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Aboriginal Women's Perspectives on "Culturally Appropriate" HIV Counselling and Testing

by

Dawn Bucharski ©

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

Centre for Health Promotion Studies

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I would like to dedicate this thesis to the Aboriginal advisory group and the Aboriginal women who participated in this study. Without their commitment, this study would not have been possible.

Abstract

A qualitative study was conducted to determine Aboriginal women's perspectives on "culturally appropriate" HIV counselling and testing. Data were collected through semi-structured individual interviews with seven Aboriginal women, and with six women in a focus group, in a western Canadian city. The data were analyzed utilizing thematic content analysis. Four major categories were explicated: Aboriginal women's life experiences that may increase their risk for HIV infection; barriers to HIV counselling and testing for Aboriginal women; guiding principles of the ideal HIV testing situation; and characteristics of culturally appropriate HIV counselling and testing for Aboriginal women. The need for sensitivity to the hardships and life experiences Aboriginal women may have experienced was a pervasive theme in all of the categories. The study concludes with directions for further research and implications for HIV policy and programming for Aboriginal women.

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Table of Contents

Page

Page

CHAPTER 1

INTRODUCTION

Health Canada (2001d) indicates that at the end of 1999, 49,800 Canadians had been infected with the Human Immunodeficiency Virus (HIV), the virus thought to cause Acquired Immunodeficiency Syndrome (AIDS). Of the total number of HIV cases, approximately 15,000 people (30%) were unaware of their infection. The current HIV epidemic in Canada primarily affects three groups of people: injection drug users (IDU), men who have sex with other men, and increasingly, women (Health Canada, 2000).

HIV infection is increasing among Canadian women. By December 31, 2000, a total of 1,330 AIDS cases and 5,419 HIV cases were reported in women living in Canada (Health Canada, 2001a). Women account for 24% of the total number of HIV positive reports in 2000, up from 10% before 1995. In 2000, 94% of newly diagnosed HIV infections among women were attributed to heterosexual contact and injection drug use (Health Canada, 2001a).

Recently, there has been an increase in HIV infection in some Canadian Aboriginal communities (Health Canada, 2001c). The number of Aboriginal people living with HIV infection has increased from 1,430 in 1996 to 2,740 in 1999, which represents a 91% increase during a three-year period. In Canada, Aboriginal people accounted for 5.5% of all prevalent infections and 8.8% of all new infections in 1999, even though they comprise only 2.8% of the general Canadian population. In 1999, the primary mode of HIV transmission in Canadian Aboriginal communities was injection drug use (64%), followed by heterosexual transmission (17%) (Health Canada, 2001c).

The proportion of Aboriginal women with HIV infection in Canada is higher than for non-Aboriginal women. Aboriginal women account for 47% of all HIV infection in Aboriginal people, whereas non-Aboriginal women account for only 20% of HIV infection in non-Aboriginal people, as reported during 1998-2000 (Health Canada, 2001c). Aboriginal women may be at risk for HIV infection through unsafe injection drug practices, or through unprotected intercourse with high-risk partners. In addition, in the under 30 year age group, more Aboriginal women than non-Aboriginal women are testing HIV positive (Health Canada, 2001c).

The full impact of HIV infection on Canadian Aboriginal communities may not yet be realized. It is believed that reported HIV/AIDS cases for Aboriginal people are incomplete for various reasons, including a reluctance on the part of Aboriginal people to be tested (Matiation, 1998b), delays in reporting to Health Canada, and misclassification or incomplete ethnic group data reports (Health Canada, 2001c). Although the total number of Canadian Aboriginal people with HIV infection is therefore unknown, the epidemic is said to "threaten the resurgence of Aboriginal cultural identity and self determination" (Matiation, 1998b, p. 3).

Statement of the Problem

HIV/AIDS is a growing concern in the Canadian Aboriginal community, especially for Aboriginal women. Despite advances in research, there still is no preventive vaccine or medical cure for this stigmatized lethal disease (Weeks, Grier, Romero-Daza, Puglisi-Vasquez, & Singer, 1998). The health, social, and economic consequences of HIV infection have a profound impact not only on those directly infected with the virus but also on the whole of society (WHO, 1998).

There are several benefits to knowing one's personal HIV status. According to Health Canada (2001d), the benefits include increased awareness of how to reduce the risk of acquiring or transmitting HIV infection, the potential to initiate antiretroviral therapy, and in the case of pregnant women, the opportunity to reduce vertical HIV transmission to the baby to 8% or less. Based on these considerations, Health Canada stresses the importance of Canadians being able to access HIV testing, especially people at highest risk for HIV infection.

HIV prevention programming includes HIV counselling and testing. This strategy is presently used to increase HIV awareness, with the aim of influencing the development of health protective behaviors. Discrimination and racism in health care have been identified as barriers to HIV testing for Aboriginal people (Matiation, 1998b; Shah & Farkas, 1985). Consequently, Aboriginal people and health care providers have frequently identified the need for culturally sensitive services (Aboriginal Nurses Association of Canada, 1996; Alberta Medical Association, 1997; Brassard, Smeja, & Valverde, 1996; DuBois, Brassard, & Smeja, 1996; Matiation, 1998b; RPM Planning Associates Limited, 1994; Shah & Farkas, 1985; Sullivan, 1991).

Little research has been done in Canada, however, to determine what is meant by *culturally appropriate* as it relates to HIV prevention programming in Aboriginal communities (Brassard et al., 1996). If the lack of culturally appropriate services is a barrier to Aboriginal people accessing HIV testing, and the number of female HIV cases within the Aboriginal community is increasing, then research to define *culturally appropriate HIV counselling and testing* for Aboriginal women is urgently required in order to redress this situation.

Purpose of the Study

The purpose of this study was to identify Aboriginal women's perspectives on the characteristics of culturally appropriate HIV counselling and testing.

Research Questions

The research question that guided this study was "What does culturally appropriate HIV counselling and testing mean to Aboriginal women?" There were four sub-questions:

- What are the factors or conditions that increase Aboriginal women's risk for HIV infection, from their perspective

- What are the barriers to HIV counselling and testing for Aboriginal women?
- What factors facilitate HIV counselling and testing for Aboriginal women?
- What are the characteristics of "culturally appropriate" HIV counselling and testing according to Aboriginal women?

Definition of Terms

Aboriginal woman:

A woman (18 years of age or older) of either First Nation or Métis ancestry.

Aboriginal people or *Aboriginal communities*:

Terms used in a general way with no intent to stereotype all individuals within Aboriginal communities as operating from an identical set of values and beliefs.

HIV pre-test counselling:

Within the context of this research, HIV counselling refers to the assessment and information provided when a woman seeks HIV testing. Current guidelines suggest that HIV pre-test counselling should include assessment of the woman's risk of HIV infection; assessment of the window period (timing of the most recent HIV risk event leading to the appropriate time-frame for HIV testing and the post-test visit); provision of information about HIV infection, HIV testing process, HIV testing options, and implications of HIV test results; and obtaining informed consent (Canadian Medical Association, 1995).

HIV testing:

A blood sample drawn to test for the presence of HIV antibodies.

Significance of the Study

Findings from this research have the potential to influence policy and programming in the area of HIV counselling and testing for Aboriginal women. The information gleaned from this study can also be used in the education of health professionals providing HIV counselling and testing. The research is particularly timely, given the current emphasis on HIV prenatal screening.

The Researcher

In qualitative research, the investigator is considered a research instrument (Morse & Field, 1995). Within this context, it was important for me to acknowledge my life experiences and how these may have influenced this research study. I am a middle-aged woman of European-Canadian descent, from a middle-class background. During the past 20 years, I have worked as a public health nurse, an educator, a manager, a community developer, a graduate student, and, more recently, a budding researcher. Over the past 11 years, I have focused much of my professional and volunteer work in the area of sexual health, working with people who are socially and economically oppressed, including Aboriginal women.

A bias I needed to acknowledge as I began this research was my growing understanding of "dominant" cultures that create multiple inequalities, especially for women. In addition, I worried that my feminist views could influence my perception of what the women told me. As I proceeded with this research as a woman in that dominant culture, I was aware of the need to truly reflect the experiences of the Aboriginal women in the study.

As a graduate student in health promotion, I valued the opportunity to practice the principles I have learned over the course of the past number of years. As a result, the research process was as critical to me as the outcome of the research. Unfortunately, I was diagnosed with cancer shortly after I had completed the individual interviews and days before the focus group. Data analysis and reporting of the findings were postponed for 18 months while I was on a medical leave of absence. I believe this had a negative impact on the momentum generated with the Aboriginal advisory group. Consequently, only two meetings have been held with this group since the initiation of the study, with a third meeting pending. On the other hand, the time lag between data collection and reporting the findings may have allowed me to be a more objective researcher, which would be a positive outcome of my medical leave.

I am sensitive to the experiences that Aboriginal people have had since European colonization. I recognize and support the importance that Aboriginal people place on self-determination, including the determination of their own research agenda, as it relates to HIV. I am honored to have been able to work with Aboriginal women as they prepare to develop HIV policy and programming that is "culturally appropriate" for Aboriginal women.

CHAPTER 2

LITERATURE REVIEW

The population health model adopted by Health Canada provides a conceptual entry for the study. Central to the population health approach is the belief that the health and well-being of Canadians is determined by "complex interactions between the social and economic factors, the physical environment, and individual physiology and behavior" (Health Canada, 1996, p. 6). Within this approach, *gender* and *culture* are identified as important determinants of health. These determinants of health can also be viewed as influencing the risk of HIV infection. The literature review is organized around the influence of gender and culture as determinants of HIV infection. This is followed by a review of the lessons learned from the two decades of HIV counselling and testing. The chapter concludes with a review of the literature pertaining to culturally appropriate HIV prevention interventions.

Gender as a Determinant of HIV Infection

Gender is a socially and culturally constructed concept (Health Canada, 1996). Gendered norms in our society have "subordinated women, inhibited their achievement of political, cultural, social and economic equality, and, as a consequence, impeded their attainment of optimal health status" (Health Canada, 1996, p. 17). Within the context of HIV, epidemiological, biological, sexual, and reproductive factors, along with the social and economic subordination of women, increase women's vulnerability to HIV infection (Health Canada, 1996; Weeks, Schensul, Williams, Singer, & Grier, 1995). These factors provide the framework for reviewing the literature on gender as a determinant of HIV infection. This literature refers to women in general and, where applicable, to Aboriginal women in particular.

