onset of sexual activity, low incidence of condom use (use associated with birth control), 30 % had a history of STD, some had knowledge deficit, and the majority were afraid of AIDS. The Report recommends that education and prevention efforts emphasize positive self-images and self-esteem.

- 5) *Evaluation of an Inuit HIV/AIDS survey (Pauktuutit 1995).*

This survey of 49 health care workers in 1995 describes their knowledge regarding STDs, HIV/AIDS, and safer sex. Results indicate a gap between knowledge and practice as well as limited knowledge of low risk activities. Also, participants indicated a lack of acceptance of people with HIV/AIDS in their communities.

- 6) *Aboriginal Street Youth and Sex Trade Workers Study for the Joint National Committee on Aboriginal AIDS Education and Prevention (Sinclair 1993).*

This study was conducted in Edmonton with street youth identified by service providers.

No indication is provided in the Final Report of sample size. The purpose of the study was to establish what type of programs exist for this population, identifying socio-demographic profiles of the target group, assessing HIV/AIDS knowledge and the impact of this knowledge on risk behaviour, current health and HIV status. Recommendations include more direct involvement of Aboriginal people in HIV/AIDS education programs, more funding, more involvement of Aboriginal organizations in HIV/AIDS education and prevention, need for HIV/AIDS prevention strategies in schools, and more mass media involvement in prevention.

- 7) *Final Report on AIDS and Aboriginal Prison Populations - Joint Committee on Aboriginal AIDS Education and Prevention. (McCaskill and Thrasher 1993).*

The purpose of this study was to assess the needs of Aboriginal prisoners in terms of HIV/AIDS education and prevention, treatment of HIV infected inmates, and to determine the extent of the problem of HIV/AIDS in the prison system. The study involved in-depth interviews with key informants involved with prison populations in Kingston, Winnipeg and Edmonton, and a telephone survey of other individuals involved with Correctional Services across Canada. The Report provides considerable insight into a variety of issues associated with prevention of HIV/AIDS transmission in prison populations.

- 8) *HIV risk behaviors become survival techniques for Aboriginal women (Mill 1997).*

This was a qualitative study of 8 HIV infected women in Northern Alberta. A model was developed to explain the relationships that exist between the women's formative years (family relationships, parental substance abuse, abuse of the child), self-esteem and survival strategies (running away, substance abuse, promiscuity and prostitution, relationships with boyfriends and husbands, children). In-depth analysis of the life histories of eight key informants revealed past experiences of unstable family relationships, frequent moves, and physical, emotional or sexual abuse. High risk behaviours associated with running away from these conditions were considered appropriate survival techniques by respondents.

- 9) *Frequency and determinants of condom use among women attending an urban community health centre (Katz 1995).*

This is a study of 1048 women attending a community health clinic in Winnipeg, Manitoba. Forty-one percent of the sample identified themselves as Aboriginal. Sixty four percent of these women reported a previous STD and 29 % reported more than 20 lifetime sexual partners. Aboriginal women were less likely to use condoms than non-Aboriginal women.

- 10) *HIV among Aboriginal people in Canada : injection drug use is a major concern*

(Nguyen et al 1998)

This paper summarizes data gathered from a number of risk behaviour surveillance studies (see 11 and 12). Of the 249 cases of AIDS among FN people (up to Oct 97), 54 % of the men and 17.8 % of the women were identified as IVDUs. IDU is becoming an increasingly important risk factor for HIV infection among Aboriginal people in Canada.

11) *Survey of Montreal's Aboriginal population's knowledge, attitudes and behaviour regarding HIV/AIDS (DuBois, Brassard and Smerja 1996).*

This study was based on a questionnaire administered to a convenience sample of 99 urban Aboriginal people (47% male). One important finding was that only 69.7 % were aware of the difference between HIV and AIDS. Other risk factors identified included multiple sexual partners, alcohol related abuse, drug use and infrequent condom use, and relatively frequent reporting of sex with a same gender partner in lifetime.

