University of Alberta

HIV Infection in Aboriginal Women

by

Judith Ellen Mill ©

A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfilment of the requirements for the degree of Master of Nursing

Faculty of Nursing

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J Mill

14503 98 Avenue
Edmonton, Alberta, T5N 0G9

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Faculty of Graduate Studies and Research

The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled HIV Infection in Aboriginal Women submitted by Judith Ellen Mill in partial fulfilment of the requirements for the degree of Master of Nursing.

Dr. Pamela Brink

Dr. Linda Ogilvie

Stan Houston
Dr. Stan Houston

28 August 1996
Date of Approval

Dedication

This thesis is dedicated to the women who have shared their life experiences with me. My learning was facilitated by the courage they demonstrated in telling their stories.

Abstract

The issue of infection with the human immunodeficiency virus (HIV) leading to AIDS (acquired immunodeficiency disease) is both complex and challenging. As the AIDS epidemic has evolved over the past decade, researchers have identified practices and behaviours that influence transmission of the HIV virus. Although a cure for AIDS has not been found, treatments that may lead to long term control of the disease have been identified. Increasingly, health care practitioners have realized the need to understand the context of the behaviours that may place individuals at increased risk of HIV infection.

HIV infection is an issue of concern in the Aboriginal community of Canada. Aboriginal women are over-represented in the number of new clients attending HIV clinics in a large urban centre serving northern Alberta. A qualitative research study was designed to explore the cultural factors that relate to HIV infection in these women. The findings are presented in two papers within this thesis.

An explanatory model for HIV illness is described in the first paper. Some of the findings relating to etiology and treatment of HIV illness are divergent from common biomedical views of the disease. In the second paper a model is developed to conceptualize the relationships that exist between the women's formative years, their self esteem and

the survival techniques they used prior to becoming HIV positive. These survival techniques may have placed them in situations that increased their risk of infection with the HIV virus.

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HIV RISK BEHAVIOURS BECOME SURVIVAL TECHNIQUES FOR ABORIGINAL WOMEN

INTRODUCTION

The search for effective strategies to prevent the spread of the human immunodeficiency virus (HIV) that leads to AIDS (acquired immunodeficiency syndrome) has presented a monumental challenge to health professionals in the past decade. Tremendous progress has been made in the area of HIV prevention, as researchers have learned how the virus is transmitted and have identified practices and behaviours that influence its' transmission. Similarly, treatment of HIV infection has advanced rapidly with new [illegible] combinations offering promise of long term control of HIV disease. Despite progress in these areas and evidence that the spread of the virus has been slowed in groups such as gay men, the epidemic continues its spread and is of growing concern for women (World Health Organization 1994).

In Canada and Alberta, HIV infection among the Aboriginal population has been identified as an issue of concern (Health Canada 1994; Alberta Health 1995). There is concern that HIV infection is widely distributed in the northern Alberta Aboriginal population (Houston and Reese 1995). The HIV infection has typically unfolded in specific sub-groups such as gay men or intravenous drug users, however in northern Alberta, cases of HIV infection have been found across many sub-groups of the Aboriginal population (Houston and Reese 1995). Although HIV sero-prevalence studies in Aboriginal people are limited (Aboriginal Nurses Association of Canada 1996), several factors point to the potential increased susceptibility of this population to HIV infection, as seen below.

The history of the Canadian Aboriginal community following European contact is marked by severe and widespread epidemics of communicable diseases that resulted in high rates of morbidity and mortality (Postl and Moffat 1988; Waldrum, Herring and Young 1995; Wotherspoon and Satzewich 1993). Aboriginal people in Canada continue to experience high rates of infectious diseases, due to social factors such as poverty, unemployment, poor sanitation and geographical isolation (Postl and Moffatt 1988). For example, the Aboriginal population experiences a tuberculosis infection rate that is approximately 40 times higher than the non-Aboriginal population (FitzGerald 1994).

The Canadian Aboriginal population also experiences social problems that may influence their susceptibility to HIV infection. Alcohol and drug abuse is a major problem in the Aboriginal population of Canada (Canadian Nurses Association 1995; Waldrum, Herring and Young 1995; Wotherspoon and Satzewich 1993). This is critically important because of the positive correlation between intravenous drug abuse and the risk of HIV infection.

Unemployment and poverty are frequently identified social problems that affect the health status of Aboriginal people in Canada (Myers et al. 1993; Shah 1990; Statistics Canada 1993a). As the AIDS pandemic has progressed, the relationship between poverty and HIV infection has become increasingly apparent. Poverty has been referred to as the "line of least resistance and one of the most powerful driving forces behind the spread of AIDS" (World Health Organization 1994:49). The debilitating impact of past and current infectious diseases, in combination with the poverty and social problems common in Aboriginal populations, leads to serious concern about their increased vulnerability to HIV infection.

An analysis of new patients attending HIV clinics in a large urban centre in northern Alberta documents that Aboriginal people, and in particular women, are experiencing higher rates of infection with the HIV virus than the non-Aboriginal population. Aboriginal people represent approximately 10.5% of the total number of new clients seen in the HIV clinics since 1985 (Houston and Reese 1996). When statistics for the HIV clinics since 1993 were analysed, the percentage of new HIV positive clients who are Aboriginal rises to 26%. The proportion of Albertans who are Aboriginal, however, is approximately 6% (Statistics Canada, 1993b, 1994). An additional concern is that the proportion of new Aboriginal clients that are female is 25%, whereas the proportion of the total new clients that are female is 7% (Houston and Reese 1995).

HIV/AIDS prevention programs in the past decade have focused primarily on individual behaviour change and therefore may be limited in their effectiveness because they do not acknowledge the broader context of disease transmission (Freudenberg 1990). Health practitioners and social scientists have increasingly argued that effective HIV prevention strategies must be predicated on knowledge about the cultural and social forces that influence the risk of HIV infection (Freudenberg 1990; Myers et al. 1993; Zwi 1993). Through greater understanding of the forces that influence individual behaviour, it may be possible to enhance those cultural forces that support HIV prevention, while minimizing those forces that hinder prevention efforts (Freudenberg, 1991).

In view of these concerns regarding HIV infection in the Aboriginal population generally, and Aboriginal women specifically, a research study was designed to explore the cultural factors that relate to HIV infection in Aboriginal women. The purpose of the study was to explore the following questions:

1. What explanatory model do HIV positive women use to describe their illness?

2. What are the cultural rules about sexual behaviour as described by Aboriginal women?

For this study, explanatory model was defined as the etiology and pathophysiology of the illness, time and mode of onset of symptoms, course of the illness, and methods of treatment for the illness (Kleinman 1980) as elicited through an open-ended interview. The cultural rules for sexual behaviour were defined as the customary responsibilities, restrictions or license for sexual behaviour according to gender, age and kinship affiliation as elicited by open-ended interviews.

A qualitative research approach was used for the study, following ethical approval from the Faculty of Nursing, University of Alberta. Five key agencies that interface with HIV positive women were identified in the urban centre where the research was carried out. Contact people were identified in each agency to assist with recruitment of participants. An information sheet (see Appendix A) was prepared explaining the study and the contact persons were asked to give it to eligible women. The research study was explained to each participant and an informed consent was signed prior to the first interview (see Appendix B). In-depth interviewing was the primary method of data collection. Guiding questions were used to focus the interviews on the question of HIV infection and Aboriginal women (see Appendix

C). At the completion of the first interview, demographic information was obtained from each participant (see Appendix D). Further details on the population, sample, methods and data analysis can be found in the two papers included in this thesis.

Early in the research process the researcher became aware that there was little published information on the topic of HIV infection in Aboriginal women. A paper style thesis was chosen therefore, to report the findings and expedite their publication. The papers will be submitted to two different journals, and therefore the manuscript style is different for each of the papers. The findings related to the first research question are incorporated in the first paper, "An Explanatory Model of HIV Illness in Aboriginal Women".

The second research question relating to the cultural rules for sexual behaviour was not answered in this study. The researcher sensed during the first interview, and confirmed in subsequent interviews, that a focus on the rules for sexual behaviour would not provide information on the cultural factors that influenced the participants' infection with HIV. The women's behaviours at the time of their infection with HIV could not be separated from their life experiences prior to their infection. As the women shared their life histories, the researcher developed insights about the inter-connectedness of the women's formative years and their infection with the HIV virus. The findings related to these areas have been combined therefore, and are included in the second paper entitled "HIV Risk Behaviours Become Survival Techniques for Aboriginal Women".

Several areas are suggested for future research in the area of HIV infection and Aboriginal women. Although the cultural rules that guide sexual behaviour in Aboriginal women were not uncovered in this research, this is an important area to explore. Research with a different population, such as women living on reserves who are not HIV positive, may be necessary to answer this question. As well, further research is necessary to test the relationships between childhood experiences, self esteem and survival techniques as described in the model developed in the second paper. Other variables, such as poverty, could be added to the model to test its relationship to the survival techniques used by the women. Finally, the influence that parents attendance at residential schools may have on their children in relation to HIV infection is an area that merits further study.

The questions that have been explored in this research study are relevant for nurses who work with Aboriginal communities in the planning of programs for the treatment and care of HIV clients. Although the findings from this study are not generalizable to other populations, they highlight the need for nurses to become aware of HIV illness from their client's perspective. This awareness will enable nurses to provide care that is sensitive to their client's values and beliefs about illness.

The research findings are also applicable to nurses working in the area of HIV prevention. A model was developed to explain the relationships between the women' experiences in their formative years, their self-esteem and the survival techniques that placed them at increased risk of HIV infection. The model demonstrates the complexity of these relationships. As health professionals, nurses are often involved with communities in the planning of programs to prevent HIV. Effective HIV prevention programs must focus not only on efforts to reduce "high risk" behaviours, but also on the broad context of the behaviour. Social, economic, political and cultural factors may result in an individual using survival techniques that place them in situations where they are more likely to be infected with the HIV virus.

REFERENCES CITED

Aboriginal Nurses Association of Canada
1996 HIV/AIDS and its Impact on Aboriginal Women in Canada. Ottawa, ONT: Health Canada.

Alberta Health
1995 Strengthening the Circle: What Aboriginal Albertans Say about their Health. Edmonton, ALTA: Author.

Canadian Nurses Association
1995 Health in Canada: Perspectives of Urban Aboriginal People. Ottawa, ONT: Author.

FitzGerald, J.M.
1994 Recent Plateauing in Number of TB Cases in Canada, Calls for Caution, not Cheers. Canadian AIDS News VII(6):3.

Freudenberg, N.
1990 AIDS Prevention in the United States: Lessons from the first decade. International Journal of Health Services 20(4):589-599.

Health Canada
1994 HIV/AIDS and Aboriginal People in Canada. Ottawa, ONT: Medical Services Branch.

Houston, S. and H.Reese
1995 Increasing HIV Infection among Aboriginal People in Northern Alberta. Paper presented at the Fifth Annual Conference on HIV/AIDS Research, Winnipeg, Manitoba, Canada.
1996 HIV Infection among Aboriginals in Northern Alberta. Poster presentation at the XI International Conference on AIDS, Vancouver, British Colombia, Canada.

Kleinman, A.
1980 Patients and Healers in the Context of Culture. Berkley: University of California.

Myers, T., L.M.Calzavara, R.Cockerill, V.W.Marshall and S.L. Bullock
1993 Ontario First Nations AIDS and Healthy Lifestyle Survey. Ottawa, ONT: National AIDS Clearinghouse.

Postl, B. and M.Moffat
1988 The Health of Canada's Native People: An Overview. Canadian Family Physician 34:2413-2419.

Shah, C.P.
1990 Public Health and Preventive Medicine in Canada (2nd ed.). Toronto, ONT: University of Toronto.

Statistics Canada
1993a 1991 Aboriginal Peoples Survey: Language, Tradition, Health, Lifestyle and Social Issues. Ottawa, ONT: Author.
1993b Census 1991: Aboriginal Data. Ottawa, ONT: Author.
1994 Census 1991: Profile of Census Divisions and Subdivisions in Alberta-Part B. Ottawa, ONT: Author.

Waldrum, J.B., D.A.Herring and D.K.Young
1995 Aboriginal Health in Canada - Historical, Cultural, and Epidemiological Perspectives. Toronto, ONT: University of Toronto.

World Health Organization
1994 AIDS: Images of the Epidemic. Geneva: World Health Organization.

Wotherspoon, T. and V.Satzewich
1993 First Nations - Race, Class, and Gender Relations. Scarborough, ONT: Nelson.

Zwi, A.B.
1993 Reassessing Priorities: Identifying the determinants of HIV Transmission. Social Science and Medicine 36(4):iii-viii.

An Explanatory Model of HIV Illness in Aboriginal Women

INTRODUCTION

Acquired immunodeficiency syndrome (AIDS) is a contemporary illness that has caused immense human tragedy and suffering during its brief existence. The search for effective strategies to prevent the spread of the human immunodeficiency virus (HIV) that leads to AIDS disease has presented a monumental challenge to health professionals for the past decade. Despite progress in limiting the spread of HIV infection in some sub-groups of the population, the epidemic continues its spread and is of growing concern for women (World Health Organization 1994). In addition, there is increasing recognition in North America that HIV infection disproportionately affects women who belong to minority groups (Smeltzer and Whipple 1991).

HIV infection is a health issue of concern in the Aboriginal population of Canada (Health Canada 1994; Waldrum, Herring and Young 1995) and Alberta (Alberta Health 1995; Feather of Hope Aboriginal AIDS Prevention Society 1994). The number of HIV infected Aboriginal people in northern Alberta has risen steadily since 1985 (Houston and Reese 1995). Concurrent with this trend is the dramatic increase in the number of Aboriginal females in Alberta who are HIV positive (Houston and Reese 1995). Aboriginal women, therefore, are one segment of the Alberta population that appears to have an increased rate of infection with the HIV virus.

Following the discovery of the modes of transmission for the HIV virus, individual behaviour change was promoted as a key strategy to decrease its spread. Although important, this approach may be limited in its effectiveness because it does not acknowledge the broader context of disease transmission (Freudenberg 1990). As the epidemic has unfolded in the past decade, health practitioners and social scientists have increasingly argued that effective HIV prevention strategies must be predicated on knowledge about the cultural and social forces that influence the risk of HIV infection (Freudenberg 1990; Myers et al. 1993; Parker 1987; Worth 1989; Zwi 1993). The need for "culturally sensitive" HIV prevention for the Aboriginal population is well documented (Sinclair 1993; Health and Welfare Canada 1990; Myers et al. 1993) and yet the literature is devoid of descriptions of what is culturally sensitive.