Epidemiological Factors

From an epidemiological perspective, women's risk for HIV infection is associated with the greater degree of HIV infection in the male population, in Aboriginal communities, and in large urban settings. The vast majority of HIV infections in North America occur in the male population. As a result of this reservoir of infection, women experience a greater probability of engaging in heterosexual activity with HIV-infected men than the other way around (Stevens, Estrada, & Estrada, 1998; Tortu, McCoy, Beardsley, Deren, & McCoy, 1998).

There is also a greater degree of HIV infection within Canadian Aboriginal communities than in the general population (DuBois et al., 1996; Health Canada, 2001c; Houston, 1995; Tseng, 1996). As discussed previously, the proportion of HIV positive cases is higher among Aboriginal women than non-Aboriginal women with more Aboriginal women being diagnosed HIV positive before 30 years of age (Health Canada, 2001c).

Higher concentrations of HIV-infected people are found in large urban settings in comparison to smaller centres (Cattarello, Leukefeld, Woolley, & Parker, 1998). Consequently, there is an increased likelihood of having unprotected sex or sharing injection drugs with an HIV-infected person living in an urban setting. Aboriginal people experience a higher degree of movement between Canadian urban and rural communities than their non-Aboriginal counterparts. This urban/rural migration leads to the introduction of HIV infection into rural and sometimes remote Aboriginal communities. (Aboriginal Nurses Association of Canada, 1996; Brassard et al., 1996; Health Canada, 2001c; Houston, 1995; Sullivan, 1991; Tseng, 1996).

Biological Factors

Biologically, women are at greater risk for acquiring HIV infection through heterosexual transmission than are men. There is a greater concentration of HIV in semen than in vaginal secretions, with male to female transmission eight times more efficient than female to male transmission (Fowler, Melnick, & Mathieson, 1997; Padian, Shiboski, Glass, & Vittinghoff, 1997; Stevens et al., 1998; Tortu et al., 1998).

Aboriginal women have not been reported to be at increased risk for HIV infection, from a biological perspective. However, their overall state of health is generally poorer than women in non-Aboriginal communities (Aboriginal Nurses Association of Canada, 1996; DuBois et al., 1996; MacMillan, MacMillan, Offord, & Dingle, 1996; Mill & DesJardins, 1996; Shah & Farkas, 1985; Tseng, 1996; Waldram, Herring, & Young, 1997), which may contribute to HIV infection in Aboriginal communities. One explanation may be that the immune system of Aboriginal women is compromised by poor nutrition and the multiple stressors of poverty (Singer, 1991; Tseng, 1996). In addition, the compounding political, social, and economic oppression Aboriginal women may experience create the conditions that may further jeopardize their health (Matiation, 1998c; Royal Commission on Aboriginal People, 1996).

Sexual and Reproductive Factors

Risk for acquiring HIV infection is influenced by a number of sexual and reproductive factors. These factors include: the age of sexual debut; the nature and timing of sexual activity in which women engage; the choice of contraception; the presence of a sexually transmitted disease (STD); and a history of childhood sexual or physical abuse.

Early sexual debut has been identified as a risk factor for both pregnancy and STD/HIV (Aboriginal Nurses Association of Canada, 1996; Health Canada, 2001b). The age of sexual debut is low for Aboriginal women. A Canadian study demonstrated that 19% of Canadian Aboriginal women had their first sexual experience at 14 years. By the age of 16 years, 33.5% of the women reported having had sex, with the balance of the women experiencing sexual activity by 18 years (Aboriginal Nurses Association of Canada, 1996).

Women's risk for acquiring HIV infection is also affected by the nature and timing of sexual activity. Oral, vaginal, or anal sex without a condom place women at risk for acquiring HIV (Hatcher et al., 1998), with the greatest risk for women who engage in unprotected anal sex (Padian et al., 1997). In addition, women's risk for HIV infection increases if sexual intercourse is engaged in during menses, or if intercourse causes bleeding, as the uterus provides a portal of entry for the virus (Royce, Sena, Cates, & Cohen, 1997).

The choice of contraceptive method is associated with HIV infection for women. Hormonal contraception, intrauterine devices, and various barrier methods associated with the use of spermicides increase women's risk of HIV infection. Theoretical explanations for the inherent risk for HIV include: increased cervical ectopy; changes in cervical mucus; disruption of normal menstrual patterns; vaginal irritation from spermicides containing nonoxynol 9; and progesterone effects, which result in the thinning of the vaginal epithelium (Fowler et al., 1997; Hatcher et al., 1998; Royce et al., 1997).

Moreover, most female-controlled birth control methods provide little if any protection from STD or HIV. This results in the need for women to practice "dual protection" (birth control method + male condom) when engaging in sexual activity (Hatcher at al., 1998). Not only does this practice become cumbersome and potentially problematic if the male partner does not want to comply but is also more costly. Kalichman and Stevenson (1997) found that 40% of the impoverished minority women in their study regularly douched as they believed douching offered birth control and STD protection.

The presence of STD is also associated with an increased risk for HIV infection. It is believed that there is a synergistic effect between the localized STD mucosal infection and HIV, thereby increasing the viral transmission efficiency. Genital ulcerative diseases such as chancroid, syphilis, or herpes consequently may have a potentiating effect on the incidence of HIV infection (Capps, Peng, Doyle, El-Sadr, & Neaton, 1998; Kalichman & Stevenson, 1997; Royce et al., 1997; Tortu et al., 1998). Another group of researchers questioned whether the presence of the STD is a marker for increased HIV risk behavior, or whether the STD is an intervening co-factor for HIV transmission (Fowler et al., 1997). Rates of STD are higher in the Aboriginal community than in the non-Aboriginal community (Aboriginal Nurses Association of Canada, 1996; Brassard et al., 1996; DuBois et al., 1996; Health Canada, 2001c; Matiation, 1998b; Sullivan, 1991; Tseng, 1996). Again, higher STD rates increase the potential for HIV infection among Canadian Aboriginal women.

A history of childhood sexual and/or physical abuse is strongly correlated with acquiring HIV infection via sexual transmission for women. Long-term sequelae of sexually or physically abused children include a greater number of lifetime sexual partners (He et al., 1998; Sherman & Steckler, 1998), and more acts of unprotected sexual intercourse, resulting in higher rates of STD (He et al., 1998; Sherman & Steckler, 1998; Zierler, Witbeck, & Mayer, 1996). In addition, women abused prior to the age of 13 years are more likely to engage in unprotected anal sex (He et al., 1998), a high risk factor for HIV infection.

Childhood sexual and physical abuse occurs within Canadian Aboriginal communities (Alberta Health, 1995; DuBois et al., 1996; Hodgson, 1990; McEvoy & Daniluk, 1995; Ross, 1996; RPM Planning Associates Limited, 1994; Yonge & Bernard, 1998). The physical, psychological, and sexual abuse of Aboriginal children in residential schools is believed to have produced a generation of potential perpetrators who now may abuse their own children (Waldram et al., 1997). In one study, Native American women reported the highest rate of rape under the age of 13 years among minority women (He et al., 1998). Seven of the eight HIV-positive Aboriginal women interviewed in a Canadian study identified sexual and/or physical abuse during their childhood (Mill, 1997).

There are many consequences of childhood sexual and physical abuse including prostitution, alcohol and drug use, and social isolation, which can increase women's risk of acquiring HIV infection. Women with a history of childhood sexual and physical abuse experience an increased propensity towards prostitution and are six times more likely to trade sex for drugs than are women with no history of abuse (He et al., 1998; Miller & Paone, 1998; Sherman & Steckler, 1998; Zierler et al., 1996). A common coping strategy for women who have been assaulted is the use of alcohol or drugs, which may reduce women's abilities to engage in HIV risk reduction behaviours (He et al., 1998; Mill, 1997; Miller & Paone, 1998; Sherman & Steckler, 1998; Zierler et al., 1996). Social isolation is also an outcome for sexually abused children; therefore when engaging in injection drug use (IDU), women may seek a social context in order to "fix," with sharing of drug paraphernalia a common occurrence (Miller & Paone, 1998).

Social Considerations

Health Canada (1996) refers to *gender* as the "array of socially determined roles, personality, attitudes, behaviors, values, relative power and influence that society ascribes to the two sexes on a differential basis" (p. 17). For women, gender inequality (Gillespie, 1997; Harlow et al., 1998; Tortu et al., 1998; Zierler et al., 1996) and gender role socialization (Gillespie, 1997; Sikkema et al., 1996; Somlai, Kelly, Wagstaff, & Whitson, 1998) not only are associated with an increased risk for HIV infection but also serve as barriers for women practicing HIV risk reduction behaviors. In this section, social factors that increase women's risk of acquiring HIV infection will be discussed including: the social context of HIV transmission; condom use; pregnancy intentions; substance use; violence; and HIV prevention efforts for women.

Social Context of HIV Transmission

Women's risk of acquiring HIV infection occurs within the context of their interpersonal relationships (Ickovics & Yoshikawa, 1998). This social context is characterized by the HIV risk behaviours of the community of people the woman belongs to, her personal power within her intimate relationship, and the cultural norms that prescribe her behaviour within sexual relationships.

Women tend to choose sexual partners from networks of people with characteristics similar to their own. If there is a pool of HIV infection within their "community," women's potential for HIV infection increases dramatically (Tortu et al., 1998). Further, if unprotected intercourse and unsafe IDU practices are viewed as normalized behaviors within their community, women's risk for HIV infection increases (Gillespie, 1997; Miller & Paone, 1998). Membership in these particular networks would not only increase women's access to sexual partners and drugs but also pressure the women to conform to the group's norms, thereby reinforcing HIV risk-taking behaviors (Miller & Paone, 1998).

Women's power within their intimate relationship affects their ability to take protective action to minimize acquiring HIV infection. Within sexual relationships, women may lack the power to negotiate condom use or the type of sexual activity they engage in (Harlow et al., 1998; He et al., 1998; Kalichman & Stevenson, 1997; Sherman & Steckler, 1998; Sikkema et al., 1996; Somlai et al., 1998).

Cultural norms also may negatively impact a woman's ability to engage in HIV risk reduction behaviours. If a woman's culturally sanctioned role is to follow the lead of her partner then she violates this cultural norm by suggesting condom use within her relationship. As a consequence, women may risk rejection or abuse by their partner (Gillespie, 1997; Somlai et al., 1998).