12) *Determinants of HIV infection in a cohort of native Canadian injection drug users. (Heath et al 1998)*

This prospective study of 1125 IDUs in Vancouver identified 300 Aboriginal participants in the study. When compared with the non-Aboriginal participants, Aboriginal IDU's are more likely to be female, more likely to be HIV positive, less likely to be enrolled in a methadone program, and less likely to have ever borrowed needles. Predictors for HIV infection included borrowing needles and being in a methadone program. The study concludes that Aboriginal IDU's carry a unique risk profile in comparison to other IDU's.

13) *WIDE - Winnipeg Injection Drug Epidemiology Study (Blanchard et al - Manitoba Health Epidemiology Unit, 1998)*

The purpose of this study is to estimate the number of IVDUs in Winnipeg. Participants will be asked for ethnic status. HIV testing (saliva) will be performed with consent. Participants will be interviewed with a questionnaire to describe IDU practices, knowledge of HIV prevention, and use of community health services. Particular attention will be paid to the health behavior and needs of Aboriginal clients. Results from this study have yet to be published.

14) *Regional First Nations and Inuit Health Surveys (National Steering Committee – Medical Services Branch)*

These surveys have recently been completed in each province under the direction of the

regional First Nations and Inuit organizations. Although general in focus, some of these surveys included questions relevant to HIV/AIDS. Analysis of this data needs to be undertaken.

3.1 Gaps in Knowledge

With the exception of the Ontario Survey there has been very little systematic research on determinants of HIV/AIDS in on-reserve communities. Most research has mainly focused on injection drug users and women in the urban population. The issue of knowledge and attitudes to condom use in particular has received some attention but little is known about sexual behavior in youth. With the high prevalence of STDs in this population, this is a concern as the same risk behaviours for STDs apply to HIV.

Social and cultural factors involved in condom and safer injection drug use need to be identified. Sexuality and sexual behaviour has received very little attention in this population. Research to date suggests that attitudes towards homosexuality are negative, but little is known about broader understandings of sexuality including attitudes towards multiple partners, early sexual experience, and the rights of women. These attitudes need to be understood in the context of traditional/spiritual world views and the impact of Christianity on Aboriginal beliefs.

The epidemiological evidence suggests a shift in mode of HIV transmission in Aboriginal persons from men who have sex with men to intravenous drug use, but we have very little understanding of why this shift has occurred and of the role played by heterosexual transmission. Although there has been an increasing amount of research on specific high risk populations such as intravenous drug users, very little of this research examines these practices from an Aboriginal perspective.

This review does not include the broader literature that describes groups at risk such as urban youth, sex trade workers etc. A review of this literature should be undertaken.

3.2 Recommendations

Investigators who have unanalyzed data pertaining to Aboriginal subjects should be encouraged and supported to complete the analysis and report the findings at meetings and in journals. Completed studies need to be disseminated widely and every effort made to plan interventions based on the results of this research. Priority needs to be given to research in youth and women to identify barriers to safer sex and prevention of injection drug use. The issue of perinatal transmission needs to be addressed with particular attention paid to understanding barriers to therapies that reduce transmission to the fetus.

Research addressing social determinants and risk factors related to Aboriginal HIV/AIDS is seriously underdeveloped. As a broad research agenda, qualitative and quantitative work

addressing the following areas needs to be undertaken.

1. Attitudes and Behaviors Towards:

- Condom use
- Age of sexual debut
- STD control
- Sex education
- Circumcision
- Sex work
- Sexual orientation
- Sexual abuse
- Women's rights

2. Youth

- Self-esteem
- Identity
- Sexuality
- Peer influences
- Generational relationships

4.0 Interventions

Interventions include primary, secondary and tertiary levels of prevention and treatment. There is very little published literature on interventions specific to Aboriginal communities. Most of the programs that have received funding have not been evaluated and thus there are no objective indicators of either process or outcomes.