A research study was undertaken in 1996 in order to increase understanding of the cultural factors that relate to HIV infection in northern Alberta Aboriginal women. The purpose of the study was to explore the question "What explanatory model do HIV positive Aboriginal women use to describe their illness". The explanatory model has been developed from in-depth interviews that elicited information on the etiology, pathophysiology, symptomology, course of the illness, and methods of treatment for HIV illness (Kleinman 1978, 1980; Kleinman, Eisenberg, and Good 1978) from the participants' perspective. In addition to these elements, information about source of infection and view of HIV illness was elicited from the participants. By articulating the explanatory model of HIV illness used by Aboriginal women, comparisons and contrasts can be made with the explanatory model of HIV illness used by professionals. This process can provide insights that are essential to the planning of "culturally sensitive" prevention and treatment programs for this population.

The tribal affiliation of each of the participants was documented when demographic information was gathered. During the interviews the woman's perception of contact with her Aboriginal traditions was explored. This was relevant because most of the women were currently living in an urban setting and may have had limited opportunities to participate in a traditional Aboriginal lifestyle. The degree of contact with Aboriginal traditions may be reflected in the participant's explanatory model of their HIV illness.

Prevalence of HIV Infection

There are few reports in the literature of the seroprevalance of HIV in the Canadian Aboriginal population. Several factors have contributed to this limited data base. In some provinces, such as Alberta, infection with the HIV virus is not reportable until an individual has progressed in the disease process to having an AIDS defining illness (Alberta Government 1988). In addition about one-third of the total cases of AIDS reported in Canada do not include the ethnic origin of the case, with the probable result that the number of Aboriginal people who have AIDS is under reported (Health Canada 1994). The seroprevalence studies that have been completed have focused on high risk groups such as intravenous drug users and prison inmates (Aboriginal Nurses Association of Canada 1996). One exception to this is a seroprevalence study that is currently underway on the Sioux Lookout reserve in Ontario but results are unavailable to date (Lawrence 1994).

In Alberta, there is concern that HIV infection may be widespread in the Aboriginal community because cases are not concentrated in any one risk group or one geographical area

(Houston and Reese 1995). In HIV clinics in an urban centre serving northern Alberta, Aboriginal people represent approximately 10.5% of the total number of HIV positive clients seen since 1985 (Houston and Reese 1996). When statistics for the Clinics for the past three years were analysed the percentage of new HIV positive clients who are Aboriginal rose to 26%. The proportion of Albertans who are Aboriginal, however, is approximately 6% (Statistics Canada 1993, 1994). In these HIV clinics, the proportion of new Aboriginal clients that are female is 25% (Houston and Reese 1995). In contrast to this, the proportion of the total new clients that are female is 7% (Houston and Reese 1995) indicating that the Aboriginal female population appear to be over represented in the HIV statistics for northern Alberta.

Theories of health, disease causation and healing

Some generalizations can be made about the theories of health, disease and healing among different Aboriginal tribal groups across Canada. Prior to contact with Europeans in the sixteenth century, Aboriginal people in Canada had developed a complex healing system based upon "rational understandings of the universe and people's place within it" (Waldrum, Herring and Young 1995:100). Health and a long life were positive values among Aboriginal people and disease interfered with the attainment of these goals. Aboriginal peoples of Canada traditionally adopted a holistic view of health that involved the balance between the physical, emotional, mental and spiritual aspects of an individual (Favel-King 1993; Malloch 1989) and included balance with the natural world (Malloch 1989).

Medicine in traditional Aboriginal society was deeply intertwined with spirituality (Waldrum, Herring and Young 1995). The practice of medicine therefore was much more complex than the healing of diseases and the prescribing of herbal remedies. Although minor illnesses could be treated with herbal medicines, more serious illnesses were viewed as a result of prior transgressions of the cultural norms and their treatment required that an individual request the assistance of a medicine man with specialized power to heal (Waldrum, Herring and Young 1995).

Disease represented a disruption in the balance of one's life and was believed to be a gift from the Creator as a reminder that an individual must work to regain this balance (Brown 1990). Rather than viewing illness as an enemy to be eradicated, Aboriginal people perceived illness as a teaching that "carries symbolic spiritual significance and can be a guide to blessings and balance" (Brown 1990:4).

The intrusion of foreign objects into the body, the loss of the soul, and the transgression of cultural taboos are examples of events that could cause disease (Medicine 1988). The concept of preventing illnesses is absent in the traditional view of disease causation (Medicine 1988).

In a study of the Ojibwa peoples of Manitoba, Hallowell (1963) found that serious illnesses resulted from the transgression of the moral order and therefore the occurrence of disease and its treatment were mechanisms to reinforce the social and moral order of society. Confession by the individual was an essential element in the treatment of diseases, and ensured public knowledge about incidents of bad conduct (Hallowell 1963). This process, through censorship of negative conduct, ensured that the moral order was upheld.

The tradition of the Plains Cree required an individual to request the healer to assist him and to present the healer with a gift as part of this request (Mandelbaum 1940; Morse, Young and Swartz 1991). Healing rituals required the "active participation by the patient, the healer's spirit helpers and the Great Spirit" (Morse, Young and Swartz 1991:1361). Among Cree "a disease must be felt" (Morse, Young and Swartz 1991:1362) by the individual before he or she seeks the assistance of a healer. Today due to the process of assimilation with European culture (Wotherspoon and Satzewich 1993) the Aboriginal women in the study will vary in the degree to which they adhere to these traditional theories of health, disease causation and healing.

DESIGN

A qualitative research approach was selected for this study. This approach was deemed to be most suitable for describing the explanatory model used by the women in the study. A qualitative approach assists the researcher to provide "information of a sensitive nature that cannot usually be uncovered in surveys or formal interviews "(Herdt and Boxer 1991:172).

METHODS

Population

The target population included all Aboriginal female clients seen at five agencies in an urban centre in northern Alberta. These sites were identified as the key agencies that interface with HIV positive women. There are approximately twenty-five Aboriginal women in northern Alberta who know that they are HIV positive (Houston and Reese 1996).

The term Aboriginal as used in this study included women who identified themselves as Metis, Native, Indian or First Nation regardless of treaty status[1]. The tribal groups that are indigenous to Alberta include the Cree and the Blackfoot (Jenness 1977), with the Cree being the most common tribe in northern Alberta. The inclusion criteria were self-report as an Aboriginal of any tribe, agreement to participate in the study, HIV positive, ability to speak and understand English, living within a 100 kilometre radius of the urban centre and over the age of 18 years. The criterion for place of residence was expanded to include women living within 200 kilometres of the urban centre.

Sample

Eight women participated in the study, representing approximately one third of the total estimated population. The demographic information relating to tribe, marital status, religion and place of residence of the participants has been summarized in Table I, following the references. Age, number of children, education level and length of time since diagnosis can be found in Table II.

Sampling Techniques

In the fifteen months prior to beginning the study, the researcher made contact with three of the key agencies and negotiated either a clinical placement or volunteer work with them. Gaining entry to the population was anticipated to be difficult because the researcher was not Aboriginal and the research topic was very sensitive in nature. By establishing professional credibility with the agencies involved prior to the commencement of the study, entry to the study population was facilitated.

Nonprobability convenience sampling (Brink and Wood 1994) was the primary technique used to recruit participants to the study. Contact persons in each of the agencies were asked to give an information sheet about the study to eligible women. The women were asked to telephone the researcher if they were interested in participating. This method was successful in recruiting only one participant. The researcher achieved greater success in recruitment by having the contact person seek permission from potential participants to have the researcher contact them. The recruitment process required many telephone calls to the contact persons and visits to the participating agencies, during the five month recruitment period. The contact people in the agencies referred the researcher to two additional agencies during the study who identified three women.

An observation made by the researcher during the interview process was that if the women were very recently diagnosed, they were less likely to be willing to be interviewed for the study. Two women who had been very recently diagnosed (eg one week and one month) were approached to be in the study and declined, saying "I am not ready to talk to anyone". In addition one participant who moved prior to the second interview was also the most recently diagnosed. Several unsuccessful attempts were made by the researcher to locate this woman in order to complete the interview process. This participant's first interview had been the most difficult: she was very guarded in her conversation and was reluctant to share details of her history.

The Interview Process

The women were interviewed using in-depth interviews. Seven of the women were interviewed twice and one woman was interviewed once. Each interview ranged from one hour to two and one half hours, with two to three weeks between the first and second interview. Six of the interviews took place in the women's homes, four took place in a prison setting, three took place in a residential treatment centre for substance abuse and one took place in the university. All of the interviews were tape-recorded, with the exception of three in prison settings. Permission was denied by prison security personnel to tape-record these interviews.

Reciprocity is an issue that was considered in carrying out research with this population (Lipson 1994). Tobacco is a traditional gift that is respected in the Aboriginal culture and was considered in the original research design as a possible gift for the study participants. Based on consultation with Aboriginal community leaders and the researcher's appraisal of each interview situation however, tobacco was not offered as a gift during the study. Participants were given $10.00 following each interview to compensate them for their time and inconvenience.

Participants were guaranteed confidentiality of data and anonymity was assured through several methods. This was especially important due to the small sample and the potential for recognition in the written reports. Only the researcher knew the identities of the women recruited to the study. The data sets were coded by number to ensure that participants' names did not appear on the interview transcripts. The demographic data were grouped in the written reports to ensure that the participants were not recognizable and to enhance anonymity.

One woman experienced some difficulty as a result of the interview as expressed in the following comments during her second interview. "I was tired for two days after the last session...I had to, you know, lay down, put everything back in it's place, like putting a square in a circle kind of thing". A list of community resources had been compiled for the referral of participants if necessary, however in this instance the researcher determined that the woman was receiving ongoing support from a counsellor.

Data Analysis

The data were analysed simultaneously with data collection (Miles and Huberman 1994). The interviews were transcribed and prepared for entry in to the qualitative data analysis software program, NUD.IST (Non-Numerical, Unstructured Data Indexing, Searching, and Theorizing). An initial list of codes was made following the first interview and was revised as necessary throughout analysis. Each code identified the common themes that emerged from the data and included descriptive information from each interview. The interviews were analysed on a line by line basis within NUD.IST and involved sending portions of data representing the different themes to the codes created by the researcher.

During the process of coding the data, memos were used to record relationships between the codes as the researcher became aware of them. NUD.IST facilitated the creation of memos and allowed the researcher to attach them to the appropriate portion of the data. A journal and field notes were used to add contextual information to the interview data and to record the subjective views of the researcher during the research process.

FINDINGS

Contact with Aboriginal Traditions

In exploring each woman's perception of her past and current contact with Aboriginal traditions, several themes emerged. Initially several women believed that they had been raised in a "white man's world" and that their Aboriginal heritage had had little influence on their lives. A variety of factors contributed to this perception: three of the women had been removed from their homes between the ages of two and eight and spent several years in non-Aboriginal foster homes. Another woman had grown up with her non-Aboriginal mother and did not learn of her father's Aboriginal background until she was aged twenty-one. A similar experience was described by another participant who was taken from her Aboriginal mother at the age of eighteen months and raised by the mother's non-Aboriginal boyfriend. One participant, although spending her first fourteen years with her Aboriginal mother, stated that "none of my family's into the Native culture".

The experience of two women provided a counterpoint to the theme of feeling part of a "white man's world". One participant believed that her early experiences with her Aboriginal culture had exerted an ongoing influence on her life. This woman's parents, due to their problems with alcohol, had delegated her care to an aunt shortly after her birth. The aunt, who was Aboriginal, cared for the woman during her first five years of life. Following the death of the aunt, the participant spent the next five years in a residential school. She recalled those years in residential school as "five long miserable years" where "everything I was taught was trying to be taken away from me". The residential school experience was followed by a series of more than thirty foster homes between the ages of ten and fifteen years, many of which were non-Aboriginal. Despite the repeated trauma experienced after the age of five, this participant believed that cultural teachings learned from her aunt, continued to influence her life:

> They say that everything you learn for your life is given to you in the first five years after you are born. All the tools you need for having a successful life. She taught me how to be traditional...she taught me how to respect myself, how to respect men...a lot of things that she taught me that are really part of me now as a woman.

The other exception to this theme was provided by a woman who had been raised on a reserve by her parents and grandmother, in an Aboriginal milieu.

Although several participants initially identified themselves as being part of a "white man's world", as the interviews progressed they described incidents or people in their lives that had enhanced their awareness of their culture. Some mentioned that they had had Aboriginal boyfriends who had exposed them to traditional beliefs:

> I met a guy when we were fixing and he asked if I'd like to go to his reserve with him. While I was there I visited a Medicine Man and started to learn about native traditions.

A few of the women recalled learning about their culture through counsellors during periods of imprisonment. Another woman, although growing up in an urban area, could recall visiting traditional healers and participating in sweat lodge ceremonies when she would visit family members on a reserve.

For most of the women interviewed, the diagnosis of HIV triggered an attempt to develop a greater understanding of their Aboriginal culture. In addition, these women felt comfortable with the Aboriginal view of spirituality:

> I have no problem today with talking of Native spirituality because it's something that's not forced upon me, it's me, it's up to me if I want to learn it, not like when I was a young kid and pushed in to the religious bullshit...

One of the woman had recently deepened her understanding of her Aboriginal culture during her stay in a drug treatment program. She found that the Aboriginal beliefs and values "fit" her own philosophy:

> I've always thought I had a calling - Native culture seemed right. It was natural for me.

Since diagnosis many of the women continue to explore aspects of their Aboriginal customs and beliefs.

EXPLANATORY MODEL OF HIV ILLNESS

Etiology

There was a strong feeling among most of the women, that they had become HIV positive for a reason. For the participant who had only known of her HIV status for three months, self-reflection on the reasons for her illness was limited. The difficult and painful process of accepting her diagnosis had prevented her from reflecting on how her HIV illness fit with her world view. Because this woman moved prior to the second interview, the researcher was unable to follow up this theme.

Two of the participants believed their HIV illness was part of the Creator's plan for them. One woman explained the reason that she had become HIV positive very eloquently:

> ...for all of the times that the Creator helped me through the years and he needed something back. Maybe, you know I was paying for my past mistakes.