Condom Use

Women's capacity to suggest condom use varies within their sexual and primary relationships for numerous reasons. Women may perceive themselves to be at no risk or low risk for HIV infection (Kalichman & Stevenson, 1997). They may believe that initiating condom use could lead to abandonment or violence, or they may simply hold negative attitudes towards condom use (Kalichman & Stevenson, 1997; Sherman & Steckler, 1998; Sikkema et al., 1996; Somlai et al., 1998). Some women have identified their lack of self-esteem or their partner's ability to persuade them not to use condoms as the reason that they engage in unprotected sex (Kalichman & Stevenson, 1997). Male resistance and male control over the use of condoms were also identified as determinants of condom use (Capps et al., 1998; Gillespie, 1997; Sikkema et al., 1996; Somlai et al., 1998; Stevens et al., 1998; Weeks et al., 1995). Peer influence could positively or negatively affect condom use for women (Kalichman & Stevenson, 1997; Santelli et al., 1996). Finally, the use of substances prior to and during the sexual act generally decreases the use of condoms (Kalichman & Stevenson, 1997; Stevens et al., 1998).

Within their primary relationships women may have different reasons for not suggesting the use of condoms. Condoms may not be used so that women can demonstrate their trust and lack of fear about potential HIV infection with their primary partner (Weeks et al., 1998). Condoms however would be used if the woman's partner supports condom use (Santelli et al., 1996; Sherman & Steckler, 1998; Weeks et al., 1998). Women may believe they are in a mutually monogamous relationship, therefore condoms are not required. Unknowingly, women may be at increased HIV risk due to their partner's HIV risk behavior with others (Gillespie, 1997; Sikkema et al., 1996; Somlai et al., 1998).

Pregnancy Intentions

Pregnancy intention is also associated with an increased likelihood of acquiring HIV infection. Society places a high value on childbearing and the role of motherhood, which may also decrease the use of condoms and increase the woman's potential exposure to HIV infection (Gillespie, 1997; Santelli et al., 1996). Therefore, women may succumb to the social pressure to have children. In order to support their children adequately, women with low incomes may engage in prostitution, again increasing their risk for HIV infection (Weeks et al., 1998).

Substance Use

Substance use is not only associated with an increased likelihood of acquiring HIV infection directly but also indirectly may increase HIV risk behaviours. Substance use may result in unsafe injection practices as well as unprotected sexual intercourse, both of which increase women's risk of acquiring HIV infection (Gillespie, 1997; Metsch et al., 1998; Sikkema et al., 1996).

Substance use is a common coping strategy for impoverished minority women (Nyamathi, Flaskerud, & Leake, 1997; Sherman & Steckler, 1998; Tortu et al., 1998; Weeks et al., 1998). Alcohol, marijuana, and crack cocaine are frequent drugs of choice, especially for impoverished women (Sherman & Steckler, 1998; Somlai et al., 1998; Turner & Solomon, 1996). The use of these drugs, particularly cocaine, is associated with impaired judgement and decreased sexual inhibitions, leading to increased unprotected sexual behavior and potential coercion (Cattarello et al., 1998; Somlai et al., 1998; Tortu et al., 1998). Burns and lesions to the lips, caused by smoking crack cocaine, provide a port of entry for HIV (Sherman & Steckler, 1998).

Sexual partner or friends of the women may influence their alcohol and drug use (Sherman & Steckler, 1998). In one study, over 50% of women identified their sexual partner or friend as their entry point for drug use (as cited in Nyamathi et al., 1997).

Regardless of who initiates women into substance use, the procurement of the drug quickly takes precedence over HIV prevention behaviors, with some women seeking various sources of income to avoid drug withdrawal (Sherman & Steckler, 1998; Turner & Solomon, 1996; Weeks et al., 1998).

Women may feel powerless to change their substance use behaviour, including women who perceive their risk of acquiring HIV (Eldridge et al., 1997; Somali et al., 1998). Crack addicts report low self-esteem, sometimes related to their addiction (Sherman & Steckler, 1998; Sikkema, Heckman, & Kelly, 1997; Somlai et al., 1998), and higher levels of life dissatisfaction and fatalism, in combination with less optimism to alter their day-to-day chaos (Somlai et al., 1998).

Needle-sharing further increases women's risk for HIV infection (Mill, 1997). Women report sharing drugs or drug paraphernalia with their IDU partner, sometimes injecting with their partner's syringe after he has used it (Eldridge et al., 1997; Metsch et al., 1998; Stevens et al., 1998). Social situations are frequently sought by women in order to "fix" or inject drugs (Cattarello et al., 1998; Metsch et al., 1998; Miller & Paone, 1998).

The sexual behavior of female drug users is also associated with an increased risk for HIV infection. Women substance users may have multiple sexual partners (Eldridge et al., 1997; Sikkema et al., 1997; Stevens et al., 1998; Weeks et al., 1998), and exchange sex for drugs or money (Eldridge et al., 1997; Metsch et al., 1998; Stevens et al., 1998; Tortu et al., 1998). In addition, women who use drugs are more likely to be involved sexually with an injection drug-using partner who may not practice monogamy or condom use with other sexual partners (Capps et al., 1998; Eldridge et al., 1997; Miller & Paone, 1998; Nyamathi et al., 1997; Sikkema et al., 1997). Drug use during sexual activity may occur without condoms which may lead to an increase in STD and ulcerative STD (Eldridge et al., 1997; Stevens et al., 1998; Weeks et al., 1998). Women's reduced power within their relationship(s) and coercive sex are additional factors associated with increased HIV risk for female substance users (Eldridge et al., 1997; Metsch et al., 1998).

Violence

The conditions that enforce violence against women in our society are similar to the conditions that increase women's susceptibility for acquiring HIV (Zierler et al., 1996). Threats and experiences of sexual and physical violence are highly prevalent among women at increased risk for HIV infection (Harlow et al., 1998; He et al., 1998; Kalichman & Stevenson, 1997; Neron, 1998; Sherman & Steckler, 1998; Zierler et al., 1996). Threats of violence are high at the time of disclosing their HIV seropositivity to their male sexual partner (He et al., 1998; Rothenberg, Paskey, Reuland, Zimmerman, & North, 1995; Zierler et al., 1996). In a multinational study of violence, 21% of the female participants reported having sex with their partner because they feared the potential repercussions if they refused (Smith, Jones, & Henry; as cited in Zierler et al., 1996).

Rape is considered an "inherently social phenomenon" about power and control, resulting in an increased risk of HIV infection among women (Zierler et al., 1996). Genital injury is experienced by 40% to 87% of the women who are sexually assaulted. The presence of lacerations and abrasions in the genital area creates an efficient route for HIV transmission. This risk for HIV is decreased if no penetration occurs or a condom was used during the assault (Neron, 1998). Coercive sex and sexual assault rates are higher among women who are homeless (Somlai et al., 1998), engage in prostitution (Pyett & Warr, 1997; Somlai et al., 1998), or experienced childhood sexual abuse (Zierler et al., 1996). The risk of HIV transmission increases with the frequency of assaults and the number of assailants (Neron, 1998).

HIV Prevention Efforts for Women

Basic research in primary prevention tailored to women and their needs is sadly lacking (Cattarello et al., 1998; Fowler et al., 1997). Prevention efforts continue to target individual behaviors, with few researchers attending to the influence of the larger contextual factors in women's lives (Cattarello et al., 1998; Gillespie, 1997; Zierler et al., 1996). For example, the use of condoms is inconsistent with the public position of the Catholic church, male attitudes towards condoms and sex, and the expectation that men have about women's prescribed social roles (Weeks et al., 1995). There is an urgent need for more female-controlled agents to prevent HIV transmission (Capps et al., 1998; Royce et al., 1997; Somlai et al., 1998; Weeks et al., 1995), such as topical microbicidal agents (Royce et al., 1997).

Economic Factors

Economic status is another risk factor for HIV infection among women. Limited income and in many cases poverty reduces women's capacity to leverage resources for their basic needs, let alone for items such as clean needles or condoms (Turner & Solomon, 1996). As a result, women may engage in "survival sex", exchanging their sexual services for resources such as food, shelter, or money (Somlai et al., 1998, p. 8). In addition, women who are economically dependent on men are less likely to engage in HIV-prevention behavior (Capps et al., 1998; Gillespie, 1997; Harlow et al., 1998; He et al., 1998; Ickovics & Yoshikawa, 1998). The risk of acquiring HIV infection increases for impoverished minority women, homeless women, and women who engage in prostitution.

In North America, the risk of HIV infection is disproportionately higher among impoverished, minority women, especially those living in inner-city neighborhoods (Sikkema et al., 1996, 1997; Somlai et al., 1998; Tortu et al., 1998). HIV infection results from higher rates of substance use, unprotected sexual activity, and STD (Somlai et al., 1998; Tortu et al., 1998). One study conducted in the United States with African American IDU men and women, determined an HIV infection rate of 47% among homeless Black women, and 45% for impoverished Black women living alone in Miami, Florida (Metsch et al., 1998).

Homeless, substance using women experience greater life chaos and daily stressors, which supercede preventive health and HIV risk reduction (Nyamathi & Stein, 1997; Sikkema et al., 1996; Sikkema et al., 1997; Somlai et al., 1998). These women are more likely to have an IDU partner (Metsch et al., 1998; Miller & Paone, 1998), experience higher rates of unprotected sex, rape, physical assault (Gillespie, 1998; Somlai et al., 1998), and to exchange sex for money (Nyamathi et al., 1997; Tortu et al., 1998). As a result, homeless, substance using women are at increased risk for HIV infection.

The need for an income may pressure women to engage in prostitution. Street prostitutes have higher rates of HIV infection than brothel workers due to: higher rates of sexual and physical assault; social isolation; lack of community support; and an absence of legal protection for women "working the streets" (Pyett & Warr, 1997; Weeks et al., 1998). Prostitutes attempt to minimize the multiple risks of their trade (e.g., loss of custody of children, acquiring HIV infection, etc.) without jeopardizing the sale of their sexual services. However, prostitutes who are sexually and physically assaulted are unable to protect themselves from possible HIV infection, and receive little community support as assault may be viewed as an occupational hazard (Pyett & Warr, 1997; Weeks et al., 1998).