Relevant literature is summarized below:

1) *The First Nations Communities Health Resources Project (FN-CHRP): Final Report (Schneider et al 1998)*

This is a collaborative study commissioned by the Assembly of First Nations in partnership with the British Columbia Centre for Excellence in HIV/AIDS. The primary objective is to produce estimates of the cost of HIV/AIDS (human and economic) in the Aboriginal population. The study surveyed 151 First Nations HIV-positive persons living in the Greater Vancouver area in 1997. Sampling involved recruitment from both clinical and non-clinical client populations (i.e., ASO's). The study has been successful in obtaining follow-up interviews with over 80% of cases recruited. Survey data was linked to hospitalization and physicians services administrative data and analysis compares treatment profiles for First Nations persons with data from the larger CHRP study of non-Aboriginal persons with HIV/AIDS. Initial

results suggest that First Nations persons with AIDS are not accessing care at an optimal level and that achieving optimal care will require a much higher expenditure on drug therapies. Significant differences were also identified with respect to antiretroviral therapy.

2) *The Canadian Aboriginal AIDS Network HIV/AIDS Skill Building Forum (CAAN 1998)*

This conference provided a workshop environment for Aboriginal representatives from across the country to address capacity building needs in the Aboriginal community to facilitate improved service provision to people infected with HIV or living with AIDS. The need for developing capacity to network and share knowledge and resources was identified as a serious gap in the institutional capacity of Aboriginal people to respond to the HIV/AIDS epidemic.

3) *Indigenous traditional medicine and HIV/AIDS : a literature review (Ketting 1996).*

This paper explores the option of utilizing traditional First Nations medicine to respond to the needs of Aboriginal people with HIV/AIDS. The review suggests that it may be possible to train traditional healers in HIV/AIDS prevention care and treatment. It also suggests that health promotion and illness prevention activities are likely to be more successful if they incorporate traditional understandings of health and healing. Spirituality should be a particularly important component of Aboriginal HIV/AIDS care.

4) *Discrimination, HIV/AIDS and Aboriginal People (Matiation 1998a).*

This report is based on consultations with individuals working in the field of HIV/AIDS and Aboriginal people. The report addresses the issue of discrimination experienced by Aboriginal people affected by HIV/AIDS, and is particularly concerned with community level discrimination in the context of anxieties and fears about HIV/AIDS. The report documents the experience of Aboriginal persons who have been denied housing and/or driven from their communities by local authorities. The Report deals particularly with Section 67 of the Canadian Human Rights Act that states the “Nothing in the CHRA affects any provision of the Indian Act or any provision made under or pursuant to that Act”. This clause is seen as potentially dangerous for Aboriginal people and their families because it provides Band Councils with the authority to override individual rights related to sexual orientation and HIV/AIDS confidentiality. The Report recommends that this issue be addressed by the Aboriginal leadership and that where cultural interpretations of Charter provisions are made, the discriminatory impact of these interpretations on APHA s must be addressed.

5) *Housing for Aboriginal People Living with HIV/AIDS : a Review of the Relevant Literature (Thoms 1996).*

This report summarizes the poor housing conditions experienced by Aboriginal people generally and particular need for supportive and culturally appropriate housing for Aboriginal persons with HIV/AIDS. The report documents jurisdictional problems associated with funding housing and recommends a national needs assessment be conducted to identify housing needs and sources of support.

6) *Care and Treatment of Aboriginal People with HIV/AIDS (McLeod and Peterson 1993).*

This Report is based on a survey in 92/93 to identify issues related to care and treatment of Aboriginal PHAs. The sample included 19 PHAs, 13 family members, 9 traditional informants, 58 health and social service providers, and 9 community representatives (N = 111). The recommendations including moving beyond education and prevention strategies to 1) providing care and treatment to Aboriginal people with HIV and AIDS; 2) ensure that Aboriginal AIDS Service Organizations are adequately staffed; 3) provide funding for Aboriginal Healing Centres; to ensure access to traditional healing; 4) educate elders and include Aboriginal historical concepts of health and sexuality; 5) educate community leaders to become positive role models promoting acceptance of alternative lifestyles; 6) address economic issues of poverty among Aboriginal people living with HIV and AIDS; 7) provide funding for FN hospice; 8) encourage advocacy with FN volunteers in local AIDS Service Organizations; and 9) provide Aboriginal specific media identifying substance abuse as a high risk behaviour.