The other woman also believed that her HIV illness was related to the Creator's overall design for her life:

> You know I believe I got it for a reason, the Creator works in strange ways sometimes. This is the Creator's way to get me to slow down and think about what I want to do.

Another woman, although not specifically referring to the Creator, believed that she had become HIV positive because she was a strong person and would be able to learn from her illness. She described her insights about her illness in the following:

> I have a positive attitude with it and I feel now that if it wasn't for that I probably wouldn't be sober right now. You know it's actually made me realize that what I'm going through is okay, it's part of me...

Some of the women expressed their belief that they deserved to be HIV positive based on their previous behaviour: "like I did it, I deserved it". Two of the women presented fatalistic views about their illness, believing that they had always known they would become HIV positive.

Source

All of the women in the study, with one exception, had a history of intravenous drug use and had shared needles. Sharing needles was the most frequently mentioned source of infection for these participants:

> I used to share needles all the time with whomever and whatever and that's the only way that I knew that I

> could have or had to have gotten it anyway is through IV drugs. Because I really didn't care who I shared needles with as long as I got that drug in to me, that was my main priority at that time.

One women initially stated that the source of her HIV had been a blood transfusion, but later suggested that there were many different ways that she could have contracted HIV, because of her history of needle sharing and unprotected sex. Another woman was uncertain about the route of infection that had caused her HIV illness. Around the time she became positive, she had engaged in unprotected sex with a man she believes to be HIV positive and had also shared needles. The one woman with no history of intravenous drug use believed that her source of infection was through unprotected sex with a boyfriend who later developed AIDS.

Symptomology

Only one of the women interviewed was experiencing any symptoms of illness at the time of diagnosis. This woman had been experiencing fatigue and recurrent infections at the time her physician suggested an HIV test. Four women were tested as part of a regular medical assessment, based on their doctor's knowledge of their previous lifestyle. Two were tested after finding out that a sexual partner had been diagnosed HIV positive. One woman was tested without her knowledge while in a detoxification centre.

None of the women in this sample had progressed to AIDS, although all had symptoms that they attributed to the HIV virus. All of the women except one had experienced a change in their energy level that ranged from fairly minimal to severe. One woman who was the single parent of a three year old described her profound lethargy in terms of its effect on her parenting:

> My energy level has decreased quite a bit. I mean there are times when I can't even get up out of bed and I have to because I have a three year old and a three year old has so much energy you know, so I really have to force myself to do these things.

Other symptoms that were mentioned included night sweats, swollen lymph glands, increased susceptibility to infections, migraines, and weight loss. One woman had not experienced any symptoms as a result of her illness and believed that because she was now taking care of herself, she was healthier than many people without HIV infection.

Pathophysiology

When asked how the virus was affecting their body, the women gave examples of physical and emotional consequences of their illness. This may reflect their inability to separate the physical and emotional aspects of the illness process. The following statement from one woman demonstrates a fairly good understanding of the role of the virus in causing disease:

> I know how the virus gets in to your little white blood cells and eat them up and they multiply.

Another woman who had lost weight since her diagnosis depicted the virus as "deteriorating, breaking down my body ... you know I'm losing weight and wasting". The woman who had known of her diagnosis for seven years described her illness in terms of a "battle" that her body was fighting:

> It's a continuous battle and you just sort of lose the battle more as you go along. The virus is still in there, there's millions of viruses in there and ... your immune system fights them and keeps them down for a while, but then they eventually take over.

Several women related emotional sequelae of their illness, when asked how the virus was effecting their body. One woman had noticed behaviour changes and found her moods changing quickly from happiness to anger. Another woman who had found her energy level to be low, was more concerned with emotions that she had experienced since diagnosis:

> ... and then there's depression, anger, hopelessness, embarrassment, revenge, afraid, numb and sometimes I feel peace.

Depression was mentioned by two women as an effect of the HIV illness on their body.

Course of illness

Most of the women reacted to their diagnosis with shock, anger, fear and at times, denial. The fear and anxiety felt by one woman had paralysed her ability to discuss her illness with her physician and review treatment possibilities:

> I was supposed to take another blood test six months ago but I didn't, I've been holding back and holding it off because I'm scared I don't want to find out more than I know.

A common need felt by the women in the first few months following diagnosis was the ability to keep their diagnosis confidential:

> You have cancer people feel sorry for you. But this, you know you can't tell everybody, I'm HIV positive .... You keep it all to yourself so you want to be as private as possible...

At the time of the interview, a broad range in the stage of disclosure was seen among the women. The most recently diagnosed woman related the precise number of people she had shared her diagnosis with, whereas another woman who had known of her diagnosis for three years had spoken to the media about her HIV infection. One woman experienced great difficulty in disclosing her illness, after her closest family members had refused to accept her diagnosis.

Despite the attempt to control who knew of their diagnosis, several of the women found that this information spread very quickly in their community. As a result, they experienced discrimination from friends, family and professionals who expressed their fear of becoming infected with the HIV virus. One woman was preparing to move at the time of the interview because of the extremely prejudicial remarks made by her roommates in regard to individuals who were HIV positive.

Prior to their diagnosis the women had all had difficulties with alcohol and/or drug abuse. Some of the woman were engaged in prostitution. For most of the participant's, their HIV diagnosis triggered a downward spiral in their lives. This painful time period was manifested by an even greater involvement in "self-destructive" behaviour that for some included attempted suicide:

> In the first two years after my diagnosis, I really didn't care about myself because I knew I was going to die anyway, I tried to kill myself on several occasions.

One woman viewed her behaviour following her diagnosis as an effort to speed up her dying process:

> I started doing IV drugs a lot worse. I pushed my son away completely at the time. I even pushed my best friends away...I was in the first stage of it, of being HIV positive...Poor me I'm dying, so I'm going to help the process along real quick like....

The following poem entitled "Crumbling Walls" was written by one participant shortly after her diagnosis:

> Raging in confusion and anger
> Fighting deep within myself
> Struggling to hold on tightly
> Walls crashing down

Emotions running
Wanting to run, so fast and far
Confusion keeps raging
Fighting to hold on

Beliefs put to the ultimate test
Gaining self control
Letting go, so as to drift
Crumbling walls, falling fast

Trust, faith and honour
Coming in to play
Feelings rapidly turning
The inner turmoil calming

Faith makes me stronger
Fear leaves me, so I can
Make peace within myself
Letting the walls crumble C.J.W. 1995

For about a year after their diagnosis several women said that they abstained from sexual relationships. Explanations for this reaction included an inability to trust men and a fear of passing the virus on to someone else.

The downward spiral in the women's lives lasted from approximately six months to three years, at which time the women "bottomed out". Several of the women described events or people that triggered a turning point in their lives: the downward spiralling process was halted and they were able to shift their life path in a more positive direction. Their love for their children was often the motivator to turning around their lives. Three of the partipicipants had their children taken away from them by child welfare. At the time of the interview, they were attempting to make positive changes in their life, in order to regain custody of their children. A mother of a young child described her turning point in a poignant interaction with her son:

> I was in my bathroom and my little boy at the time, he was 18 months old and he was crying on the outside of the door and was banging on the door, kicking at the door. I was going to OD. I had two grams of cocaine in a rig ... I was going to end it all. I didn't want to die of AIDS ... I had put some in my arm and I stopped because I'd heard this little kid on the other side of the door, "Mommy, Mommy". I sort of stopped and I said, "Nancy you may have a disease that's going to kill you but you still have somebody here that needs you".

For another mother, a sexual assault was the tragic event that was the turning point in her life. Two of the women committed crimes resulting in a period of imprisonment. During this time, with the help of professional counsellors, the women began to accept their HIV illness and to plan changes in their lifestyle. The path that these women chose was not an easy, straightforward one and included setbacks along the way.

At the time of the interviews most of the participants expressed the feeling that their illness had effected some very positive consequences. They had experienced personal growth in their lives and related that they were feeling more honest with themselves, had developed greater self-respect and had been able to view their lives from a more positive perspective:

> ... All these negative things that I used to think and do, I turned it all in to a positive thing you know.

One woman, despite having lost her husband to AIDS, viewed her HIV illness as one of the best things that had happened to her:

> I always tell people that being positive is not all bad. I hear people saying this is one of the best things that's ever happened to me and ... it's true because I don't think I would have come to this point this fast if I didn't have all this stuff to look at ... I'd start waking up and seeing things and I really needed to change ... I need to build my self esteem ... I need to be a better person ... it just makes you look at your life differently.

As a consequence of greater self-respect, the women spoke of having more respect for others. They were all participating, or planning to, in charitable work in their communities. There was a common feeling that the insights they had gained since becoming HIV positive could be shared with other women. The exception to this theme came from the woman who had been most recently diagnosed: she did not fully accept her illness and therefore was not yet able to reflect on any positive consequences of it.

Treatment

The women's views of treatment for HIV illness, as well as their experience with different treatment modalities, were explored in the interviews. When asked about how they were treating their illness, seven of the women emphasized the need to stay healthy. To maintain their health the women used a variety of strategies: alleviating stress in their lives, ensuring they received adequate nutrition, exercise and rest and avoiding contact with other infectious diseases such as colds. Two of the women believed that they should not interfere with the natural process of dying:

> I don't like to take pills especially pills that are supposed to keep me alive. I mean the way I look at, if I'm going to die, I'm going to die...

For several of the women, the decision of when to seek treatment would be based on their assessment of whether they felt "sick". At the time of the interview, they did not feel sick and had not sought treatment:

> If I start feeling sick and when I start getting symptoms well then I'll take it.

Most of the participants had done a lot of reading about HIV illness and its treatment since their diagnosis and were utilizing this knowledge in making their decisions about treatment. An exception to this finding was the woman from a reserve who had not read about HIV illness, and knew little about possible treatments for it.

Only three participants were taking anti-retroviral treatment for their HIV illness at the time of the interviews. One woman had been prescribed anti-retrovirals, but was not taking them because they would interfere with the dying process and she had an aversion to taking pills based on her history of substance abuse:

> There's just too many pills to take and in my addict's mind it's like I'm doing something wrong.

Several of the women with a history of drug abuse had difficulty with the notion of taking pills. A common concern of the women who had experienced taking anti-retroviral drugs, or had thought about it, was the potential side effects from the drugs. One woman who had taken anti-retrovirals prior to being interviewed said:

> I started and I only stayed on it for a couple of months and then the side effects were muscle spasms, muscle aches so bad that I couldn't walk. I couldn't move. I just laid in bed and it hurt.

Another woman had not taken any medication for her HIV illness, and did not plan to, because of her belief that anti-retrovirals were potentially harmful:

> Well I'm concerned about their side effects. I don't want to take rat poison. I think if you're dying, you're dying and everything should be natural. I really don't want to take chemicals.

Most of the women who had delivered a baby since their diagnosis, had taken anti-retrovirals during their pregnancy to decrease the likelihood of passing the virus to their babies. One woman had not taken anti-retrovirals during pregnancy, on the advice of her physician.

All of the participants were aware that there were traditional Aboriginal treatments for their HIV illness. Some of the women had participated in healing circles or sweat lodge ceremonies to assist them in maintaining their health. One woman became very involved with learning traditional dancing, as she began to follow a "healing path". One of the incarcerated women was participating in sweat lodge ceremonies while in prison, whereas the other imprisoned woman planned to do this after her return to her own community. Several participants had consulted, or were planning to consult, medicine men to explore the use of herbs and medicines for their illness. One woman had visited a traditional healer about a year prior to the interview, but had not followed through with his advice at the time:

> He would tell me that there was hope and that there were drugs that could cure it. At the time I didn't pay any heed to it. I was still using drugs and didn't give a shit. What he taught me has stuck with me, he helped me to accept my HIV.

For some women, the concept of spirituality was connected to their view of treatment. For example, one participant explained that she hoped to achieve spiritual health by participating in sweat lodges and healing circles: "I believe that if you keep your spirit healthy you know, you stay healthy and have a more open mind".

Several of the partipicipants were taking alternative treatments such as herbs and vitamins. These therapies were taken to build the immune system, purify the blood and improve energy levels. In addition one woman who had read extensively on HIV illness, felt that the illness resulted in vitamin depletion and necessitated extensive vitamin replacement. The goal of alternative therapy in general was the maintenance of optimum health. The treatments used by the women in the study for their illness is summarized in Table III.

DISCUSSION

Several themes in the findings of this study are relevant for health care providers, in particular those working in the area of HIV/AIDS prevention and care. At the outset of the study, the researcher was unsure how much contact each participant would have experienced with their Aboriginal culture. A very interesting theme that emerged from the data was the finding that all of the women, whether they lived in urban or rural settings, demonstrated values and beliefs that were congruent with traditional Aboriginal values. Although several women felt that they had been raised in a "white man's world", some of the Aboriginal beliefs that they had learned as children persisted and were evident in their world view as adults. The women were often not aware, themselves, that their beliefs were grounded in their Aboriginal culture. In the planning of HIV/AIDS programs with Aboriginal people, health professionals should not pre-judge the degree to which a population adheres to traditional values and beliefs, based on information such as place of residence.

A summary of explanatory models used by Aboriginal people for other diseases is pertinent to the discussion of these findings in order that comparisons and contrasts can be made. In a study of explanations of hypertension in an Ojibwa community, Garro (1988) found that although participants cited many different causes for their illness, the concept of balance was the basis for most of these causes. Treatment, therefore, focused on restoring the body's balance through activities such as stress reduction, abstaining from alcohol, diet and weight loss. These activities were related to living a healthy lifestyle and are similar to the strategies of "staying healthy" used by the women in this study as part of their treatment. Another similarity in the two explanatory models was the finding that for many of the participants biomedical treatment was used primarily when symptoms of the illness were present. Participants in Garro's study, like the women in this study, used traditional treatments such as herbal remedies alone or in combination with biomedical medicine, to control their illness. One area where the two models are different relates to the etiology of the illness: in the explanatory model for hypertension, imbalance was the primary cause, whereas in the model for HIV illness payment for past mistakes and the ability to learn from the illness were the main causes cited.

Explanatory models of diabetes among the Ojibwa (Garro 1995) and a group of Ojibwa and Cree urban residents (Hagey 1984) have been described. Both models were similar in their findings that diabetes could be attributed to the individual being "out of balance", and was related to diet. A finding in Garro's model of diabetes that was similar to the one for HIV illness in this study, was that the perception of symptoms was a trigger for using medication to treat the illness. The respondents in Garro's study defined diabetes as a "white man's sickness" that could be differentiated from illnesses that resulted as payment for wrong doing or due to bad medicine. Hagey (1984), on the other hand, found evidence of the belief that diabetes resulted as a payment for a past wrong.