Aboriginal Culture as a Determinant of HIV Infection

Culture, the way in which a particular group of people lives, has been identified as a significant determinant of health (Health Canada, 1996). Culture is learned and reflected in the beliefs and values, language, concepts, and patterns of behavior within the group. Symbols, structures, and institutions also mirror the culture of a group. Culture is a dynamic concept that is continually influenced by a variety of factors (Airhihenbuwa, DiClemente, Wingood, & Lowe, 1992; Masi, Mensah, & McLeod, 1995).

The dominant cultural values that promote the "perpetuation of conditions such as marginalization [and] stigmatization" (Health Canada, 1996, p. 16) create the social environment that may contribute to additional health risks, such as HIV infection for Aboriginal people. Political, social, and economic factors that may influence the risk of HIV infection within Aboriginal communities are discussed in this section. This section ends with a discussion of Aboriginal peoples' view of health and illness.

Political Factors

Various political influences have had an impact on the Aboriginal way of life. Assimilation practices, European colonization, and discrimination specifically towards Aboriginal women have affected Aboriginal people's culture and lives. Aboriginal self-government is viewed as an approach that will support Aboriginal people's attention to priority health issues, such as HIV infection, in their communities.

Over 100 years ago, the Canadian government sought to "civilize" Aboriginal people. The government's doctrine of assimilation was often couched in humanitarian and Christian terminology. Sending Aboriginal children to residential school was one strategy used to support this philosophy. Although the official goal of these schools was to provide education and technical training, "they were, in effect, instruments of assimilation" (Waldram et al., 1997, p. 15). The legacy of the residential school lives on today as numerous Aboriginal people learn how to live their lives after being subjected to years of emotional, physical, and sexual abuse (Royal Commission on Aboriginal Peoples, 1996).

Other factors had great repercussions on Aboriginal culture. The introduction of European diseases resulted in the decimation of Aboriginal people. The decline of the fur trade industry by 1821 increased levels of poverty for Aboriginal people. In addition, the introduction of alcohol also had a negative impact on Aboriginal people. Further, the compulsory movement of Aboriginal people to reserves and the influence of missionaries and other dominant European ideologies also negatively influenced the culture of Aboriginal people living in Canada (Waldram et al., 1997).

Discrimination towards Aboriginal women was introduced in Canada during the assimilation process. Aboriginal women were disadvantaged not only by the Indian Act and other 19th century laws but also by Victorian ideals rooted in patriarchy. For example, Aboriginal women could not own or inherit property or vote in band elections and were considered the responsibility or "property" of their husbands (Royal Commission on Aboriginal Peoples, 1996, p. 100; Swampy, 1982). Aboriginal women ceased to be "Indian" when they married non-Indian men, whereas Aboriginal men who married non-Indian women did not suffer the same repercussions (Royal Commission on Aboriginal Peoples, 1996, p. 101). Writings by the early missionaries, the fur traders, and the North West Mounted Police blamed a plethora of problems on Aboriginal women. At the same time, Aboriginal women experienced all manner of abuse at the hands of both Aboriginal and non-Aboriginal men (Brodribb, 1984; Carter, 1993).

Today, Aboriginal people want recognition of their Aboriginal nationhood. They believe that the political and territorial integrity of Canada would not be threatened by this recognition. It is from this premise that self-government is viewed as an inherent right—not as a 'gift' from an "enlightened Canada" (Royal Commission on Aboriginal Peoples, 1996, p. 25). Self-government reflects the importance of Aboriginal participation and control in decision making that affects Aboriginal people and their communities.

Aboriginal determination extends to health and health care issues, such as HIV/AIDS in Aboriginal communities (Matiation, 1998c). Aboriginal leaders view the transfer of responsibilities for health care to First Nations communities as positive because the process has increased Aboriginal control over health care and reflects their needs and traditions more clearly. Initiatives are under way to improve the jurisdictional problems that have contributed to the divisions between the federal and provincial governments, relative to HIV/AIDS issues (Matiation, 1998c). Strategies such as the Alberta Aboriginal HIV/AIDS strategy are based on the principles of Aboriginal control and design. This approach is viewed as respectful of the distinct needs and traditions within the various Aboriginal communities in Alberta, while ensuring the "availability of culturally appropriate HIV/AIDS programs and services for Aboriginal people" (Matiation, 1998a, p. 36).

Social Factors

Various social factors increase Aboriginal women's risk for HIV infection and reduce their capacity to engage in HIV risk reduction behaviours. The social factors discussed in this section include Aboriginal women's cultural roles, sexual practices, substance use, and violence.

Within the Aboriginal culture, women are socialized into various roles that may influence their risk for HIV infection. One study identified the role of Aboriginal women as a "wife and mother" in Alberta during the 1980's (Swampy, 1982, p. 9) The pubescent female was taught to be "kind and to respect her husband" (p. 10), and that, while single, she was "completely under her father's control" (p. 10). Condom use was not condoned because the role of Aboriginal woman was to bear children. In general, the degree of passivity and compliance, along with decreased personal power within the context of the relationship, deters Aboriginal women from encouraging condom use, thereby placing them at higher risk for HIV infection (Brassard et al., 1996; Swampy, 1982).

Aboriginal women's sexual practices may also increase their risk of acquiring HIV infection. In a more recent Canadian Aboriginal study (Aboriginal Nurses Association of Canada, 1996), the majority of women had one sexual partner, although some women questioned the fidelity of their partners. Condom use was not practiced 67%

of the time for numerous reasons including the assumed safety of being in a monogamous relationship, women's belief that her partner did not have HIV, and alcohol or drug use. Seventy percent of the Aboriginal women engaged in vaginal sex, while 4% of the respondents engaged in anal sex. Thirty percent of the respondents reported fear of physical abuse by their partner should they refuse to have unprotected sex.

Substance use is a common and available means of coping with stressful life experiences and chaos in women's lives. Aboriginal women are no different in this regard. Substance use and prostitution may be initiated in response to sexual and physical abuse, which increases Aboriginal women's risk for HIV infection (Neron, 1998). Aboriginal women are disproportionately represented among injection drug users who frequent needle exchange sites (Brassard et al., 1996; Houston, 1995).

Violence in Aboriginal communities is also associated with an increased risk of HIV infection among Aboriginal women. The social problems that Aboriginal people experience are "a legacy of history" (Royal Commission on Aboriginal Peoples, 1996, p. 59). Family violence arises from a fundamental power imbalance between women and men. For Aboriginal women the power imbalance in their intimate relationships may be further compounded by oppression and discrimination by the dominant non-Aboriginal culture (National Clearinghouse on Family Violence, 1997; Royal Commission on Aboriginal Peoples, 1996).

Economic Factors

Many of the health problems that Aboriginal people experience, such as HIV infection, invariably are related to their economic status (Alberta Health, !995; Mill & DesJardins, 1996; Tseng, 1996). Low levels of education, higher rates of unemployment, and welfare dependency lead to lower income levels for Aboriginal people.

The level of education achieved within the Aboriginal community is lower than that for non-Aboriginal Canadians (Brassard et al., 1996; RPM Planning Associates

Limited, 1994). In the 1991 Aboriginal Peoples Survey (APS) conducted by Statistics Canada, approximately 50% of the Aboriginal people between the ages of 15 and 49 years had completed secondary school and only 3% had completed a university degree (as cited in Waldram et al., 1997).

Relatively higher rates of unemployment and welfare dependency exist for Aboriginal people (25%) compared to their non-Aboriginal counterparts (10%) (Waldram et al., 1997). In some northern communities, unemployment rates reach as high as 90% due to seasonal employment. The rate of welfare dependency is two to four times higher among Aboriginal people than among Canadians in general (Royal Commission on Aboriginal Peoples, 1996). It is not surprising, then, that the reported income levels for Aboriginal people are lower. In 1991, 54% of Aboriginal people reported an annual income of less than $10,000, compared to 34% of non-Aboriginal Canadians (DuBois et al., 1996; Royal Commission on Aboriginal Peoples, 1996; Waldram et al., 1997).

Aboriginal people's movement towards self-reliance and self-government will require increased educational and training opportunities for Aboriginal people. "Aboriginal people want to make a decent living, to be free of dependence on others, free of the social stigma and sense of personal failure that go with dependence, and free of the debilitating effects of poverty" (Royal Commission on Aboriginal Peoples, 1996, p. 38). The transformation of Aboriginal communities from economic dependence to self-reliance promises to be challenging. Resources for education and training will increase Aboriginal peoples' capacity to meet the employment and business opportunities that self-government will create (Royal Commission on Aboriginal Peoples, 1996).

Aboriginal Concept of Health and Illness

The Aboriginal concept of health and HIV illness is both unique and inclusive. Health is viewed in a holistic manner with four interrelated constructs - the mind, the body, the emotions, and the spirit need to be in balance in order for the person to be healthy (Malloch, 1989). The Medicine Wheel is often used to frame this concept of health, because it represents "the sacred circle of life" (Alberta Health, 1995).

Health and well being are viewed as a process within the Aboriginal culture. Having good health is perceived as a gift from the Creator, one that should be appreciated. If an individual maintains health by attending to the balance of the four core constructs, then it is thought that the individual is showing respect for and appreciation of the Creator's gift. When an individual has achieved a balance within these core constructs, he or she is provided with gifts: a sense of purpose; a sense of the meaning of life; a sense of direction; and a sense of connectedness with all things (Brown, 1990). "Good health is maintained when one lives in a balanced relationship with oneself, one's family, one's community, the earth and the world." (Shestowsky, 1993, p. 7).

Illness is also viewed as a blessing among Aboriginal people. "It is the Creator's way of nudging us to restore balance in our lives." (Brown, 1990, p. 4). Illnesses such as HIV provide a message, with symbolic significance, to bring about healing of the individual and community (Brown, 1990). The first lesson that is to be learned is in relation to taking personal responsibility for becoming ill or developing HIV infection. The second lesson has to do with reflecting on one's life in order to learn the lessons that HIV has brought so that balance may be restored. Attending to the physical and the spiritual dimensions is considered germane to the healing process (Brown, 1990).

HIV Counselling and Testing

A review of the literature on HIV counselling and testing revealed interesting insights into lessons learned during the past two decades of HIV testing. Principles and components of Canadian HIV counselling and testing in general will be identified followed by a discussion of the specific suggestions for HIV testing of pregnant women. In addition, assumptions that guided the development of HIV counselling and testing practices in the first decade of HIV testing will be identified along with changes to HIV counselling practices in the second decade of HIV counselling and testing.