7) *The Feather of Hope Aboriginal AIDS Prevention Society : a community approach to HIV/AIDS Prevention (Mill and Desjardins 1996).*

This report describes a culturally sensitive HIV/AIDS prevention program for Aboriginal people in northern Alberta. The program is based on a community-development approach and credits success to establishing credibility in the Aboriginal community through consultations with elders and an emphasis on community empowerment.

8) *Aboriginal Inmates and HIV Testing: Program Implications (Calzavara et al 1998)*

This study surveyed 597 randomly selected male and female inmates from six correctional centres in Ontario. Thirteen percent of the sample was Aboriginal. The study concludes that Aboriginal inmates are not at greater risk of HIV infection but are less likely to test for HIV than non-Aboriginal inmates.

9) *HIV Test Kit Proves User Friendly for Health Provider: Comprehensive and Confidential for Client (Henning et al 1994).*

This paper describes an HIV test kit that was developed in Northwestern Ontario to alleviate client fears about confidentiality and provider concerns about lack of experience in counselling. The test kit contains guidelines for assuring confidentiality and a culturally sensitive educational pamphlet to use in counselling. Since introduction of the test kit, HIV tests have increased from 14 to 85 in a twelve month period.

- 10) *AIDS Education and Prevention by the James Bay Cree (Smeja, Valverde and Petawabano 1994).*

This paper describes a decentralized approach to AIDS awareness activities among the Cree of James Bay. Participatory learning methods were used to involve local facilitators and educators in the development of a community-based AIDS awareness program. Projects have included activities ranging from regional workshops, to television shows, to school sexuality workshops. A forty-percent drop in chlamydial infections between 1989 and 1992 is partially attributed to the program.

- 11) *Cost Effectiveness of Streetworks' Needle Exchange Program in Edmonton, Alberta. (Jacobs et al 1998).*

This study is based on a survey of 100 randomly selected clients of a needle exchange program in Edmonton, Alberta. Sixty-six percent of respondents were Aboriginal. The study found that respondents shared needles about 8% of the time and would likely share needles three times more often without the needle-exchange program. The study estimates that the program likely prevents 26 HIV infections per year at a cost of \$7,673 per infection averted. By comparison, the cost of treating an HIV infection is estimated to be \$150,000.

- 12) *Aboriginal-Specific HIV/AIDS Prevention, Care and Support Services in Alberta (RPM Associates Ltd. for Health Canada and Alberta Health 1994)*

This Report summarizes literature and reports on key informant interviews with 41 respondents working for Aboriginal and AIDS organizations in Alberta. The literature review is organized to identify key cultural practices and to provide associated recommendations for program planning. Recommendations are very specific and useful. For example; "The best time for a workshop would be Monday or Tuesday evening between the beginning of November and the end of March". The Report also catalogues and summarizes the key dimensions of all HIV/AIDS prevention, care and support services available to Aboriginal people throughout Alberta. Unfortunately, little evidence of evaluation of these programs is provided.

- 13) *HIV/AIDS Prevention, Care and Support Services for Metis People in Alberta (RPM Planning Associates Ltd. for Health Canada and Alberta Health 1995).*

This Report is similar to 12 described above but focuses on cultural issues and services specific to Metis people and communities in Alberta.

4.1 Gaps in Knowledge

These reports begin to identify the complex needs of Aboriginal people, families and communities in the area of HIV prevention and treatment of AIDS. Evidence from the FN-CHRP study suggests First Nations people with HIV/AIDS are experiencing less than optimum treatment protocols. Research to date has identified discriminatory attitudes and an absence of culture-based models for prevention and care as major barriers. There is virtually no research on which prevention programs have worked and which have not. Also required is more research on the special needs of Aboriginal people and their families living with HIV/AIDS, barriers to HIV testing (access, confidentiality etc), access and compliance with combination therapies, uptake of voluntary prenatal screening (access, confidentiality), and the palliative care needs of Aboriginal people with AIDS both on and off reserve.