Garro (1990) distinguished between "white man's sickness" that was due to broad societal changes and "Anishinaabe sickness" that was related to an individual's actions, such as inappropriate behaviour. Biomedical treatment was effective for "white man's sickness", whereas a traditional healer was necessary to treat "Anishinaabe sickness" (Garro 1990). Garro (1990) concluded that confusion about the etiology of a disease often resulted in the "concurrent or sequential use of both medical systems" (447). This explanation may partially explain the variety of treatment regimes for HIV illness chosen by the women in this study. Confusion may exist regarding the etiology of HIV illness, because it is a fairly new disease faced by Aboriginal people.

A review of the literature did not reveal any biomedical "explanatory models" for HIV illness. This may be due to the tendency among health professionals to view sickness from the perspective of disease rather than illness (Kleinman 1980). Disease refers to an alteration in the structure and/or function of the body whereas illness is a much broader concept that encompasses the individual's perception of and experience with the disease (Kleinman 1978, 1988). One study done in the early 1980's (Bolognone and Johnson 1985) compared the congruence of lay perceptions of AIDS with those of professionals, however the professional explanatory model was constructed through the use of a content analysis of available literature. The components of the professional model were not detailed in the report of the study.

In the absence of a published biomedical explanatory model for HIV illness, current knowledge of HIV disease will be summarized. HIV disease is caused by a virus, the human immunodeficiency virus that, as the name implies, affects the immune system of the body (Miedzinski 1992). Transmission of the virus occurs primarily through infected blood, sexual contact or from mother to child during pregnancy, delivery or early postpartum. Spread of the virus can be inhibited or prevented through behaviours such as the use of condoms and clean needles and, more recently, through drug treatment during pregnancy to prevent vertical transmission (Peckham and Gibb 1995). The replication of the virus leads to the suppression of the immune system, resulting in the individual becoming susceptible to opportunistic infections. Symptoms of the disease often do not occur for many years after infection and include fatigue, malaise, fever, night sweats, lymphadenopathy, opportunistic infections and weight loss (Miedzinski 1992).

Serological testing to detect the virus or its antibodies is available to assist physicians in the diagnosis of HIV infection. Decisions regarding treatment of the disease are based on laboratory tests to assess the status of the individual's immune system. As immune function declines, treatments to prevent opportunistic infections and reduce viral replication may be initiated, and include a range of pharmaceuticals. AIDS represents "the severe end of a spectrum of clinical disorders" (Miedzinski 1992:1401), caused by the HIV virus. To date, death has been the almost inevitable consequence of AIDS, however new drug combinations offer promise of long term control of HIV disease.

Several aspects of the explanatory model of HIV illness described by the study participants are congruent with the biomedical explanation of the disease. The women knew that HIV was a viral disease and attributed sharing needles or having sex with infected partners as the likely source of their illness. They had a fairly good understanding of the pathophysiology and common symptoms of the disease. In general, the women were well informed about the treatments available for HIV disease and the side effects associated with them.

The descriptions that the women gave of their experiences with HIV illness demonstrated their perception of HIV as an illness rather than a disease. Their conceptualization of their illness included individual, familial, and societal responses to their HIV infection. The concept of the "experience" of an illness is absent from the biomedical model of HIV disease. Several of the experiences described by the women in the study have been found in studies with other populations. Disengagement from sexual relationships following diagnosis with HIV is common (Adam and Sears 1994). The difficulties encountered with disclosure and subsequent discrimination described by the study participants were comparable to findings in a recent study by Moneyham et al(1996). The profound stigr [illegible]t HIV illness is capable of generating (Alonzo and Reynolas 1995) was experienced by the woman in this study.

Some of the findings relating to etiology and treatment were also in contrast to common biomedical views of the disease. The belief by some of the women that their HIV illness was a payment for past mistakes, may add an additional challenge to the complex area of HIV prevention. How can community workers and health professionals influence the lives of women so that they avoid the mistakes that would lead to HIV infection? From an Aboriginal perspective, is it inevitable that women who use intravenous drugs or engage in prostitution will become HIV positive as payment for these transgressions from morally accepted behaviour? Health care workers must broaden their efforts in the area of HIV prevention to include programs that address the broad social, economic and political determinants of health. For example, examining the social issues that lead to prostitution and drug abuse and developing strategies to reduce these "high risk situations", may be fundamental to effective HIV prevention.

The view of treatment also provides relevant information for health care providers. Evidence of the belief that "a disease must be felt" (Morse, Young and Swartz 1991:1362) before the assistance of a healer is sought was described by some of the women. The participants did not independently seek the assistance of a health professional to determine their diagnosis. Some of the women indicated that they would not seek treatment until they felt "sick". In the biomedical view of HIV disease, treatment for HIV infection is recommended on the basis of a serological test to assess the status of the immune system, rather than when the individual feels their illness. Based on the explanatory model described in this study, the initiation of treatment by Aboriginal people may occur at a much later stage of illness. This may raise ethical issues within the biomedical community based on the knowledge that early treatment of HIV disease can prolong life. Further debate and discussion on this complex issue is necessary to ensure that treatment options that are congruent with the communities' beliefs and values are available and accessible.

Aboriginal women are interested in biomedical, traditional Aboriginal or alternative treatments (or a combination of these) for their HIV illness. The women emphasized the need to stay healthy in managing their HIV illness. Generally, there was reticence among the participants about engaging in some of the recommended biomedical treatments and about taking pills, based on their concerns regarding side effects of the medications and their history of drug use. The exception to this feeling was the willingness on the part of the participants to take medications during pregnancy to protect their unborn child from the virus. Treatment programs for HIV illness in Aboriginal individuals and communities must provide a range of options and treatment modalities. In order to achieve congruence with Aboriginal views, treatment programs should be based on the maintenance of health, including its physical, emotional, mental and spiritual aspects.

The purpose of this study was to explore HIV illness from the women's perspective. The small sample and qualitative approach used does not permit the findings to be generalized to other populations. The explanatory model of HIV illness described by Aboriginal women however, provides insights that may be useful in planning programs for the prevention and treatment of HIV infection in Aboriginal communities. Several areas of divergence from the biomedical view of HIV disease have been identified and consideration of these may help to improve the cultural sensitivity of HIV programming. Programs for HIV prevention must be based on knowledge of the communities' values and beliefs about the etiology, pathophysiology, symptomology, treatment and course of HIV illness. For example treatment services for HIV disease may need to include a range of therapies including but not limited to biomedical, traditional and alternative.

Limited epidemiological data reveals that the Aboriginal population of northern Alberta, and in particular women, have an increased rate of infection with the HIV virus. In addition, professionals and agencies working in this area are concerned about the issue of HIV infection in Aboriginal communities. As the HIV epidemic has unfolded there has been an increasing awareness of the need to explore the cultural and social forces that influence the transmission of the HIV virus. The stories told by the Aboriginal women in the study provide validation that these women are influenced by their traditional cultural beliefs and that these beliefs are reflected in their explanatory model of HIV illness.

NOTES

1. In Canada the term "Status" Indian refers to those individuals legally recognized by the federal government under the Indian Act, to be Indian (Waldrum, Herring and Young 1995).

REFERENCES CITED

Aboriginal Nurses Association of Canada
1996 HIV/AIDS and Its Impact on Aboriginal Women in Canada. Ottawa, ONT: Health Canada.

Adam,B.D. and A.Sears
1994 Negotiating Sexual Relationships after Testing HIV-Positive. Medical Anthropology 16(1):63-77.

Alberta Government
1988 Public Health Act, Communicable Disease Regulations. Edmonton, ALTA: Queen's Printer.

Alberta Health
1995 Strengthening the Circle: What Aboriginal Albertans Say about their Health. Edmonton, ALTA: Author.

Alonzo,A.A. and N.R.Reynolds
1995 Stigma, HIV and AIDS: An Exploration and Elaboration of a Stigma Trajectory. Social Science and Medicine 41(3):303-315.

Bolognone,D. and T.M.Johnson
1985 Explanatory Models for AIDS. In The Social Dimensions of AIDS. D.A.Feldman and T.M.Johnson, eds. Pp. 211-225. New York:Praeger.

Brink,P.J. and M.J.Wood
1994 Basic Steps in Planning Nursing Research: From Question to Proposal. Boston: Jones and Bartlett.

Brown,L.
1990 What is Health? What is a Healthy Community? Four Worlds Exchange 2(1):4-7.

Favel-King,A.
1993 The Treaty Right to Health. In The Path to Healing: Report of the National Round Table on Aboriginal Health and Social Issues. Pp. 120-129. Ottawa, ONT: Minister of Supply and Services.

Feather of Hope Aboriginal AIDS Prevention Society
1994 Feather of Hope Aboriginal AIDS Prevention Society Annual Report. Edmonton, ALTA: Author.

Freudenberg,N.
1990 AIDS Prevention in the United States: Lessons from the first decade. International Journal of Health Services 20(4):589-599.

Garro,L.C.
1988 The Response to Chronic Disease: Changing Models of Illness in an Ojibwa Community. In Health Care Issues in the Canadian North. D.E.Young, ed. Pp. 61-73. Edmonton, ALTA: Boreal Institute for Northern Studies.
1990 Continuity and Change: The Interpretation of Illness in an Anishinaabe (Ojibway) Community. Culture, Medicine and Psychiatry 14(4):417-454.
1995 Individual or Societal Responsibility? Explanations of Diabetes in an Anishinaabe (Ojibway) Community. Social Science and Medicine 40(1):37-46.

Hagey,R.
1984 The Phenomenon, the Explanations and the Responses: Metaphors Surrounding Diabetes in Urban Canadian Indians. Social Science and Medicine 18(3):265-272.

Hallowell,A.I.
1963 Ojibwa World View and Disease. In Man's Image in Medicine and Anthropology. I. Galdston ed. Pp. 258-315. New York: International Universities Press Inc.

Health and Welfare Canada
1990 Joint National Committee on Aboriginal AIDS Education and Prevention. Ottawa, ONT: Minister of Supply and Services.

Health Canada
1994 HIV/AIDS and Aboriginal People in Canada. Ottawa, ONT: Medical Services Branch.

Herdt,G. and A.M.Boxer
1991 Ethnographic Issues in the study of AIDS. The Journal of Sex Research 28(2): 171-187.

Houston,S. and H.Reese
1995 Increasing HIV Infection among Aboriginal People in Northern Alberta. Paper presented at the Fifth Annual Conference on HIV/AIDS Research, Winnipeg, Manitoba, Canada.
1996 HIV Infection among Aboriginals in Northern Alberta. Poster presentation at the XI International Conference on AIDS, Vancouver, British Colombia, Canada.

Jenness, D.
1977 Indians of Canada. Ottawa, ONT: Minister of Supply and Services Canada.

Kleinman, A.
1978 Concepts and a Model for the Comparison of Medical Systems as Cultural Systems. Social Science and Medicine 12(2):85-93.
1980 Patients and Healers in the Context of Culture. Berkley, CA: University of California.
1988 The Illness Narratives: Suffering, Healing and the Human Condition. New York: Basic Books.

Kleinman, A., L.Eisenberg, and B.Good
1978 Culture, Illness, and Care: Clinical Lessons from Anthropologic and Cross-Cultural Research. Annals of Internal Medicine 88(2): 251-258.

Lawrence, C.
1994 HIV Seroprevalence Data Gathering. Presentation to the Third Canadian Conference on HIV/AIDS and Related Issues in Aboriginal Communities. Toronto, Ontario, Canada.

Lipson, J.G.
1994 Ethical Issues in Ethnography. IN Critical Issues in Qualitative Research Methods. J.M.Morse, ed. Pp. 333-355. Thousand Oaks, CA: Sage.

Malloch, L.
1989 Indian Medicine, Indian Health. Canadian Woman Studies 10(2&3): 105-112.

Mandelbaum, D.G.
1940 The Plains Cree. Anthropological Papers of the American Museum of Natural History XXXVII(II):251-264.

Medicine, B.
1988 Aboriginal Views of Health. In Inner City Health: The Needs of Urban Natives. Proceedings of the 9th Symposium on the Prevention of Handicapping Conditions, Edmonton, Alberta, Canada.

Miedzinski, L.J.
1992 Early Clinical Signs and Symptoms of HIV Infection. Canadian Family Physician 38:1401-1410.

Miles,M.B. and A.M.Huberman
1994 Qualitative Data Analysis: An Expanded Sourcebook. Thousands Oaks, CA: Sage.

Moneyham,L., B.Seals, A.Demi, R.Sowell, L.Cohen, and J.Guillory
1996 Experiences of Disclosure in Women Infected with HIV. Health Care for Women International 17(3):209-221.

Morse,J.M., D.E. Young, and L.Swartz
1991 Cree Indian healing practices and western health care: A comparative analysis. Social Science and Medicine 32(12):1361-1366.

Myers,T., L.M.Calzavara, R.Cockerill, V.W.Marshall, and S.L. Bullock
1993 Ontario First Nations AIDS and Healthy Lifestyle Survey. Ottawa, ONT: National AIDS Clearing House.

Parker,R.
1987 Acquired Immunodeficiency Syndrome in Urban Brazil. Medical Anthropology Quarterly 1(2):155-175.

Peckham,C. and D.Gibb
1995 Mother-to-child transmission of the human immunodeficiency virus. The New England Journal of Medicine 333(5):298-302.

Sinclair,B.J.
1993 Aboriginal Street Youth and Sex Trade Workers Study. Report prepared for The Joint National Committee on Aboriginal AIDS Education and Prevention. Edmonton, ALTA: Alberta Indian Health Care Commission.

Smeltzer,S.C. and B.Whipple
1991 Women and HIV Infection. Image: Journal of Nursing Scholarship 23(4):249-256.

Statistics Canada
1993 Census 1991: Aboriginal Data. Ottawa, ONT: Author.
1994 Census 1991: Profile of Census Divisions and Subdivisions in Alberta-Part B. Ottawa, ONT: Author.

Waldrum,J.B., D.A.Herring, and T.K.Young
1995 Aboriginal Health in Canada: Historical, Cultural, and Epidemiological Perspectives. Toronto, ONT: University of Toronto.