HIV counselling and testing became available in Canada in 1985. By 1990, the Canadian Medical Association (CMA) had developed counselling guidelines for HIV testing in Canada, which have been updated twice since then. The CMA identified underlying principles to guide HIV testing. First, testing for HIV would be voluntary in Canada. Second, HIV testing would occur only after the individual had given their "informed consent" for the test. In order to obtain informed consent, the person had to understand the purpose and the harms and benefits of being tested. In addition to the individual's voluntary consent, individuals also had to be deemed capable of making an informed choice about HIV testing.

The most recent edition of the Canadian guidelines identifies the components of HIV pre-test and post-test counselling (CMA, 1995). During HIV pre-test counselling, the HIV tester would assess the person's risk of HIV infection and determine the person's most recent HIV risk event in order to calculate the timing of the HIV test, or window period. Information about HIV infection would be provided along with high and low HIV risk activities and specific ways to reduce a person's HIV risk. Next, the tester would discuss the various HIV testing options, such as nominal (HIV results linked to person), non-nominal (tester knows the identity of the person tested), and anonymous testing (person chooses and does not disclose their identifying code) (CMA, 1995). The limitations of the HIV test would also be discussed with the individual seeking testing. HIV testing would proceed once the individual understood all aspects of the test and provided her/his consent. The post-test counselling session is used to inform the individual of their test results while reinforcing any risk reduction behaviors that had been discussed in the previous session. If the individual tested positive, then emotional support is provided and appropriate referrals are made (CMA, 1995; Norton, Miller, & Johnson, 1997; Sikkema & Bissett, 1997).

In addition, the Canadian Medical Association recommends offering HIV counselling and testing to all pregnant women. However, these medical experts suggest that the procedure for HIV testing be slightly different for pregnant women. A difference would be that a pregnant woman would be given a separate requisition for HIV testing; therefore, she would not jeopardize her other prenatal screening should she decide not to have HIV testing done at that time. Similar information about HIV testing would be provided to obtain informed consent, along with additional information about potential mother-to-child HIV transmission (Canadian Medical Association, 1995). Again, the same two principles used in general HIV counselling and testing would apply for HIV testing of pregnant women—that is, testing is voluntary, and informed consent is sought prior to proceeding with the HIV testing. Alberta now offers HIV testing for pregnant women; however, the approach that is used is called the "right to refusal". What this means is that pregnant women need to know before seeking prenatal care that they will be offered HIV testing and that they have a right to refuse HIV testing if they so choose. Given the current practice in Alberta, pregnant women may proceed with HIV testing if they are unaware of their choice to refuse testing, or if they do not feel confident enough to refuse the test given the power differential between the pregnant woman and her physician.

Several assumptions guided the introduction and delivery of HIV counselling and testing within public health clinics. The first assumption was that HIV counselling and testing would "fit" the traditional approach used by public health in the battle against STD. The interaction was more likely didactic, with the person receiving direction from the professional or "expert" (Sikkema & Bissett, 1997; Valdiserri, 1997). This approach has not been viewed as empowering for the person seeking testing. The second assumption was that testing negative for HIV would result in behavior change, which has turned out not to be the case. Experts assumed that if a person knew they were HIV negative, the person would utilize their acquired HIV prevention information from the pre-test counselling session to maintain their negative HIV status. What was learned by experts was that the provision of information alone was not sufficient to change HIV risk behaviour (Holtgrave et al., 1995; Kamb, Dillon, Fishbein, & Willis, 1996; Norton et al., 1997; Phillips & Coates, 1995; Valdiserri, 1997).

As a consequence, subsequent guidelines from the Centres for Disease Control (CDC) in the United States called for the adoption of a "client-centered" or non-directive approach in the second decade of HIV counselling and testing (Grinstead, 1997; Sikkema & Bissett, 1997). This view focused on tailoring the prevention messages to match the world-view or special circumstances of the individual. HIV testers were to focus on the person's culture, gender, age, level of education, sexual orientation, and any other concerns that may negatively impact their ability to engage in HIV risk reduction behaviours (Fishbein & Guinan, 1996; Holtgrave et al., 1995; Sikkema & Bissett, 1997; Valdiserri et al., 1993).

In addition, future HIV counselling and testing interventions were to be grounded in behavioral science theory as there was a clearer understanding of the type of information that individuals need in order to change or maintain a given behavior. A number of researchers explored the applicability of various behaviour models to HIV counselling and testing interventions (Fishbein & Guinan, 1996; Norton, Miller & Johnson, 1997). The merits of Prochaska and DiClemente's (1982) *Transtheoretical Model of Behaviour Change* (TTM) were frequently identified relative to other behavioural models (Fishbein & Guinan). In this model, the individual is assessed for their readiness to change their HIV risk behaviour with an appropriate stage-related intervention provided (Prochaska & DiClemente, 1982).

About the same time, Waterston (1997) argued that the scientific community needed to stop focusing solely on the individual as this was limiting HIV prevention efforts and research. She suggested that ignoring the social factors in the spread of HIV infection, such as women's power differential in their relationships and their cultural norms, women's risk of acquiring HIV infection increased. Other researchers also agreed that societal issues and structures produce the requisite conditions for increased HIV infection which need to be addressed if the HIV epidemic is to be arrested (Choi and Coates, 1994). Examples of the issues and structures Choi and Coates (1994) identified include: increased employment opportunities; accessible and affordable condoms and needles; poverty; sexual inequality; discrimination of oppressed minorities; and stigmatization against HIV infected individuals.

Various researchers emphasized the importance of understanding the determinants of behavior within a given population in order to mount effective HIV counselling and testing interventions. This would include an understanding of the language and customs within the group, along with the prevalence of the behaviors that placed them at risk for HIV infection (Fishbein & Guinan, 1996; Grinstead, 1997; Holtgrave et al., 1995; Phillips & Coates, 1995).

"Culturally Appropriate" Prevention Interventions

A review of the HIV literature relative to *culturally appropriate* prevention interventions sheds some light on how this phrase has been defined. In this section, I discuss HIV prevention programming during the first and second decades of HIV infection. Next, *culturally appropriate* HIV interventions are defined for minority women, followed by a review of available literature on HIV prevention programming for Aboriginal people. No evidence is available that describes Aboriginal women's perspectives on culturally appropriate HIV counselling and testing.

In the first decade of the HIV epidemic, the predominant HIV prevention programming was male oriented with few programs addressing the needs of women, such as sexuality, gender roles, and power differential within racial and class distinctions (Majumdar & Roberts, 1997; Siegel, Karus, & Raveis, 1997; Weeks et al., 1995). This emphasis was congruent with the epidemiology of HIV infection at that time, as mostly gay men were affected. Patriarchy and racism were identified as systemic forces working to oppress women and increase their vulnerability for HIV infection, including the lack of attention by many researchers to the specific HIV prevention needs of women (Neron, 1998; Weeks et al., 1995).

By the second decade, the need for gender-specific and culturally appropriate HIV prevention programming for women was identified, and research agendas were more likely to reflect prevention needs of women, including minority women. The studies reviewed focused on HIV prevention interventions tailored to the needs of impoverished minority women living in the United States (Airhihenbuwa et al., 1992; Kalichman & Stevenson, 1997; Nyamathi, Bennett, Leake, Lewis, & Flaskerud, 1993; Siegel et al., 1997; Weeks et al., 1995). One group of researchers (Kalichman & Stevenson, 1997) identified the need to provide skill building to increase women's self-efficacy and power, leading to a reduction in their HIV risk behaviors. Airhihenbuwa et al. (1992) suggested manipulating the environment (e.g., providing access to needle exchange, etc.) and using persuasive communication to influence the beliefs, attitudes, and decisions of the community relative to HIV prevention.

Three ethnocultural studies addressed both genders in their HIV prevention and programming efforts. Goicoechea-Balbona (1998) developed a culturally sensitive model of health care delivery for African-American, Spanish-Caribbean, and English-French children with HIV/AIDS and their families. While working with the World Health Organization's Global Program on AIDS, Scrimshaw, Carballo, Ramos, and Blair (1991) developed HIV/AIDS Rapid Anthropological Assessment Procedures (HIV RAP). This tool was used to gather baseline data on AIDS-related beliefs and behaviours for specific communities of people. These data would then guide the development of culturally appropriate HIV interventions for the specific community. The developmentally and culturally sensitive instrument developed by Stanton et al. (1995) was used to assess HIV risk behaviours of African-American youth living in low-income neighbourhoods and to monitor the impact of HIV education on the behavior and outcomes.

The focal point for two other HIV prevention studies related to the diverse needs of various ethnocultural communities in Canada (de Burger, 1996; Majumdar & Roberts, 1997). The first study focused on supporting various ethnic minority women in a peer education role within their respective communities (Majumdar & Roberts, 1997). Ethnic populations represented in this study included Central and South Americans, Arabs, Barbadians, Indians, Bangladeshis, Laotians, and a diverse group of women from the local multicultural council. The second study was a three-phase national study with researchers and members of three of Canada's non-dominant ethnocultural communities working collaboratively to develop HIV prevention programming. Programming was to increased HIV knowledge and risk reduction practices for people from the Latin-American, Caribbean, and South Asian communities within their cultural context. Active community participation in the development of HIV interventions was paramount to the success of the programming (de Burger, 1996).

However, only one study (Siegel et al., 1997) was found that specifically addressed HIV counselling and testing from the perspective of women from ethnocultural communities. This particular group of researchers studied HIV counselling and testing behavior of African-American, Puerto Rican, and Caucasian women. They learned that HIV infected women tend to delay getting tested for HIV once they recognize their personal vulnerability, and they also delay seeking medical treatment. The principal obstacles to testing included fear of learning one's test results, denial, survival issues, hopelessness, and lack of time arising from caring for others. Another barrier to accessing testing or health care was the women's distrust and suspicion of the health care system and providers.