4.2 Recommendations

Qualitative studies are needed which will provide rich data on the lived experience of Aboriginal people with HIV/AIDS. Cultural practices that affect the design and delivery of interventions need to be investigated, including the potential role of traditional Aboriginal medicine and the role of elders. Wider attention needs to be paid to understanding the effectiveness of traditional understandings of health and healing in the prevention of substance abuse and in relation to issues such as social development of youth and gender relations.

Studies underway or under consideration should identify that Aboriginal people have participated so that conclusions can be drawn that reflect the experience of Aboriginal people. Funded programs (prevention, education, and interventions) must be evaluated. These evaluations must be summative and not just process evaluations and must involve outcome measures that are relevant and useful for other initiatives. Evaluation should be performed by qualified personnel and not only by staff who are involved in the program. Results of these evaluations should be disseminated widely so that others can benefit from the lessons learned. Evaluation research can contribute in important ways to the development and implementation of new programs and services.

Community-level interventions related to HIV/AIDS but also to STD control, prevention and treatment of substance abuse, and youth oriented programs generally need to be documented and evaluated from the perspective of what can be learned for HIV/AIDS prevention and care. A review of international programs and interventions undertaken in different ethnocultural environments may provide useful insight into developing interventions for Aboriginal communities in Canada. While the situation of Aboriginal people with HIV/AIDS in Canada is unique, there are many lessons that could be learned from interventions in related areas and from the experience of indigenous peoples and other ethnocultural communities in other countries.

5.0 Research Methods and Ethics:

Research on HIV/AIDS in the Aboriginal community requires a community-based or participatory focus (Barlow et al 1998). HIV/AIDS research in general has supported this methodological approach. In the area of HIV prevention research particularly, involving research subjects in the research process is essential in order to increase participation rates in difficult to access communities and to increase the likelihood that research results will have any impact (Allman, Myers and Cocerill 1997). Given further concerns about confidentiality and other ethical issues, the development of collaborative relationships involving research communities and scientists has become accepted practice (National Planning Forum for HIV/AIDS Research 1996).

Research in the Aboriginal community has also moved strongly in this direction (Kaufert and Kaufert 1998; O'Neil and Commanda 1998; O'Neil, Reading and Leader 1998). Aboriginal communities, tired of decades of externally controlled research agendas which appear to do little to benefit communities, are insisting that all forms of research, regardless of the methodology, must be developed in full partnership with Aboriginal organizations and communities. Indeed, many organizations insist that the research agenda be developed under the control of the aboriginal community, and require strict protocols governing access to data and publication. For example, the Kanawake Schools Diabetes Prevention Project has developed an elaborate Code of Ethics detailing the rights and responsibilities of all research partners at all stages of the research process. This protocol was developed to reflect emerging ethical principles for aboriginal research developed by various national Aboriginal organizations and the Royal Commission on Aboriginal Peoples. The protocol has been widely disseminated through public presentations and publications and is increasingly incorporated in other research initiatives in the Aboriginal community (Macaulay et al 1998).

Unlike more traditional approaches to participatory and community-based research, research partnerships with Aboriginal communities are more concerned with control over access to data. In the Kahnawake Protocol, the community retains control over the data, has the right to approve publication (or provide a dissenting opinion), but also has obligations to their scientist partners to provide an opportunity for continuing analysis and publication. These general principles have been incorporated into the First Nation and Inuit Regional Health Survey Code of Ethics (McDonald et al 1998). An issue requiring further discussion is the possible effect of the Access to Information Act which requires public access to federally funded research projects.