World Health Organization
1994 AIDS: Images of the Epidemic. Geneva: World Health Organization

Worth, D.
1989 Sexual Decision-Making and AIDS: Why Condom Promotion among Vulnerable Women is Likely to Fail. Studies in Family Planning 20(6):297-307.

Wotherspoon, T. and V. Satzewich
1993 First Nations: Race, Class and Gender Relations. Scarborough, ONT: Nelson.

Zwi, A.B.
1993 Reassessing priorities: Identifying the determinants of HIV transmission. Social Science and Medicine 36(4):iii-viii.

Table I. Tribe, marital status, religion and residence

	n	%
Tribal Status		
Cree	6	75%
Ojibwa	2	25%
Marital Status		
Single	5	62.5%
Common Law	3	37.5%
Religion		
None	2	25%
Roman Catholic	3	37.5%
United Church	1	12.5%
Traditional	2	25%
Place of Residence		
Urban	7	87.5%
Reserve	1	12.5%

N=8

Table II. Age, # children, education level and time since diagnosis

	M	SD	Range
Age (years)	30.4	6.3	21-42
Number of Children*	3.8	1.8	0-6
Education Level	10	1.2	9-12
Time since Diagnosis (months)	26.3	26	3-84

N=8

*None of the children were HIV positive, despite five of the women delivering their most recent child since their diagnosis.

Table III. Treatments used by Participants for their HIV Illness

Participant	1	2	3	4	5	6	7	8
Biomedical								
Anti-retrovirals		+	+				+	
Antibiotics				+				
Traditional								
Sweatlodges	+						+	
Healing Circles		+				+		
Dancing		+						
Smudging/Prayer					+	+	+	
Healer/Elder	+	+				+		
Staying healthy	+	+		+	+	+	+	+
Alternative								
Vitamins	+			+			+	
Herbal Remedies	+	+						
Reike							+	

N=8

HIV Risk Behaviours Become Survival Techniques for Aboriginal Women

Introduction

Health practitioners confront complex and challenging problems in their efforts to address the widespread effects of the human immunodeficiency virus (HIV). In the first decade of the epidemic, researchers have documented knowledge, attitudes and practices that are related to HIV infection. Individual behaviours, such as needle sharing and unprotected sex, that increase the likelihood of exposure to the HIV virus have been identified. In addition, factors that promote or prohibit an individual's ability to chose behaviours that are less likely to expose them to the virus have been explored (Connors, 1994; Nyamathi, Stein & Brecht, 1995). These areas of understanding have contributed to the establishment of a broad knowledge base that has guided the efforts of health practitioners in HIV prevention.

Behaviour change, based on knowledge of factors that increase the risk of HIV infection, has been successful in limiting the spread of the virus in some populations, such as gay men. The epidemic however, continues its spread in other segments of the population. The need for research that describes the context in which the "risk behaviours" take place is advocated to achieve greater success in the prevention of HIV infection (Carrier & Bolton, 1991; Freudenberg, 1990; Kane & Mason, 1992; Zwi, 1993). Through greater understanding of the context of individual behaviour, it may be possible to "identify and strengthen the cultural forces that support prevention while also challenging those that block it" (Freudenberg, 1990, p.589). Kane and Mason (1992) argue the need to move beyond the epidemiologic concept of "risk group", to explore "the more complex and difficult questions of how and why risk situations .... are produced" (p.210).

HIV infection among the Aboriginal people in Canada has been identified as an issue of concern by governments (Health Canada, 1994), professional groups (Aboriginal Nurses Association of Canada, 1996), community agencies (Feather of Hope Aboriginal AIDS Prevention Society, 1994), and individual members of the Aboriginal population (Alberta Health, 1995). Studies of the prevalence of HIV infection in the Aboriginal population have primarily focused on specialized sub-groups such as prisoners and injection drug users (Aboriginal Nurses Association of Canada, 1996). Statistics available on new HIV patients in northern Alberta support the expressed concern about HIV infection among Aboriginal people. In HIV Clinics serving northern Alberta, Aboriginal people generally and Aboriginal women specifically are over-represented in the numbers of new HIV positive clients seen since 1985 (Houston & Reese, 1995).

In light of the concern that Aboriginal women may be at increased risk of HIV infection, a research study that focused on HIV illness in this population was undertaken in 1996. The purpose of the study was to understand the cultural factors that relate to HIV infection in Aboriginal women. One of the questions explored in the study was "What are the cultural rules about sexual behaviour as described by Aboriginal women?" It was anticipated that by understanding the rules that guided sexual behaviour, cultural forces that enhanced or inhibited prevention strategies could be identified.

Gender and HIV Infection

Several authors have argued that society must address HIV/AIDS as a women's issue because of the rapid increase in infection in women and the special issues that women face (Berer, 1993; Health & Welfare Canada, 1992; Pearlberg, 1991; World Health Organization, 1992). In Africa the heterosexual pattern of HIV disease has risen from a male/female ratio of 1:1 to 1:1.5 (Ankrah, 1991). Experience in many developing countries has demonstrated that women are at risk of HIV infection, however prevention strategies have not focused on the particular concerns of women (Berer, 1993).

HIV/AIDS (acquired immunodeficiency syndrome) was initially defined in North America as a disease primarily affecting homosexual males (Panos Institute, 1990). This definition resulted in the failure by society to acknowledge the broader social context of the disease, including the unique experience of women (Krieger & Fee, 1994). Women were left with the erroneous belief that HIV was not an issue of concern to them. Official recognition of HIV/AIDS as a women's issue was gained at a meeting of international agencies in 1989 (World Health Organization, 1990). The decision was made following this meeting to focus on women at the World AIDS day in 1990.

Women, because of their traditionally passive role in relationships with male partners, frequently lack the power to negotiate safer sexual practices (Health & Welfare Canada, 1992; Smeltzer & Whipple, 1991). The lack of power, combined with a reluctance by Aboriginal women to discuss reproductive health (Walker, 1994), may lead to women continuing in sexual relationships that they know are unsafe. These factors, in combination, demonstrate the need to consider the perspective of women in understanding the issues relating to HIV/AIDS.

Prevalence of HIV Infection

In northern Alberta the Aboriginal female population appear to be over represented in the HIV statistics. A summary of the new clients visiting HIV clinics in a large urban centre serving northern Alberta since 1985 is presented in Table I and II. From the tables it is evident that the proportion of Aboriginal people generally, and Aboriginal women specifically, is increasingly rapidly. Although the proportion of Albertans who are Aboriginal is approximately 6% (Statistics Canada, 1993, 1994), Aboriginal people represent approximately 10.5% of the total number of HIV positive clients seen in the HIV clinics since 1985 (Houston & Reese, 1996).

Aboriginal Sexuality

Two major constraints hinder the description of normative sexual behaviour among the Aboriginal peoples of northern Alberta. Firstly, there is a paucity of authoritative work in the literature on the normative sexual behaviour of Aboriginal people (C. Urion, personal communication, September 28, 1995). This finding may be related to the fact that sexual behaviour cannot be observed or manipulated by researchers in order to document the sexual mores, behaviours, and customs of a cultural group (Brink, 1987). A second limitation relates to the different tribal affiliations of the participants in the study. Women with Cree and Ojibwa tribal backgrounds participated in the study, with the majority of women being Cree.

Mandelbaum (1940) provides one account of the traditional mating practices of the Plains Cree prior to

European contact:

1)Pre-marital sexual relationships, particularly among young men, were tolerated.

2)Marriages occurred at young ages: women commonly married three or four years after puberty, while men often did not marry until about twenty-five years.

3)Marriages were frequently arranged by the family and often included an exchange of wealth.

4)Adulterous wives were commonly beaten and then given by the husband to her lover.

5)Polygyny and wife exchange were practised.

6)Unmarried young women were usually escorted when they went out of camp, however if a man came upon a young woman alone, he could decide he wanted to have sexual relations with her. The women usually submitted to these advances.

7)Female virginity at the time of marriage was not of great concern.

Incest that included mating between father and daughter, mother and son, or brother and sister was a taboo, however the Cree allowed marriage with certain cousins (Driver, 1969). Among the women in the study, a variation in adherence to these traditional mating beliefs was anticipated, due to the process of assimilation (Wotherspoon & Satzewich, 1993).

Design

In order to explore the cultural factors that may have influenced HIV infection in Aboriginal women, a qualitative research approach was used. The need for research that explores the context of behaviours relating to HIV infection has been advocated, as a complementary approach to research that is focused on individual behaviour and the epidemiology of HIV (Zwi, 1993). A qualitative approach is congruent with the story-telling method of transferring information in the Aboriginal culture.

Methods

Population

In northern Alberta there are approximately twenty-five Aboriginal women who know that they are HIV positive (Houston & Reese, 1996). Five key agencies that interface with HIV positive Aboriginal women in a large urban centre serving northern Alberta were identified. The target population included all Aboriginal female clients seen at these five agencies.

Inclusion criteria for the study were agreement to participate in the study, self-report as an Aboriginal of any tribe, ability to speak and understand English, HIV positive, over the age of 18 years, and living within a 100 kilometre radius of the urban centre used for the study. The residence criterion was expanded to include a 200 kilometre radius of the urban centre. The term Aboriginal as used in this study included women who identified themselves as Native, Indian, Metis or First Nation regardless of treaty status[1]. The Cree and Blackfoot are the major tribes indigenous to Alberta, with the Cree being the most common tribal group in northern Alberta (Jenness, 1977).

Sample

Eight women agreed to participate in the study, representing approximately one third of the total estimated population. The mean age for the women in the study was 30.4 years (SD 6.3) with the age range from twenty one to forty two. The mean length of time since diagnosis was 26.3 months (SD 26.0), with the range being from 3 months to 7 years. Six of the women who participated were members of the Cree tribe and two belonged to the Ojibwa tribe. The religious affiliation reported by the participants was as follows: three reported being Roman Catholic, two reported traditional, two reported none and one reported United Church.

The mean educational level for the participants was grade 10 (SD 1.2) with the range being from grade 9 to grade 12. Seven of the women had children, with the mean number of children being 3.8 (SD 1.8) and range in number of children being three to six. None of the children were HIV positive, despite five of the women having had their most recent child since their diagnosis. Five of the women were single and three were living in a common law relationship. Seven of the women lived in urban settings and one woman lived in a reserve in north-central Alberta.

Sampling Techniques

The primary technique used to recruit participants was nonprobability convenience sampling (Brink & Wood, 1994). An information sheet about the study was prepared and contact persons in each agency were asked to give it to eligible women. If interested in participating, the woman was asked to telephone the researcher. This sampling method resulted in the recruitment of only one woman and therefore the strategy for recruitment was revised. The contact persons were asked to request the permission from potential participants to have the researcher contact them. Using this recruitment method, in combination with many telephone contacts with the contact people and visits to their agencies, the remaining seven women were recruited. During the five month recruitment period, the contact people in the agencies referred the researcher to two additional agencies who identified three participants.

Gaining entry to the study population was anticipated to be challenging because of the sensitive nature of the topic and the non-Aboriginal status of the researcher. To offset this potential problem, the researcher made contact with three of the key agencies in the fifteen months prior to the commencement of the study. A clinical placement for the researcher was arranged with two of the agencies and volunteer work was contributed to a third one. Entry to the study population was facilitated by establishing trust and rapport with personnel at these agencies.

The Interview Process

In-depth interviews were the primary method of data collection for the study. The interviews were tape recorded and transcribed by a professional transcriptionist. Seven of the participants were interviewed twice and one could be interviewed only once. This woman had moved prior to the second interview and had not left a forwarding address. She was the most recently diagnosed (three months) and was having difficulty disclosing her HIV status to her family members. Two other women who had been recently diagnosed (one week and one month) did not wish to participate in the study because they did not wish to talk with anyone.

A total of 15 interviews took place: five occurred in the participant's homes, four took place in a prison setting, three were completed in a substance abuse treatment centre, two occurred in a community agency and one took place at the University of Alberta. The interviews ranged in length from one hour to two and a half hours, with two to three weeks between the first and second interview. Three of the interviews that took place in a prison setting could not be tape recorded because permission was denied by security personnel to bring tape recording equipment into the facility. Following each interview, the participants were given $10.00 as compensation for their time and inconvenience.

Due to the small sample size and sensitive nature of the study, confidentiality and anonymity were critical to the success of the research. To ensure confidentiality, the data sets were coded so that the participants names did not appear on any of the interview transcripts. This ensured that the researcher was the only person to know the identities of the women recruited to the study. Anonymity was maintained by grouping the demographic data to ensure that the participants in the written reports were not recognizable.

Data Analysis

Each interview transcript was entered in to the qualitative software program NUD.IST (Non-numerical Unstructured Data Indexing, Searching and Theorizing) for analysis. The data were analysed on a line by line basis within NUD.IST, simultaneously with data collection (Miles & Huberman, 1994). Following the first interview a preliminary list of codes was made. Each code represented a theme or sub-theme that had emerged from the data. During data analysis portions of the interviews that pertained to a theme were stored at the appropriate code. The codes used in the analysis were revised throughout the analysis process, as new themes became evident. At each code memos were created to record the researchers reflections about things such as why the code was created and how it was related to other codes. Memos were also written for each document to record subjective information about each participant and their interview. Contextual information about each interview and the researcher's subjective views about the research process were recorded in field notes and a journal respectively.

Findings

During the first interview the researcher sensed that focusing on the cultural rules of sexual behaviour from the women's perspective would provide a very narrow understanding of the context of their behaviour. The women's behaviour at the time of their infection with HIV could not be separated from their life experiences prior to their infection. It was decided therefore to broaden the areas explored in the interview, in order to elicit a macroscopic view of the women's lives. As the women shared their life histories, the researcher developed insights about the inter-connectedness of the women's formative years and their infection with the HIV virus.

The Formative Years

Family Relationships

Several themes emerged from the women's narratives about the early years in their families. All of the women with one exception had experienced turbulent childhoods, including frequent moves and unstable family units. None of the women had grown up with both of their biological parents, and four of them had not known their father. Carol had spent more than ten years with a former boyfriend of her mother. She had recently learned that her mother and other relatives had tried unsuccessfully to find her over the years:

> Well he disappeared with me basically, he kidnapped me...they looked for me for a long time but couldn't find me...they call me the lost one.