Culturally appropriate interventions in the literature cover a range of topics, including the exploration and discussion of cultural norms pertaining to drug use

(Nyamathi et al., 1993; Weeks et al., 1995), gender role differences and expectations (de Burger, 1996; Scrimshaw et al., 1991; Weeks et al., 1995), power inequalities (de Burger, 1996; Scrimshaw et al., 1991; Weeks et al., 1995), attitudes towards sexual education (de Burger, 1996), and local group knowledge of HIV/AIDS (Scrimshaw et al., 1991). Patterns of social support, ethnic pride and identity, spirituality, and religious issues were also identified as being key to effective interventions for women to reduce their HIV risk (Weeks et al., 1995).

Available Aboriginal-specific literature on HIV prevention programming for Aboriginal women and men concurs with the proposed interventions for diverse ethnocultural communities. Tseng (1996) and Matiation (1998b) identified the need for a full range of accessible, confidential HIV testing for Aboriginal people, including anonymous HIV testing. Interventions grounded in traditional Aboriginal symbols and social values were to be determined and directed by Aboriginal people (Brassard et al., 1996; Aboriginal Nurses Association of Canada, 1996; Matiation, 1998a, 1998b, 1998c; Sullivan, 1991). Programming was to be offered by members of the community, in places where they naturally gathered, or through the provision of outreach services for special populations such as prostitutes (Brassard et al., 1996; DuBois et al., 1996; Matiation, 1998a, 1998b, 1998c; Sullivan, 1991).

Specific topics covered for Aboriginal interventions were much the same as the culturally appropriate interventions identified for other ethnocultural communities. Messages were to be rooted in the specific needs of the community (Mill & DesJardins, 1996; Sullivan, 1991), with an emphasis on sexism, racism, poverty, and violence (Brassard et al., 1996; Aboriginal Nurses Association of Canada, 1996; RPM Planning Associates Limited, 1994; Sullivan, 1991). Pride of self and nation were to be emphasized along with respect for self and other (Brassard et al., 1996; Sullivan, 1991). The potential destruction of the Aboriginal race as a result of HIV infection was another message identified for dissemination (Brassard et al., 1996).

No research has been done in Canada to define *culturally appropriate* HIV counselling and testing for Aboriginal people. The Canadian Medical Services Branch (as cited in Matiation, 1998b) identified that the provision of HIV counselling and testing for Aboriginal people needs to be by a person who "is sensitive to the issues of sexual identity, culture and living conditions" (p. 17). In addition, Aboriginal people and health-care providers have also identified the lack of culturally appropriate services for Aboriginal people (Aboriginal Nurses Association of Canada, 1993; Alberta Medical Association, 1997; Brassard et al., 1996; DuBois et al., 1996; Matiation, 1998b; RPM Planning Associates Limited, 1994; Sullivan, 1991; Shah & Farkas, 1985).

Summary of the Literature Reviewed

Based on a review of the literature, women, especially Aboriginal women, are at increased risk for acquiring HIV infection. Various epidemiological, biological, and sexual and reproductive factors are associated with an increased risk for HIV infection for women. The political, social, and economic subordination of women further enhances the necessary conditions for women to acquire HIV infection. The experience for Aboriginal women acquiring HIV infection is further compounded by their experiences of systemic discrimination and oppression, poverty, and abuse.

The review of the first decade of HIV testing and counselling literature identified the need for a client-centered approach, tailored to the special circumstances of the individual, and based on a model of behaviour change to prevent HIV risk behaviours. The second decade of HIV counselling and testing also emphasizes the importance of attending to broader societal structures including the gender and culture of minority communities at greater risk of acquiring HIV infection.

The literature review identified little Canadian research relative to HIV prevention programming in various ethnocultural communities, especially within the Aboriginal community. Active community participation in the development of the HIV programming is a major consideration. Interventions that address sexuality, substance abuse, violence, gender roles, and power differentials within their racial and class distinctions were identified as critical components of women-centered programming. Finally, the literature identifies a need for culturally appropriate prevention services to redress the growing HIV epidemic within the Aboriginal community in Canada (Matiation, 1998b). No research studies were found that specifically addressed culturally appropriate HIV counselling and testing among Aboriginal populations. The present study was an attempt to begin to address this gap.

CHAPTER 3

RESEARCH METHODOLOGY

In this chapter, I discuss the research design, sampling methods, data collection methods, and data analysis used in this study. The chapter concludes with the strategies used to ensure rigor, and the ethical considerations of this study.

Research Design

An exploratory descriptive qualitative research design was used for this study because little is known about what constitutes "culturally appropriate" HIV counselling and testing from the perspective of Aboriginal women. A qualitative design is particularly appropriate when little is known about the phenomenon under study and when the research is exploring a phenomenon from the "emic" perspective (Morse & Field, 1995).

An advisory group guided the study to ensure the relevancy and sensitivity of the research. The advisory group was comprised of four female members of the Alberta Aboriginal community: a female Elder, and three other female Aboriginal leaders. Membership on the advisory committee was determined through conversations with an Aboriginal woman who has worked on HIV prevention initiatives in Aboriginal communities across Alberta and Canada. Together we decided to invite a female Elder from northern Alberta, an HIV positive Aboriginal woman, and an Aboriginal woman who was working with Aboriginal people in HIV prevention. These women agreed to participate on the advisory group. Knowledge about Aboriginal culture relative to health and illness and to HIV counselling and testing comprised the qualifications of the members of the advisory committee.

The advisory group was responsible for a number of activities, including reviewing the individual interview guide for relevancy, clarity, and sensitivity; providing suggestions regarding recruitment of Aboriginal women for the interviews; and reviewing the preliminary findings and questions to guide the focus group interview. The advisory group will receive the findings and recommendations from this study as they have indicated their interest in informing the appropriate Aboriginal leaders, starting with Aboriginal Chiefs and Councils.

Unfortunately, I started an 18 month medical leave of absence shortly after the second advisory group meeting in February 2000. I believe my leave of absence had a negative impact on the enthusiasm and energy generated within the advisory group. I have been attempting to set up another meeting with this group and plan to share the findings and recommendations from the study with them at that time, and confirm the advisory group's previous recommendation for dissemination of the findings. Perhaps my medical leave allowed me to be a more objective researcher, as I was able to step back and then re-immerse myself in the data after an 18 month break.

Sampling

Nonprobability sampling was used to conduct the study. Participants were recruited who could provide understanding of the subject of HIV counselling and testing for Aboriginal people and who were willing to share their thoughts during the interview process (Miles & Huberman, 1994; Patton, 1990). The criteria for selecting the research participants were as follows:

- women of Canadian Aboriginal ancestry (First Nations, Métis);
- ability to speak and understand English;
- 18 years of age or older; and
- living within 100 kilometers of Edmonton.

These sampling criteria were broad so as to include a diversity of participants. As the study progressed, participants were selected according to the specific information needs of the study (e.g., including one woman who was pregnant and another woman who was HIV positive).

Recruitment for this study was guided by the Aboriginal advisory group. The group generated a list of Aboriginal people who worked in various agencies and who may know Aboriginal women who would be interested in participating in the study. Based on the recommendation of the advisory group, I contacted the agency people to briefly discuss the study and to set up appointments to meet with them. During my meetings with the agency contacts, I provided them with information about the study and their role in the recruitment of participants (see Appendix A). The agency person was asked to invite interested Aboriginal women to call me, and to provide Aboriginal women with a copy of the information letter (see Appendix B) about the study. In one case, the agency contact person had obtained permission from the potential participant for me to contact her, as it would be "easier" for the potential participant.

The advisory group also provided suggestions regarding compensation. The group determined it was appropriate to provide $20.00 to study participants. This gift of money was to acknowledge the participant's time for the study interview. This practice has been incorporated in a number of studies exploring condom use and HIV prevention strategies (Brassard et al., 1996; DuBois et al., 1996; Kalichman & Stevenson, 1997; Santelli et al., 1996).

Seven Aboriginal women were recruited to participate in individual interviews through my connection to the agency person. Six different women were recruited to participate in a focus group to respond to the findings from the individual interviews. The final sample size was determined by the adequacy of the data. This refers to the "sufficiency and quality of the data" (Morse, 1989, p. 123). After interviewing seven participants and conducting one focus group, no new information was learned; therefore "saturation" was reached. Consequently, there was no need for further individual interviews or focus groups.

Data Generation

Individual Interview Guide

The primary strategy used to generate data for this study was conducting individual interviews, using a semi-structured interview guide (see Appendix C). This form of data collection allows the interviewer to learn more about the participant while gaining rich, in-depth descriptions on the research topic. Individual cues from the participant can be responded to, thereby influencing the flow of the conversation. There is greater responsibility on the part of the participant to explain or elaborate on initial statements or thoughts with relatively little prompting by the interviewer. Generally, greater depth of information is obtained with this data-collection technique than with the use of focus groups (Morse & Field, 1995; Patton, 1990).

The advisory group reviewed the individual interview guide for relevancy, clarity, sensitivity, and completeness, with several changes suggested. For example, the advisory group recommended eliminating a question asking Aboriginal women about factors that influence HIV risk for Aboriginal women. The group believed that this information would evolve during the interview, based on the participant's own experiences. The group also suggested re-ordering the questions so that information would flow more easily from other people's experiences during HIV counselling and testing to recommendations about "culturally appropriate" counselling and testing. The final change was to replace the words "culturally appropriate". The Elder in the group felt that these were "big words" and could be replaced with Aboriginal women describing HIV testing that was done in a "good way". All of these suggestions were incorporated into the individual interview guide.

In addition, the advisory group suggested a change to the background data sheet. Their recommendation was to eliminate the probe about whether an Aboriginal woman was a "status" or "non-status" Aboriginal woman. The advisory group said it was sufficient to ask the participants whether they were First Nations or Métis on the data sheet and their recommendation was incorporated.

Next, the individual interview guide was pilot tested with two women. It became clear through this process that the wording of the first question needed to be broader. As it stood, the question focused narrowly on the Aboriginal woman's experience of puberty. This question was re-worded asking participants about their life experiences growing up as an Aboriginal woman. Further changes were made to enhance the clarity of the balance of the questions, without compromising the intent of each question. After incorporating these changes, I piloted the tool again with greater success in that the questions were clear to the respondent and useful information was gathered (see Appendix C).

Individual Interviews

Individual interviews were conducted from October 30, 1999 to February 1, 2000. An appointment was made with each of the women who indicated her willingness to participate in the study at a mutually agreed upon time. The initial interview with each participant was held at a location of her choosing. Five of the interviews were held in Aboriginal agencies, with the other two were held in a health care setting. The interview space supported confidential disclosure with a minimum of disruption in the immediate vicinity. An information letter about the study was reviewed and discussed with the participant (see Appendix B). Informed consent for participation in the study was then obtained (see Appendix D). At the end of the interview demographic data were obtained (see Appendix E). These data included information about the participant's age, level of education, Aboriginal status, type of current relationship, and HIV risk behaviours.