Research partnerships also require innovative approaches to project management that operationalize these ethical principles. Increasingly, Aboriginal organizations assume the Principal Investigator role on grant funded projects, and/or a primary contractor relationship with scientists as sub-contractors. Administrative control is vested in representative Advisory or Steering Committees, who draw their authority from the appropriate governing Aboriginal body. This last point is particularly important in First Nations and Inuit contexts where the accountability of Advisory/Steering Committees is mandated by duly constituted governing

bodies at the community and regional levels. In Manitoba, the Assembly of Manitoba Chiefs is developing a research management infrastructure which is intended to interact with all health related research involving First Nations people and will require researchers to provide a portion of research funds to support the operational requirements of this management structure.

Equally important as ethics and administrative control is capacity building. Increasingly, the separation implied by community scientist partnerships is artificial as Aboriginal scientists assume responsibility for much of the technical expertise required in health research. Training initiatives such as the Summer Institute in First Nations Applied population Health Research (offered jointly by the Assembly of Manitoba Chiefs and the University of Manitoba), provide opportunities for Aboriginal Health Technicians to upgrade their skills in the utilization of research results. Capacity building at the community level which results in the development of broad research skills have become fundamental to any proposed health research.

These general developments have particular importance for the future of HIV/AIDS research in Aboriginal communities. Ownership of seroprevalence data, for example, raises important questions related to confidentiality and dissemination of results (Matiation 1998b). Resistance to HIV/AIDS research or prevention initiatives by community leadership is a barrier to broad regional or national research initiatives that will require intensive communication strategies involving appropriately constituted research management bodies.

6.0 Summary and Recommendations:

Clearly, research to date in this area is inadequate to the task of preventing further spread of the epidemic or to providing effective and culturally appropriate treatment to Aboriginal people with HIV/AIDS. Much of the current knowledge is relevant particularly to urban Aboriginal people, with few studies of relevance to the on-reserve population. However, these two situations, while unique are inextricably linked through migration and mobility of the Aboriginal population, and research should establish these connections clearly.

This review has underscored the desperate need for more knowledge of the social determinants and risk factors associated with the transmission HIV. Studies addressing risk groups and behaviors are underway or beginning to appear in the literature, but a broader perspective is necessary. Of particular concern are studies that address issues of self-esteem and development of identity among Aboriginal youth who are over-represented in high risk groups.

Tracking the epidemic has been the primary focus of past research. Although it is important to maintain surveillance research in order to identify changes in transmission patterns and to guide prevention programs, seroprevalence studies should not dominate the research agenda as they have in the past. Clearly, HIV/AIDS is likely to become a serious public health problem in Aboriginal communities. More seroprevalence research is not essential to demonstrate this reality. Indeed, the potential harmful effects of continued emphasis on

seroprevalence must be taken into consideration in this regard. Studies which underestimate the magnitude of the epidemic run the risk of reinforcing prevailing attitudes in many communities that HIV/AIDS is not an Aboriginal problem. On the other hand, studies which report dramatic increases in HIV/AIDS in the Aboriginal community will likely exacerbate negative stereotypes and discrimination both against Aboriginal people by the wider society as well as discrimination within the Aboriginal community towards people with HIV/AIDS and their families. Seroprevalence studies linked to prevention and treatment evaluations, or to analytical studies of risk behaviours, should satisfy both surveillance needs as well as meet ethical and cultural concerns.

Interventions for prevention and treatment also require more intensive investigation in order to determine what works in the Aboriginal cultural context. Program developments must be evaluated and a wider review of related interventions in the Aboriginal and international environment should be undertaken.

Finally issues of ethics and research methodologies must be given careful consideration at all levels of research. This is a “double-jeopardy” area for research sensitivity related to issues of confidentiality, collaboration with affected groups, organizations and communities, and for ownership and control of research data. In the Aboriginal context, research in general is increasingly guided by detailed ethical protocols developed by representative organizations and communities in the context of recent research. A central principle of these protocols is Aboriginal control over the research process. Partnerships, collaborative administrative structures, and participatory methodologies are essential. Finally, research in Aboriginal communities must accommodate capacity-building in terms of research training for aboriginal researchers at all levels of a project.

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