Five of the women had spent many of their childhood years in foster homes or institutions. Karen described the pain she felt when her mother surrendered her to social services:

> I felt they didn't really care and when my Mom let social services take me away, that really topped the cake. So I hit the streets.

The parent's school history, particularly a history of residential school, was explored with six of the women. One woman believed that her mother may have attended a residential school, however the remaining five women stated that they knew nothing about their parent's schooling.

At the time of the interviews most of the women who still had parents living, had limited or no contact with them. The relationships they described were frequently strained as shown by Sandy's description of her contact with her mother:

> Not much - we have an unhealthy relationship. She's alcoholic. She knows I'm HIV positive and she doesn't want to talk to me about it.

Karen had essentially broken contact with her mother and stated that she could not be in the same house with her. Jenny, despite having grown up in more than thirty foster homes, was trying to re-establish a relationship with her parents. She describes a recent visit to her parents home in the following passage:

> We had a really good time my Mom and Dad and finally I was able to talk to my Mom, woman to woman, not as her child ... and I told her I didn't blame her for what had happened in the past.

Troubled relationships with siblings and other family members were also described by the participants. When asked if Sandy had any family members that she was close to she replied:

> No, my relatives were kind of upper class and they didn't want anything to do with me - I was kind of the black sheep of the family, just like my mother was the black sheep of her family.

Five of the women had not felt that their family members had been supportive since learning of their HIV diagnosis. Linda had given up her house in another city and moved to be near her sister for support. Her bitterness that the promised support did not materialize is captured in the following:

> My sister had asked me to move back here, she was going to give me support and everything else with my HIV right, and she would be here for my boy when I passed on. So let's just forget about her giving me support, because the day I moved back here she moved to Vancouver.

Parental Substance Abuse

Six of the participants related a history of drug or alcohol problems in one or both parents. The problems with substance abuse had profound impact on the women's lives. Linda had very painful memories of her parent's drinking problems and talks of her perceptions of them:

> We got apprehended [children taken from parents by social services] because my parents were always drinking...My father tried to work, and every time he did work and every time he got paid he just went out and got drunk - same with the welfare cheques they'd go out and get drunk...Bottom line was, [for] my parents, their alcohol was more important than their own kids...I remember I even had to go out and steal a can of milk for my baby sister because she didn't have any milk - she was a baby and I was only five.

Sandy, like several of the women, viewed her parent's alcohol problems as contributing to their inability to care for her:

> Well I went back and forth between my alcoholic mother and the foster homes up until I was eight.

Physical, Emotional and Sexual Abuse

The abuse that the women in the study had experienced was both pervasive and severe. History of abuse was explored with seven of the participants. It was not discussed with Christine who was interviewed only once. All of the seven women recalled having being abused during their childhood years: five of the women described physical and sexual abuse, one woman recalled only physical abuse and one woman only remembered being sexually abused. The abuse was perpetrated by parents, step parents, foster parents, extended family and friends. Many of women described incidents in their lives that although not defined as "emotional abuse", would appear to have had the same results. Anne spoke of her relationship with her mother as she was growing up:

> She's not a person you could talk to. Not a person you could touch and she'd never say I love you. She'd never give hugs and things like that, so I think I probably really never felt that I was worthy of that.

The women were both the recipients and observers of episodes of physical abuse in their homes. Carol recalled beatings she had received with a belt from her step-father, as well as those she had endured from her step-father's wife:

> ...but she would, she was physically abusive to myself and my half sister and so that terminated when I was 14. I tried to protect my sister and I pulled a knife on her and said if she ever touched me or her again...

Her mother's abuse evoked vivid memories for Linda:

> I just got tired of seeing my Mom get beaten up all the time, you know I'd be sleeping and my Mom she'd be screaming her head off because my Dad would beat her up and I'd walk in to the room and there was blood all over the place and she's bleeding like a stuffed pig...

Jeannette's ability to find a safe haven with her grandparents during abusive situations was an exception among the women:

> I didn't really like being around them when they were drinking cause there was so much abuse going on at that time, and I didn't want to be around there so I spent most of my time with my grandparents...

Jeannette was the only participant living on a reserve during her childhood years, in close proximity to her relatives.

The experiences of sexual abuse related by the participants was deeply painful and at times difficult to re-count. During one of the interviews Jenny, on the verge of tears, asked to have the tape recorder turned off. She told the researcher she had been tied down and raped by a cousin at the age of nine years. Although willing to have this trauma shared in the study, Jenny's memory was too painful to record on the tape. Karen had been sexually abused by her step-father from the time she was eight until she was taken in to care by social services at age fourteen. When discussing the times she had been sexually abused, Jenny compared the long term sequelae of the sexual abuse to that of a hurt that damages the inner self:

> It's like someone could come up to me now and smack me on the side of the head and I'd get a bruise and the bruise would go away. Someone could come up and call me a bitch and that would hurt me more than the slap because that doesn't go away, it stays inside.

Survival Strategies

Running Away

By the time most of these women reached their early to middle teen years, they were unable to cope with the situations in their homes and eventually "hit the streets". Running away was a very prevalent theme for all of the women and included leaving home, family and/or communities. Linda recalled her frustration and anger during those times and her desperate attempts for attention:

> I just wanted somebody to talk to, but nobody would listen to me...I blew police cars up, hurting other people, doing drugs, not going to school, running away...climbing out of windows at night and running away...

Many of the women described attempts by their parents or step-parents to control their increasingly difficult behaviour. After living in a series of foster homes, institutionalization was the next step for Karen:

> After I was about fourteen I lived in institutions on and off - according to my mother I was "hard to control"...But I kept running away from the institutions and group homes.

Sandy and Carol were also in institutions with programs for "hard to control" teenagers, but eventually ran away from them and, seeing no other alternatives, resigned themselves to a life on the streets.

At the time she left the reserve, Jeannette had not planned to live on the streets, however, her move to the city resulted in her "getting in with the wrong crowd". As with the other women, Jeannette expressed the need to run:

> Yeah, I was kind of running away from my life on the reserve because things weren't going well for me over there. I was having a lot of problems with my relations, my parents and my family, their brothers and sisters....

At age fifteen, Jenny was institutionalized at a youth assessment centre, after experiencing sexual abuse and running away from several of the more than thirty foster homes she had been in. She said she was put in the centre:

> ...to make sure that I had all my marbles and find out why I was being bad ... They just didn't want me to be bad anymore so they put me away.

Jenny ran away from the institution and went to live with a man who eventually became her husband. Although Christine and Anne did not live on the streets, they became involved in a lifestyle, such as intravenous drug use and promiscuous relationships, that placed them at high risk of HIV infection.

Substance Abuse

In the time period prior to becoming HIV infected, all of the women had problems with substance abuse. Seven of the women had used intravenous drugs and their use ranged from occasional binges to severe addiction. Alcohol abuse had been a problem for all of the women and several of them had been in treatment centres. Linda, Carol and Jeannette had been in treatment centres since learning of their HIV diagnosis, whereas Christine had been in alcohol treatment centres three times prior to becoming HIV positive. Christine discussed the process of learning to deal with an addiction:

> I think almost every time you go there you learn something different, so it's like, yeah I did, and then I fell back in to it.

At the time of interview Christine was still struggling with her alcohol addiction.

All of the women who used intravenous drugs shared needles despite knowing that various diseases such as hepatitis and HIV could be spread through needle sharing. They spoke of not caring about who they shared needles with when they were desperate for a "fix". A sense of urgency is felt when Jeannette discusses sharing needles in the following passage:

> ...When you're a heavy user like you would want that fix right away and that's the way it was. I wanted it right now and I didn't want to waste my time to go look around for another needle...so I ended up using somebody else's needle.

Karen also spoke of times when she would share needles:

> ...but clinics close and vans [needle exchange vans]

> run on certain hours, so if we missed the van and had to dope up right now, we would use a dirty needle. We want to do our drugs right now, not in three hours.

Isolation from the world was necessary for Linda and Sandy when they were using drugs and therefore they found it difficult to access needle exchange vans. Linda recalled waiting until darkness to approach a needle exchange van:

> I would come out of my little shell, it was really dark, because I didn't want people to see me and by the time I came out of my hiding place like I was already high and already dislocated ...I couldn't make it down to the needle exchange because it would be closed by then...

<u>Promiscuity and Prostitution</u>

In the years before they tested positive for HIV, six of the women had worked as prostitutes and one women described herself as promiscuous. This theme was not explored with Christine. The women articulated several reasons for their involvement in these sexual relationships. Anne found closeness in her many relationships:

> Because I wanted a relationship. I wanted to be close to somebody and so I was fairly promiscuous during those years.

Prior to working as a prostitute, Jenny had been involved in many relationships because "I wanted to be loved". Linda believed "prostitution and drug abuse went hand in hand" and that prostitution had one advantage over sexual abuse:

> Well when I first started prostituting, I did it because I thought that was what I had to do. I thought that well, if I'm being sexually abused, I might as well get paid for it.

The women spoke of prostitution as a necessity to support themselves and their drug habits.

Most of the women regularly used condoms to protect themselves from sexually transmitted diseases when working as prostitutes. It was interesting that Linda expressed greater concern for protecting her boyfriend and the partners of her customers than herself:

> When I used to prostitute on the street I used to wear condoms all the time...I guess I didn't want to contract something from somebody else and give it to my mate at that time...I guess I was one of those caregiver people, I always cared about somebody else more than myself...I didn't want to infect him and then [have him] go home to his wife and infect her...

Sandy had found it easier to use condoms when she was working as a prostitute:

> ...When you are getting paid you could take better care of yourself. Now, cause I've been taken advantage of so many times, I don't care. Also as your addictions get stronger, it's more difficult to take care of yourself.

Jeannette on the other hand, recalled that the only time she used condoms with her customers was when she was not drunk or high on drugs.

Under certain circumstances the women would not use condoms with their customers. These situations occurred infrequently and all were related to the women's substance abuse. Linda said that occasionally she would be too drunk to ask her partner to use a condom whereas Carol mentioned times when her drug use would influence her use of condoms:

> I always used condoms except for two or three times I was at my lowest you know cause I'd be really coked out and I'd need that next high...

Sometimes customers would offer more money to have sex without a condom. Carol recalled these situations:

> There were a couple of times when I didn't and that's when I was at my lowest, they'd pay me extra and I'd feel totally disgusted.

Four of the women stated that their willingness to engage in sex without a condom with a customer would depend on how desperate they were for drug money at the time.

Relationships with Boyfriends and Husbands

In addition to prostitution, all of the women had been involved in sexual relationships that did not include payment. These ranged from "one night stands" to longer stable relationships of up to nine years. In these relationships the women might use condoms on the first few nights with their boyfriends, but in general the women did not feel the need to use condoms to protect themselves from sexually transmitted diseases. Anne describes her feelings about her risk of HIV infection:

> Well I never thought about disease. I was still feeling pretty bullet-proof or something...I figured cause I knew them...It's not to worry about. They're nice people. They're clean...They wouldn't give my anything.

Carol found condom use with her boyfriend difficult, due to its strong association with prostitution and equated it to "turning a trick".

Birth control methods, such as the pill, IUD's and condoms, were sometimes used in these relationships. Preventing pregnancy however did not seem to be a high priority for the women, based on their comments and the number of children to whom they had given birth. Sandy referred to the value placed on having children in the Aboriginal culture:

> I respect myself as the giver of life. In the Native culture, a woman is referred to as a giver of life because she can produce a child. This is the highest honour in the Native culture...

Jeannette believed that many Native women, including herself, did not use birth control because of their desire to have children.

Since leaving home, the women had all been involved in abusive relationships with men. Most of the women had been physically abused and three of the women had also been sexually abused. Jenny recounted an extremely painful memory of a severe beating inflicted by her first common-law husband just before she left him:

> He beat me so bad that my cousins couldn't pull him off me...I woke up in the morning, my whole left side was black and blue. I couldn't hardly move my fingers. And I remember just aching and I had to look after my son...I left with my baby [and] just a few clothes. I cleaned up my house [before leaving]. I washed down the walls and I remember looking at the blood splatter and I didn't want anybody to see it so I washed it all down.

Following her diagnosis with HIV, Anne was involved in an abusive relationship. She had told her boyfriend that she was HIV positive and had wanted him to use condoms to protect himself from infection. He refused to wear condoms, which she viewed as an effort to control her:

> I think it was a form of control, you know. Because if he became infected then that was something he could blame on me and use against me...and then he got me pregnant which tied me to him further...and then that's when he started hitting...

Children

Seven of the women in the study had children and of these six had voluntarily or involuntarily given up one or more of their children to social services. For some, the loss of custody was temporary, for others it was permanent. Carol and Jeannette had completed treatment for their alcohol problems in order to regain custody of their children. All of the women who had experienced this loss had found it extremely difficult, although Linda and Jenny tried to frame the situation in a positive way. Linda had retained custody of her youngest child, but viewed giving up her four older children as one of the best decisions she had made. She recalled her thoughts at the time she surrendered them:

> Well Linda you know you got a choice, you can let them go through life like you did or else you can get them an education and open new doors for them.

Jenny became very emotional when she spoke of her children and it was evident that she still suffered a profound sadness when she thought of them. She had five children who were now living in two separate homes:

> I'm still attached to my children. I loved them enough to give them up and not drag them down with me. And I thank God everyday that they never saw me the way I was, when I was high.

Anne was the only one who was caring for all of her children at the time of the interview.

Looking Back ...

Knowledge of Sexually Transmitted Diseases

The women in the study had learned about sexually transmitted diseases (STD's) from a variety of sources. Linda and Christine remembered having sexuality education as part of their school curriculum. Several of the women mentioned that they learned about STD's from other prostitutes when they were working on the street, however none of the women recalled discussing the prevention of STD's with their mothers. Jeannette believed that according to Native traditions, mothers would not discuss these matters with their daughters:

> ...There's a lot of Native mothers that don't talk about stuff like that with their teenage daughters...They don't know themselves because we've been raised the Native way.

Most of the women had known about the HIV virus and how it was spread prior to becoming infected themselves, however they did not feel that it was an issue of concern to them. Anne had been involved in many relationships during the

1980's when she learned about HIV infection, but had not personalized the risk:

> It was just out there somewhere and this wasn't really touching me...I had never, ever practised safe sex. Sort of knew what it was but had never used condoms...

All of the women, with the exception of Jeannette, had become very knowledgeable about HIV infection since learning of their diagnosis. At the time of the interview, Jeannette had been unaware that sexual transmission was one of the modes of transmission of the virus.