I conducted all interviews in order to establish and maintain rapport with the participants. Rapport was built based on my ability to "convey empathy and understanding without judgment" (Patton, 1990, p. 317). I tried to use words that the participant used during the course of the interview. Questions were clear so that the participant was better able to answer what was being asked.

Individual interviews allowed me to learn more about the participant while gaining rich, in-depth descriptions on the research topic. Participants appeared comfortable and relaxed and shared openly, with the exception of the one woman who is an injection drug user (IDU). She told me that she does not like to talk about being HIV positive and her answers were very brief relative to the other study participants.

Using the semi-structured interview guide (see Appendix C), the interview began by asking the participant to describe her life growing up as an Aboriginal girl. This open-ended question allowed the participant an opportunity to express her experiences, moving to more sensitive questions as the interview progressed. The arrangement of questions in this manner allowed for the initiation and development of trust and respect throughout the course of the interview. The remaining three major questions included the woman's or other Aboriginal people's HIV testing experiences, the ideal HIV counselling and testing experience, and what a comfortable HIV counselling and testing experience would be for Aboriginal women. Each individual interview lasted from one to one-and-a-half hours.

A second individual interview was scheduled for five of the seven women following analysis of each initial interview. The purpose of the second interviews was to clarify or confirm my understanding of their experiences from the initial interview and to further expand on their ideas. In addition, discussion was guided by the categories emerging from the analysis of the data. The second interviews were usually shorter, ranging from one-half to one hour long. These interviews were conducted in person beginning the last week in January 2000. Unfortunately, two of the seven women were unavailable for the second interview.

Focus-Group Interview

A focus group was conducted following the conclusion of the individual interviews. The focus group interview was designed primarily to validate the findings from the individual interviews (Brink & Wood, 1994; Morgan, 1997). A semi-structured interview guide was used to initiate and guide the discussion (see Appendix F). The interview guide was reviewed by the advisory group. The opening question provided each participant the opportunity to introduce herself to the group. Subsequent questions were designed to promote the exploration of important similarities and differences in the experiences of the women relative to information generated by the individual interviews. Selected findings and categories from the individual interviews were presented throughout the focus group discussion to stimulate further exploration and discussion of the findings.

Recruitment for the focus group proved to be more difficult than for the individual interviews. A member of the advisory group approached a group of Aboriginal women she knew to assess their willingness to participate in the focus group. Only three women came to the scheduled focus group. As a result, the focus group was postponed until the following week.

The focus group was held on March 5, 2000, at a retreat centre for Aboriginal people. I co-facilitated the focus group discussion with a professional community-based focus group facilitator. The focus-group interview was approximately two hours. An information letter about the study was discussed (see Appendix G) prior to obtaining informed consent (see Appendix H). At the end of the focus-group discussion, demographic data were obtained with the permission of the participants (see Appendix E). Data included information about the participants' age, level of education, Aboriginal status, relationship status, and HIV risk behaviours.

The focus group sample consisted of six Aboriginal women. Three of the women described themselves as First Nation and Métis (Bill C-31), two women as Aboriginal, and one woman as Métis. Five of the participants were between 30 – 36 years, and one was 18 years. One participant lives in a city, two live in a town, and three live in a rural community. Three of the women are married with children, one woman and her children live with her partner, one woman is single and one woman describes her relationship as undecided. Three of the women had attended a post-secondary institution, one completed Grade 11, and two completed Grade 8. Four of the women work full time, and two women do not work outside of their home.

While the focus-group interview process allows participants who are frequently not heard to "give voice" (Morgan, 1997, p. 21) to their thoughts and experiences on the research topic, this was not the case here. The focus-group participants provided support for the findings from the individual interviews: however, discussion was not spontaneous, with very little interaction between the participants. The co-facilitator and I had difficulty sparking the women to speak freely. Reasons for the lack of spontaneous discussion may be related to the nature of the group, as participants knew each other and hence may have been concerned with confidentiality. Perhaps Aboriginal women's communication style does not support a free exchange within a group setting. The level of education for the participants was lower in the focus group than the individual interviews, which may have negatively influenced the women's interactions within the focus group, or perhaps having two non-Aboriginal facilitators posed a barrier.

Documentation of Generated Data

Interviews were tape recorded and transcribed verbatim. Data generated by the interviews and focus group were augmented through the use of field notes, methodological memos, analytical memos, and a personal journal. These sources of data facilitated the tracking of decisions and the evolving analysis throughout the research process (Rogers & Cowles, 1993).

Field notes recorded the activities and behaviors of the participants during the interviews and focus-group sessions. These notes provided the necessary context through which the participant's response was better understood. The use of labels to describe the behaviour was avoided. The field notes were synchronized with the interview data via key phrases from the interview and supplemented the tape recording (Brink & Wood, 1994; Miles & Huberman, 1994; Rogers & Cowles, 1993).

Methodological memos were used to record my rationale for various decisions that were made during the course of the study. Clear documentation of the changes to the interview questions was identified in the methodological memos, along with the rationale for these changes, as mentioned previously. This is considered to be an integral component in substantiating the rigor of the study (Miles & Huberman, 1994; Rogers & Cowles, 1993).

Analytical memos were also kept throughout this study. These memos captured my initial insights, which could then be confirmed through further data collection and data analysis. In this way, I was able to track the actual path of data analysis in order to demonstrate the procedures and the lines of inquiry that were used during the research study (Miles & Huberman, 1994; Rogers & Cowles, 1993).

In addition, I kept a personal journal (Brink & Wood, 1994; Morse & Field, 1995). Initially, this tool was used to capture my thoughts and to record my feelings about responses during the research process. The women's descriptions of the violence they experienced generated strong feelings for me. Often I came home from the interview exhausted emotionally and needed to rest. As personal as my journal became, it played an essential role in establishing the rigor of the research (Rogers & Cowles, 1993). Given the 18 month lag between conducting of the focus group and beginning of data analysis, the memos and personal journal were even more critical in helping me recall decisions that had been made, as well as thoughts and insights that had occurred.

Data Analysis

In qualitative research, data analysis is not a distinctive stage, but part of an ongoing process that is initiated with data collection. Data from transcripts (individual interviews, focus-groups discussions), field notes, personal journal, and methodological and analytical memos were analyzed. This analysis was organized by utilizing the four cognitive processes of qualitative research (Morse & Field, 1995).

The first stage involved *comprehending* the data through my immersion in it. Recorded data were transcribed into a compatible format for use with the NUD*IST software program. Comprehension of the data was supported through the use of question and content analysis (Morse & Field, 1995). The research question and sub-questions were used as an organizing framework for the data analysis. Within these large categories, each line of the transcript data was examined and coded. These codes were constantly compared with codes and data from other interviews with the same and different participants. As the analysis proceeded, codes were compared and clustered with similar codes into broader categories. Comprehension of the data was considered complete when I had sufficient data to "identify stories that are part of the topic, identify patterns of experience, and predict their outcomes" (Morse & Field, 1995, p. 127).

Data comprehension was supported by the use of summaries from each individual interview. This assisted me in understanding the specific situation and context of each participant. In addition, data from the field notes, memos, and my journal were also utilized to increase understanding as the categories emerged. The NUD*IST software program allowed for easy retrieval of the data. I found that my ability to generate reports using NUD*IST enhanced my ability to sort and comprehend the data.

The next step was to *synthesize* the data, or to weed out the "significant from the insignificant" (Morse, 1994, p. 30). The writing process supported the synthesis of the data, making relationships among the categories more evident. Direct quotations from the participants were used to summarize and illustrate the emerging categories. Saturation of the data was achieved when the major categories of the data were identified, and no new categories emerged.

The *theorizing* phase was an active and strenuous process of assessing for links between the synthesized data to existing theory. I determined whether similar concepts from other settings or contexts could be used to explain the data. Literature was reviewed from a variety of areas including health care delivery, mental health services, HIV counselling and testing, and HIV prevention. In addition, literature relating to women, including minority women and especially Aboriginal women was identified relative to each of the aforementioned areas.

Recontextualizing is said to be "the real power of qualitative research" (Morse, 1994, p. 34). This occurs when the researcher determines whether the emerging findings are applicable to other settings. Established theory and the work of other researchers played a critical role at this juncture. Certainly, meetings with the research committee, the advisory group, and the research participants allowed the collective insights and experiences to support the process (Miles & Huberman, 1994).

Strategies to Ensure Rigor

Many researchers have debated the scientific merits of qualitative research relative to quantitative research. Four factors that complicate the debate include the variety of qualitative methodologies, the creative features of qualitative inquiry, the absence of concrete boundaries between quantitative and qualitative research, and the tendency to measure qualitative research using quantitative criteria (Sandelowski, 1986; Sandelowski, 1993). Nevertheless, rigor in research is required to ensure that the results are trustworthy. Criteria used to evaluate the trustworthiness of qualitative research include truth value, applicability, consistency, and neutrality (Lincoln & Guba; as cited in Sandelowski, 1986).

Truth value, or credibility, refers to the faithful interpretation and representation of the women's experiences in the study. This was achieved through a number of activities during the research process. Pilot testing of the individual interview guide resulted in greater clarity of the questions being asked of the women. Transcripts of each individual interview captured the women's thoughts verbatim, with their voices heard through their quotes. Categories that emerged were grounded in words directly quoted from the women as much as possible. As well, women at the second interview confirmed that the written summaries provided to them had adequately and appropriately captured their comments. My ability to record my own experience in my journal also allowed separation from the participants' experience, thereby increasing the credibility of the findings.

Applicability refers to whether the findings "fit" into contexts other than the study situation. Applicability was achieved in two ways during the research process. The initial results of the individual interviews were taken to two other groups of Aboriginal women: the advisory group and the focus group. Both these groups of Aboriginal women identified that the initial findings from the study "fit" based on their knowledge and life experiences as Aboriginal women.