Self Esteem

All of the participants made comments that are indicative of low self esteem prior to becoming HIV positive. Seven of the women expressed negative feelings about their self worth and one woman was taking medication for depression. The women mentioned repeatedly during the interviews that they had not cared about themselves. Linda had made many positive changes in her life since becoming HIV positive, but recalled her feelings prior to these changes:

> I didn't really give a whole lot of hell about anything... including myself, especially myself, because I wasn't worth it you know.

When asked if she believed she could have made different choices with her life prior to becoming HIV infected, Carol echoed similar sentiments about her self-image:

> I always, ever since I was a kid, the way I was brought up is, I was a continuous failure, so...I'd abuse myself instead of getting angry with others or instead of dealing with other people and saying hey look what you did to me or confronting them, I took it out on myself.

Two of the women related their low self esteem directly to their ability to protect themself from pregnancy and sexually transmitted diseases. For example, when exploring Sandy's ability to influence her partner's use of condoms, she said:

> Oh yes, sometimes I had the feeling I just couldn't say no. I would feel obligated to, like that was all I was good for. I had low self-esteem - I just didn't think of using condoms.

Looking back on her life prior to her diagnosis, Anne was able to reflect on her behaviours. She believed that if she had cared more for herself that she would have been able to protect herself from STD's and prevent pregnancies. In the following passage, Anne shares her insights:

> I know I had a very low self esteem and looking back it's easy to tell. When you look back...I hated myself, I'd do sort of self destructive things like drinking a lot and not caring about myself or not caring for myself and I didn't protect myself from pregnancy all the time.

Carol recalled the time in her life when she believes she became infected with the HIV virus. After being raped by someone she knew, she went "off the deep end for two months". During this time Carol used drugs heavily and shared needles:

> I was using day and night where I'd be up four days, sleep one day, constant...my first two weeks, two to three weeks I shared with three other people I figure and that's where I knew I didn't care, I just wanted a fix...

When discussing condom use with Jenny, she recalled leaving the decision up to her boyfriend.

> Well I didn't think I was really worth much you know, so I mean it didn't occur to me.

Jeannette's feelings about herself were revealed when she was discussing the loss of her children because of her problems with alcohol abuse:

> ...Just everything was getting the best of me you know. I just couldn't handle life I guess...but I ended up losing my children.

Although not all of the women referred to their "self esteem", their comments reflect how they were feeling about themselves during the time prior to their HIV infection and provides powerful images of their self esteem.

Discussion

The life histories of the women in this study revealed many common characteristics. Most of the women had lived in unstable family situations, moved frequently and experienced strained inter-familial relationships. All of the women, with one exception, had endured physical, emotional and/or sexual abuse during their childhood years. Although parental substance abuse was common, only one women had been able to live with another close family member during these troubled times. Running away from these situations was seen as the best alternative and for many of the women this led to a life on the streets. In recalling this time period in their lives, most of the women described feelings about themselves that demonstrated low self esteem.

Despite having knowledge about methods to protect themselves from diseases such as HIV, the women engaged in behaviours that placed them at high risk for infection with the HIV virus. Intravenous drug use, alcohol abuse, promiscuity, prostitution and involvement in relationships where they continued to be victimized became part of the women's lives. These lifestyles are commonly termed "high risk" behaviours for HIV infection. Implicit in the conce of high risk behaviours however, is that there is an element of choice in adopting these behaviours. I would maintain that these behaviours were survival techniques that the women used to cope in their individual situations. Research by Kane and Mason (1992) supports the contention that "when viewed in context, risk behaviours can be seen as interrelated survival techniques" (p.220).

The findings in this study support other research that has been done in the area. Several studies have tested the relationship between childhood abuse and HIV infection. Zeirler et al. (1991) found that female victims of child sexual abuse were more likely to be prostitutes and heavy consumers of alcohol and less likely to have completed high school. A study of HIV positive adults by Allers and Benjack (1991) reported that the majority of participants had been physically or sexually abused in childhood and that these survivors of childhood abuse were more likely to report revictimization in adult relationships, chronic depression and alcohol or drug abuse.

In an extensive review of the literature on the impact of child sexual abuse, Browne and Finkelhor (1986) found that aggression and running away are common initial effects of child sexual abuse. Depression, poor self-esteem, revictimization, substance abuse and problems with interpersonal relationships were among the long term effects documented in this review. Bagley and Ramsay (1986) found that women with poor self-esteem were four times more likely to have a history of child sexual abuse than non-abused women. A relationship between low self esteem and the likelihood of AIDS-risk drug behaviours, such as needle sharing, was found in a recent study with intravenous drug users (Simpson, Knight & Ray, 1993).

A recent study by Johnsen and Harlow (1996) found that women who had been sexually abused had significantly less efficacy concerning HIV prevention, more hard substance abuse and more sexual victimization in adulthood when compared to nonabused women. Briere and Runtz (1987) also found a significant increase in substance addiction and revictimization among women who had been sexually abused. Evidence of a relationship between severe physical or sexual abuse in childhood and depressive symptoms in adulthood has also been documented (Hall, Sachs, Rayens & Lutenbacher, 1993). A study of alcoholic women revealed that they were significantly more likely to have experienced sexual abuse as children (Miller, Downs, Gondoli & Keil, 1987).

In a study of Aboriginal street youth in Alberta (Sinclair, 1993), participants stated that lack of self worth and caring about themselves was a significant factor in engaging in behaviours (eg unsafe sex, drug abuse) that placed them at risk for HIV infection. The phenomena of needle sharing described by women in this study was also found in a study of the effect of drug withdrawal on risk behaviour (Connors, 1994). Connors (1994) compared the withdrawal from drugs to chronic pain that made the avoidance of needle sharing and use of injection cleaning equipment very difficult.

The literature pertaining to the prevention of HIV infection has focused on the identification of behaviours and groups that may be at increased risk of infection with the virus. Although the need to understand the context of the behaviour has been acknowledged in recent literature, current behavioural theories may be insufficient to explain the complex factors that lead to HIV infection. These theories are predicated on the assumption that individuals are in control of their behaviour when faced with situations that may be detrimental to their health. For example, in the Health Belief Model (Rosenstock, Strecher & Becker, 1994) an individual's ability to take action against a health threat is based on her perceived susceptibility to the illness and its perceived severity. These factors are mediated by the perceived efficacy of and barriers to taking action and the individual's self-efficacy (Rosenstock et al. 1994). Self-efficacy refers to the individual's belief that they are competent to take the appropriate action against the health risk. Using the Health Belief Model for HIV prevention, it is incumbent upon the health professional to promote behaviour change by influencing the individual's beliefs about their health.

Bandura's social cognitive theory has also been applied to AIDS prevention (Bandura, 1994) and shares some similarities with the Health Belief Model. The theory acknowledges that information about health risks is a necessary but insufficient component of behaviour change. In addition to information, an individual must have a sense of self-efficacy in order to achieve control over her behaviour in high risk situations (Bandura, 1994). Bandura emphasizes the individual's control over their behaviour: "People who are fully informed on the modes of transmission and effective self-protective methods acquire the virus only if they allow it to happen to themselves" (Bandura, 1994, p.44). Bandura acknowledges that there may be personal, cultural, religious or economic barriers that could impede an individual's ability to take self-protective action. He suggests that these barriers to behaviour change can be mitigated through different programs and approaches. The women in this study did not demonstrate self-efficacy or control over their lives at the time of their infection. Bandura's model is limited in its ability to explain the findings in this study because it does not acknowledge that an individual's self-efficacy may be influenced by events that took place many years prior to the high risk situation.

A model (see Figure 3) has been created to visualize the relationships that are hypothesized to exist between the women's experiences in their formative years, their self esteem and the survival techniques that placed them at increased risk of HIV infection. Further research is required to test the relationships between the variables in the model. For example, alcohol abuse in parents may contribute to their children's vulnerability to sexual abuse through environmental and psychological factors (Miller et al. 1987).

A model proposed by Pepper and Henry (1991) is helpful to the understanding of the development of self esteem from an Indian[2] perspective. The model proposes four conditions that are necessary to the development of self esteem in Indian[2] children: connectiveness, uniqueness, power, and appropriate role models. Of these four conditions, the conditions of connnectiveness and appropriate role models were lacking for the women in the study. Connectiveness refers to the need for children to become attached or bonded to family members. In traditional Indian[2] families, in addition to the parents, the extended family was responsible for providing children with a feeling of connectiveness (Pepper & Henry, 1991). Appropriate role models are necessary so that children learn values, goals and interpersonal behaviour (Peppler & Henry, 1991). Inadequacies in the area of connectiveness and role models may have contributed to the low self esteem seen in the study participants. The substance abuse problems of their parents, the families' urban lifestyle and the limited contact with extended family members are factors that may have made it difficult for these conditions to be met.

The finding that most of the women did not know if their parents had attended a residential school was interesting. This unexpected finding may be explained by the difficulty that adults who have attended residential schools have in discussing this experience with their children (Assembly of First Nations, 1994; Ing, 1991). In a study to determine the effects of residential schools on Native[2] child rearing practices, Ing (1991) concludes that residential schools contributed to "the breakdown of traditional and cultural child-rearing patterns" (p.82). By prohibiting the children in residential schools from speaking their language and isolating them from their culture and families, traditional child rearing patterns could not be passed down from the elders (Ing, 1991). Although the relationship between residential school attendance and the child rearing that the women in the study experienced has not been established, this area merits further exploration in future research.

The cultural rules that guided the sexual behaviour of Aboriginal women were not uncovered in this research. Research with a different population, such as women living on reserves who are not HIV positive, may be necessary to explore this question. For the women interviewed in this study it was more critical to explore their life histories in order to develop a greater understanding of the factors that influenced their HIV infection. The findings of the study corroborate other research in the area of HIV infection and expand knowledge by documenting that Aboriginal HIV positive women experience similar backgrounds to those of non-Aboriginal women.

The women in this study experienced vulnerable childhoods in which they were subjected to emotional, physical and/or sexual abuse. Their formative years were characterized by troubled and often broken relationships with their parents. Unable to cope with these situations during their teen years, these women ran from their homes and families. Rather than escaping from the pain they had known however, they were confronted by more pain and often seemingly insurmountable challenges on the streets. The strategies used by the women to survive placed them in situations where they were highly likely to be infected with the HIV virus. Linda survived as a prostitute by shutting down her feelings to enable herself to carry on:

> I took a shower and I scrubbed and everything, I just felt dirty, but then I had to shut that down...and the more I shut down those feelings the harder I became, the uglier I got inside. And the uglier I got inside, the more violent I became...I wanted so much deeply to feel you know, every time a feeling came up I'd slap it down. Put a big lid on it.

Risk behaviour or survival technique?

NOTES

1. In Canada the "Status" Indian refers to those individuals legally recognized by the federal government under the Indian Act, to be Indian (Waldrum, Herring & Young, 1995).

2. The term Native was used by the authors of these

paraphrases. I have followed their terminology.

REFERENCES CITED

Aboriginal Nurses Association of Canada. (1996). _HIV/AIDS and its Impact on Aboriginal Women in Canada._ Ottawa, Canada: Health Canada.

Alberta Health. (1995). _Strengthening the Circle: What Aboriginal Albertans Say about their Health_. Edmonton, Canada: Author.

Allers, C.T. & Benjack, K.J. (1991). Connections Between Childhood Abuse and HIV Infection. _Journal of Counselling and Development, 70,_ 309-313.

Ankrah, E.M. (1991). AIDS and the Social Side of Health. _Social Science and Medicine, 32_(9), 967-980.

Assembly of First Nations. (1994). _Breaking the Silence: An Interpretive Study of Residential School Impact and Healing as Illustrated by the Stories of First Nations Individuals_. Ottawa, Canada: Author.

Bagley, C. & Ramsay, R. (1986). Sexual Abuse in Childhood: Psychosocial Outcomes and Implications for Social Work Practice. _Journal of Social Work and Human Sexuality, 5,_ 33-47.

Bandura, A. (1994). Social Cognitive Theory and Exercise of Control over HIV Infection. In R.J. DiClemente & J.L. Peterson, (Eds.), _Preventing AIDS: Theories and Methods of Behavioral Interventions_ (pp. 25-59). New York: Plenum.

Berer, M. (1993). _Women and HIV/AIDS_. London: Pandora.

Briere, J. & Runtz, M. (1987). Post Sexual Abuse Trauma: Data and Implications for Clinical Practice. *Journal of Interpersonal Violence, 2*(4), 367-379.

Brink, P.J. (1987). Cultural Aspects of Sexuality. *Holistic Nursing Practice, 1*(4), 12-20.

Brink, P.J. & Wood, M.J. (1994). *Basic Steps in Planning Nursing Research: From Question to Proposal.* Boston: Jones and Bartlett.

Browne, A. & Finkelhor, D. (1986). Impact of Child Sexual Abuse: A Review of the Literature. *Psychological Bulletin, 99*(1), 66-77.

Carrier, J. & Bolton, [illegible]. (1991). Anthropological Perspectives on Sexuality and HIV Prevention. *Annual review of Sex Research, 2,* 49-75.

Connors, M.M. (1994). Stories of Pain and the Problem of AIDS Prevention: Injection Drug Withdrawal and Its Effect on Risk Behavior. *Medical Anthropology Quarterly, 8*(1), 47-68.

Driver, H.E. (1969). *Indians of North America*. Chicago: The University of Chicago.

Feather of Hope Aboriginal AIDS Prevention Society. (1994). *Feather of Hope Aboriginal AIDS Prevention Society Annual Report*. Edmonton, Canada: Author.

Freudenberg, N. (1990). AIDS Prevention in the United States: Lesson from the first decade. International Journal of Health Services, 20(4), 589-599.

Hall, L.A., Sachs, B., Rayens, M.K. & Lutenbacher, M. (1993). Childhood Physical and Sexual Abuse: Their Relationship with Depressive Symptoms in Adulthood. IMAGE: Journal of Nursing Scholarship, 25(4), 317-323.

Health and Welfare Canada. (1992). Women and AIDS: A Challenge for Canada in the Nineties. Ottawa, Canada: Minister of Supply and Services.

Health Canada. (1994). HIV/AIDS and Aboriginal People in Canada. Ottawa, Canada: Medical Services Branch.

Houston, S. & Reese, H. (1995). Increasing HIV Infection among Aboriginal People in Northern Alberta. Paper presented at the Fifth Annual Conference on HIV/AIDS Research, Winnipeg, Canada.

Houston, S. & Reese, H. (1996). HIV Infection among Aboriginals in Northern Alberta. Poster presentation at the XI International Conference on AIDS, Vancouver, Canada.

Ing, N.R. (1991). The Effects of Residential Schools on Native Child-Rearing Practices. Canadian Journal of Native Education, 18(Supplement), 65-118.

Jeness, D. (1977). Indians of Canada. Ottawa, Canada: Minister of Supply and Services Canada.

Johnsen, L.W. & Harlow, L.L. (1996). Childhood Sexual Abuse Linked with Adult Substance Use, Victimization and AIDS-Risk. AIDS Education and Prevention, 8(1), 44-57.

Kane, S. & Mason, T. (1992). "IV Drug Users" and "Sex Partners": The limits of Epidemiological Categories and Ethnography of Risk. In G. Herdt & S. Lindenbaum (Eds.), The Time of AIDS, Social Analysis, Theory, and Method (pp 199-222). Newbury Park, CA: Sage.

Krieger, N. & Fee, E. (1994). Man-Made Medicine and Women's Health: The Biopolitics of sex/gender and race/ethnicity. International Journal of Health Services, 24(2), 265-283.

Mandelbaum, D.G. (1940). The Plains Cree. Anthropological Papers of the American Museum of Natural History, XXXVII(II), 245-247.

Miles, M.B. & Huberman, A.M. (1994). Qualitative Data Analysis: An Expanded Sourcebook. Thousand Oaks, CA: Sage.

Miller, B.A., Downs, W.R., Gondoli, D.M., & Keil, A. (1987). The Role of Childhood Sexual Abuse in the Development of Alcoholism in Women. Violence and Victims, 2(3), 157-172.

Nyamathi, A., Stein, J.A. & Brecht, M. (1995). Psychosocial Predictors of AIDS Risk Behavior and Drug Use Behavior in Homeless and Drug Addicted Women of Color. Health Psychology, 14(3), 265-273.

Panos Institute. (1990). The 3rd Epidemic: Repercussions of the Fear of AIDS. London: Author.

Pearlberg, G. (1991). Women, AIDS and Communities. Metuchen, NJ: Scarecrow Press.

Peppler, F.C. & Henry, S.L. (1991). An Indian Perspective of Self-Esteem. Canadian Journal of Native Education, 8(2), 145-160.

Rosenstock, I.M., Strecher, V.J. & Becker, M.H. (1994). The Health Belief Model and HIV Risk Behavior Change. In R.J. DiClemente & J.L. Peterson (Eds.), Preventing AIDS: Theories and Methods of Behavioral Interventions (pp. 2-24). New York: Plenum.

Simpson, D.D., Knight, K. & Ray, S. (1993). Psychosocial Correlates of AIDS-Risk Drug Use and Sexual Behaviors. AIDS Education and Prevention, 5(2), 121-130.

Sinclair, B.J. (1993). Aboriginal Street Youth and Sex Trade Workers Study. Report prepared for The Joint National Committee on Aboriginal AIDS Education and Prevention. Edmonton, Canada: Alberta Indian Health Care Commission.

Smeltzer, S.C. & Whipple, B. (1991). Women and HIV Infection. Image:Journal of Nursing Scholarship, 23(4), 249-256.

Statistics Canada. (1993). Census 1991: Aboriginal Data. Ottawa, Canada: Author.

Statistics Canada. (1994). Census 1991: Profile of Census Divisions and Subdivisions in Alberta-Part B. Ottawa, Canada: Author.

Waldrum, J.B., Herring, D.A. & Young, T.K. (1995). Aboriginal Health in Canada: Historical, Cultural, and Epidemiological Perspectives. Toronto, Canada: University of Toronto.

Walker, J. (1994). HIV/AIDS in the Aboriginal Community. Keynote address at the Third Canadian Conference on HIV/AIDS and Related Issues in Aboriginal Communities. Toronto, Canada.

World Health Organization. (1990). World AIDS Day 1990 to focus on women. AIDS Health Promotion Exchange, 2, 1-2.

World Health Organization. (1992). Why women and HIV? It takes two to tango. AIDS Health Promotion Exchange, 3, 1-3.

Wotherspoon, T. & Satzewich, V. (1993). First Nations: Race, Class and Gender Relations. Scarborough, Canada: Nelson.

Zierler, S., Feingold, L., Laufer, D., Velentgas, P., Kantrowitz-Gordon, I. & Mayer, K. (1991). Adult Survivors of Childhood Sexual Abuse and Subsequent Risk of HIV Infection. American Journal of Public Health, 81(5), 572-575.

Zwi, A.B. (1993). Reassessing Priorities: Identifying the Determinants of HIV Transmission. Social Science and Medicine, 36(5), iii-viii.

Figure 1. Comparison of Aboriginal and Non-Aboriginal Clients attending HIV Clinics serving northern Alberta (Data provided by Dr. Stan Houston, University of Alberta, 1996)

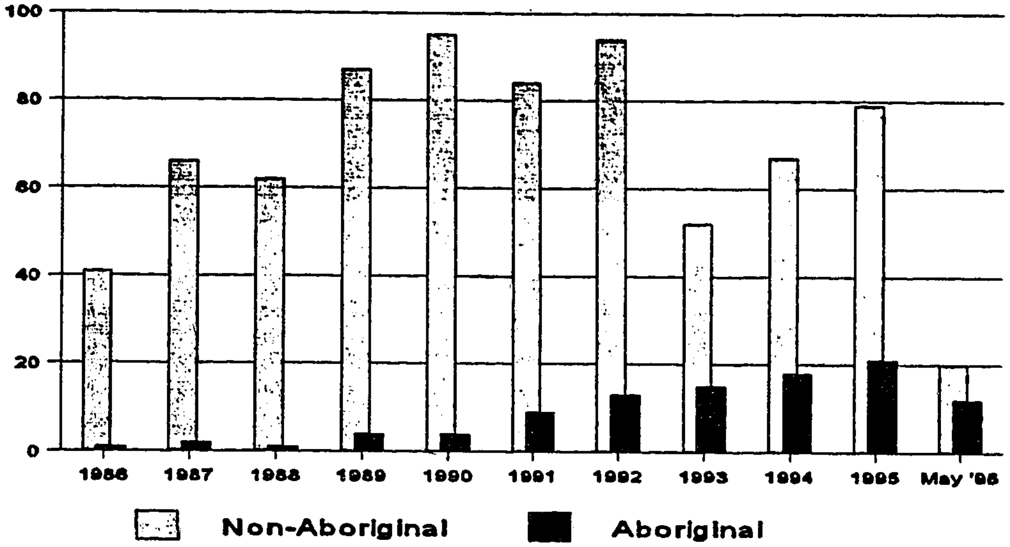


Figure 2. Comparison of Aboriginal Male and Aboriginal Female Clients attending HIV clinics serving northern Alberta (Data provided by Dr. Stan Houston, University of Alberta, 1996)

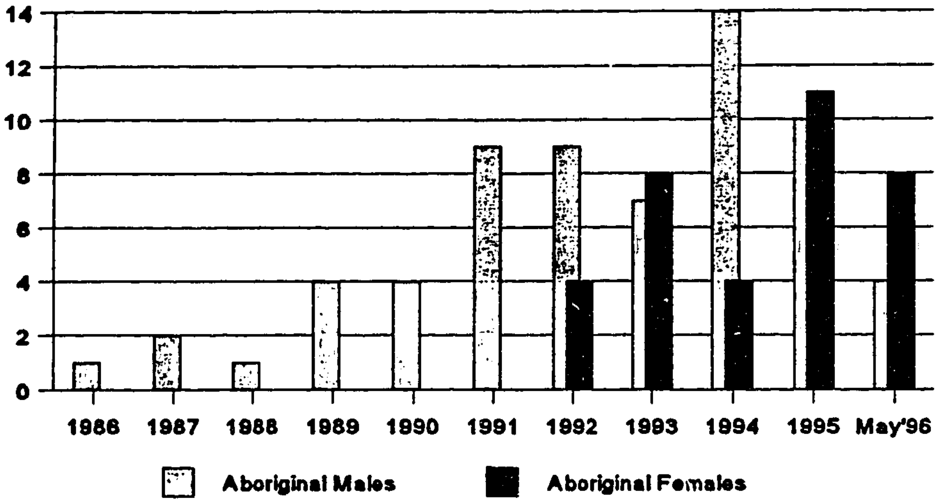
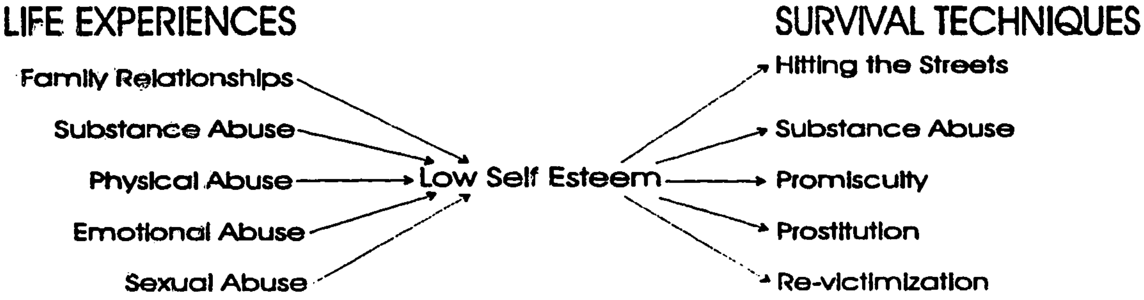


Figure 3. Formative life experiences, self esteem and survival techniques



Appendix A

Information Sheet

Project Title: HIV Infection in Aboriginal Women

Researcher: Judy Mill, R.N. Phone: 455-8207

I am a graduate nursing student in the Faculty of Nursing at the University of Alberta. I am doing a research study and request that you consider taking part in it.

This study is to learn about HIV illness in Aboriginal women. To be in the study you must be Aboriginal and have had a blood test to determine that you are HIV positive. You may be Native, Metis, First Nation or Indian to be in the study. It does not matter if you are status or non-status. I will ask you some questions about your illness. I will talk with you one or two times if you are in the study. Each talk will take one to two hours. I will tape-record the talk.

Our talks will be kept strictly confidential. You are free to take part in the study and may ask any questions that you have about it. If you decide to be in the study and later change your mind, you may withdraw from the study.

If you want to be in the study call me at 455-8207. You may also call to find out more about the study. If you prefer you may complete the tear off sheet below. Leave it with the director and I will contact you.

Sincerely,

Judy Mill

Please call me about the study on HIV infection in Aboriginal women.

Name: ___________

Phone: ___________

Project Title: HIV Infection in Aboriginal Women

Appendix B

Informed Consent Form

PROJECT TITLE: HIV Infection in Aboriginal Women

INVESTIGATOR:	**SUPERVISOR:**
Judy Mill, R.N.,B.N.	Dr. Pamela Brink, R.N., PhD.
Master of Nursing Candidate	Professor, Faculty of Nursing
University of Alberta	University of Alberta
455-8207	492-2097

PURPOSE: This study is to talk to you about your HIV illness. Also I want to talk about your sexual practices.

PROCEDURE:
* If you agree to be in the study you will be asked to be interviewed at least once and maybe twice.
* The first interview will be in person at a place that you chose.
* The second interview may be either in person or by telephone.
* Each interview will last for about one hour and may be longer.
* Each interview will be tape-recorded.
* You will receive $10.00 after each interview for your time and inconvenience

PARTICIPATION: It is your choice to be in the study. You may refuse to answer any question. You may stop an interview or leave the study at any time. Just say that you want to do this. If you do not take part in the study your care will not be affected. You may not receive any benefit from the study. By being in the study you may help other women in the future. I will be happy to answer any questions you may have now or at a later time.

Your name will not be used in the study. The researcher and the typist are the only people who will listen to the taped interviews. The tapes and the typed interviews will be kept in a locked drawer for at least seven years after completion of the study. The typed record will be kept by myself.

The typed record of our talk may be used in the future for further research. It may be used for the teaching of others or for writing articles. No one will know that you were the

Informed Consent (cont'd)

one I talked with in the teaching material or articles. I will get ethical approval before any further research is done on your interviews.

After the study ends, I will write a report about this research. The comments you make in the interview may be used in this report. Your name and any information that might identify you will be removed.

CONSENT: I, _______________ (Print name) agree to take part in this research study as a volunteer. The purpose of the study has been explained to me and my questions have been answered. I understand that I can phone the person below if I have any more questions. I know that each interview will be tape-recorded. The information will be kept confidential. I know that I may leave the study at any time. I have been given a copy of this form to keep. I agree to receive $10.00 after each interview.

_______________ Participant

_______________ Date

_______________ Researcher

I would like to receive a summary of the study when it is finished.

Name: _______________

Address: _______________

City: _______________

Postal Code: _______________

Appendix C

Guiding questions for interviewing

Cause of HIV

What caused your HIV?

Pathophysiology of HIV

How do you think HIV has effected your body?

Symptoms of HIV

When did you first know you had an HIV?

What kind of things did you notice first? And then?

Course of HIV

Can you tell me how HIV has effected you since you were first diagnosed with it?

Treatment of HIV

Tell me what you have done to treat HIV ? Start from the first thing you did until now?

Usual Sexual Practices

We know that HIV infection can be related to sexual practices. I would like to know more about your usual sexual practices.

Could we start with your most recent sexual partner?

Probes:
- was this sexual experience part of a long term relationship? - short term relationship? Can you tell me about it?

- can you describe your relationship with your partner?

- who initiated the experience? - was it voluntary for you?

- was there any payment for this sex?

- can you tell me how you view sex (eg pleasurable, responsibility)

- were there drugs or alcohol involved with this sexual experience?

- can you tell me about any things you did to protect yourself from sexually transmitted diseases? pregnancy?

Was this sexual relationship different from other relationships you have had? Can you describe the similarities? differences?

Use the same probes to explore as many previous sexual relationships as possible.

Appendix D

Demographic Information

1. Age
2. Place of residence (eg. urban, reserve, rural)
3. Level of education
4. Tribal affiliation
5. Religious affiliation (eg. traditional, Christian, none)
6. Marital status
7. Number of children
8. History of non-medical drug use - Injection, non-injection