The next criterion refers to the *consistency*, or the *audit trail*, discussed earlier in the chapter. Field notes, methodological memos, analytical memos, and a personal journal were used to track the decisions I made and the evolving analysis during the research. My audit trail proved to be invaluable, especially considering the break between data collection and data analysis. In addition, these activities strengthened the rigor of the study so that other researchers are able to follow the decisions that I made and arrive at comparable conclusions.

The final criterion is *neutrality*, or *confirmability*, in qualitative research. This is said to have been achieved when truth value, auditability, and applicability are established. Confirmability refers to the "findings themselves, not to the subjective or objective stance of the researcher" (Sandelowski, 1986, p. 34). Confirmability of this study will be further determined when the findings of this study are reported and others find them relevant to their experiences.

Ethical Considerations

Ethical approval for this study was received from the University of Alberta Health Research Ethics Board (HREB). Based on recommendation from the HREB, minor changes to the information letter (Appendix B) were made.

I discussed with participants the purpose and the procedures of the study prior to initiating the individual interviews. Anonymity and confidentiality were discussed and assured throughout the research process. Only code numbers were used to identify tapes and transcripts. Tapes, transcripts, and notes will be kept for at least seven years in a locked filing cabinet. The consent forms and code lists will be kept for five years in a separate locked filing cabinet. Study participants chose pseudonyms, that were then used in the reporting of the research findings. No identifying information will be used when the information and findings from this research are published. These data may be used for a future study if approval from the appropriate ethics review board is received by the researcher.

The information letter was written at a Grade 2.3 level, using the Flesch-Kincaid Grade level (see Appendix B). Once all questions and concerns were discussed to the satisfaction of the participant and myself, I obtained an indication from each woman as to whether she was willing to proceed with the interview. Next each participant was invited to sign the consent form (see Appendix D). The consent for participation in the individual interviews is in keeping with the recommendations of the Health Research Ethics Board. The reading level of the consent form is Grade 5.4 using the same scale.

Consent for participation in the focus-group interview(s) was obtained prior to beginning that interview, in the same manner as explained above. The information letter for participants about the focus group was written at a Grade 2.3 level, using the Flesch-Kincaid Grade level (see Appendix G). The consent form for participation in the focus group was in keeping with the recommendations of the Health Research Ethics Board (see Appendix H). The reading level of the consent form was Grade 5.4, using the same criterion previously identified. In addition to the protocol adhered to in the individual interviews, focus-group participants were encouraged to respect and maintain the confidentiality from the discussion generated during the group process.

Participation in either the individual interviews or the focus group did not result in participants' experiencing personal discomfort, to my knowledge. Referral to an appropriate counselling service would have occurred if this had been the case.

CHAPTER 4

RESEARCH FINDINGS

The research findings are organized around four broad categories: Aboriginal women's life experiences; the HIV testing experience and barriers to testing among Aboriginal people; the ideal HIV testing situation; and dimensions of "culturally appropriate" HIV counselling and testing within Aboriginal communities. In this chapter I will elucidate these four major categories, following a brief description of the sample. In the presentation of findings, pseudonyms, chosen by the women themselves, are used to identify participants.

Sample

The primary sample consisted of seven Aboriginal women who were interviewed between October 30, 1999 and February 1, 2000. Three of the women described themselves as First Nation Aboriginals and four of the women as Métis. The age of the participants ranged from 27 to 42 years: five were younger than 30 years, one was 35 years, and one was 42 years. All of the participants lived in Edmonton, Alberta with a population of approximately 700,000 people. Three of the women were single parents, three were married with children, and one woman and her children were living with her partner. Six of the women had attended a post-secondary institution: one woman graduated with a Bachelor of Arts degree; three women had almost completed or were in the process of completing an undergraduate degree; and two women graduated with a diploma in corrections or social work. One woman's highest level of education was Grade 9. Five of the women worked full time, one woman attended school full time, and one woman did not work outside of her home.

Aboriginal Women's Life Experiences

A discussion of the participants' life experiences within a dominant non-Aboriginal culture provided the context for the findings related to the major research questions. Three major sub-themes were identified: childhood sexual abuse; discrimination; and sexuality and relationships. A discussion of these sub-themes is important because it leads to an understanding of the women's perspectives of the ideal HIV testing situation and the evolving definition of *culturally appropriate* services for Aboriginal women seeking HIV testing.

Childhood Sexual Abuse

Childhood sexual abuse was a common occurrence in the Aboriginal communities of these participants. Six of the seven women were sexually abused repeatedly during their childhood. Two of the women were sexually abused at 4 years of age, three women between 6 and 9 years, and one woman at 12 years. The perpetrators ranged from fathers to foster fathers; from mother's male friend to mother's partner; from distant to close members of the family; and from acquaintances to total strangers:

> Dallas: I was nine years old, my first [sexual abuse] experience. . . . It was somebody within my family.
>
> Lulu: When I was fours years old [I was sexually abused]. I just barely remember [this experience] as something that I saw happen, rather than something that happened to me. . . . It was totally removed from me. . . . At the age of six [I was sexually abused by] a family member, although it was a fairly distant family member, and at the age of nine, but it was not a family member.
>
> Raven: I was raped by one of my mom's boyfriends.
>
> Maureen: My uncle [sexually abused me]. It happened until I was ten years old [and started when] I was four years old.
>
> Courtney: I don't remember a whole bunch of what happened, but I know he raped me in the back alley, in a culvert, in the snow. . . . I look at twelve years now and I think, I went through that at twelve. . . . I remember one time in a car with five guys [when I was seventeen]. . . . I couldn't [protect myself]. They

> dropped me off in the north end [after they raped me]. I had to walk home that time.

> Vanessa: I was twelve. Towards the end [of my stay in a foster home my foster dad] got me and my sister extremely drunk on wine. I went into my bedroom and passed out. I recall having a dream about kissing my teacher, because he had a beard like [my foster dad]. I woke up the next morning extremely sore with blood on my underwear. In retrospect, I think he raped me because my first sexual contact [after that] said I wasn't a virgin. . . . I was also abused before I was eight. When I was [living] with my mother, she'd bring men home. I was abused by [these] men [sexually].

The women attempted to explain the occurrence of sexual abuse within Aboriginal communities. One woman believed that sexual abuse within Aboriginal communities was a direct result of Aboriginal men losing their traditional role as the "protector" of women and children:

> Lulu: Most of the Aboriginal female friends that I have, every single one of them has experienced some sort of sexual abuse. These are women who have got university education, who are working in the Aboriginal community. . . . I think the [sexual abuse] has a lot to do with the absence of that [male] protector. I was raised by a single mother, and the protection wasn't always there.

Another woman believed that the displacement of cultural norms for Aboriginal men to protect women was an outcome of the colonization process and the socialization that occurred through residential school experiences and other assimilation practices. While living in these schools, Aboriginal children were frequently abused:

> Raven: Our teachings . . . have been displaced. . . . Within my own family because of residential schools, . . . it was very abusive; there was a lot of abuse, sexual abuse and mental abuse.

The experiences of sexual abuse negatively affected the women's mental and emotional health in a variety of ways. The women spoke of not feeling "valuable," of being "screwed up" and of learning how to "close off" their feelings as a result of their sexual abuse experiences:

> Lulu: I think that from that [sexual abuse] experience [at the age of four years] and others that happened after it, it just ate away at me. When I talk about the inability to see myself as valuable and to make choices for myself, I think that's where it came from.
>
> Maureen: I finally went to the cops [to report the sexual abuse that my uncle did to me]. Like, it was last year I went to the cops. Maybe that's why I'm so screwed up.
>
> Courtney: The next day [after being sexually abused at 12 years] I cried. . . . I remember that day. I stopped crying on that day and I just closed right off.

Vanessa was receiving ongoing psychiatric care because she had been diagnosed with major depressive disorder, posttraumatic stress disorder, agoraphobia, and social phobia. She believed that her disorders were a consequence of the abuse in her life.

Early childhood sexual abuse also influenced the women's use of alcohol and drugs as they attempted to "forget" these experiences. One woman spoke of her addiction by the age of 12 years, and two other women had been through alcohol and drug recovery programs. Alcohol and drug use led to "partying", defined as engaging in multiple sexual relationships while under the influence of alcohol or drugs. The women used words such as promiscuous and self-destructive to describe their behaviour at this time:

> Courtney: I started drinking quite a bit [after being raped at age 12]. . . . I didn't realize what I was doing. I was being very self-destructive. . . . The whole year [I was sixteen] I just part[ied]. I overdosed on drugs . . . and ended up in hospital, and [I was] pretty promiscuous. . . . I know I ended up [having unprotected sex] with lots and lots of people, and lots of it was because of drinking too. Once you get past a certain point, you really don't care. I mean, there were some times I've woken up and I was with somebody and I didn't—you know, I had no idea how we even got to that point.
>
> Raven: [Using alcohol and drugs] was helping me forget the mistakes I made and that kind of thing. But in the same sense I was making new mistakes. And that's where I became really sexually active, . . . two straws short of a hooker but didn't get paid.

The acquisition of blood-borne pathogens was yet another consequence of alcohol and drug use stemming from childhood sexual abuse for two of the women. Vanessa contracted Hepatitis C from her sister while sharing a needle to inject drugs. Maureen became HIV positive, likely through unprotected sexual intercourse with her partner, who was an injection drug user.

Childhood sexual abuse also had an impact on the women's abilities to develop intimate relationships with men. One woman, Lulu, found that she had a "dislike" for heterosexual men because of the sexual abuse she had experienced, "I had a dislike, hate even, for men. Scared of them and still am to some extent. . . ." Another woman, who was sexually abused when nine years old, felt irritated when touched by a man:

> Dallas: That [sexual abuse] affected me in my early relationships because I didn't like to be touched. I just did not like to be touched. And the first relationship I was talking about, the one I have kids, I never liked him touching me. I never liked him to touch me, and he had no idea why....Touch me, he was always touching me, always touching me. On my inner thighs, he was just always, had to be touching me. It irritated me and I kept it in for so long.

In addition, early childhood sexual abuse had an impact on the women's relationships with other people, within and outside their families. The women spoke of feeling responsible for relationships ending, and for causing parental "grief". One woman felt responsible for breaking up her mother's engagement when she disclosed being sexually abused by her mother's fiancée: "I remember feeling bad because my mom was crying and I had made them fight, because my mom had cared for him. They were engaged or whatever. So I remember feeling bad, that I shouldn't have said nothing" (Raven). Courtney spoke of the "grief" she caused her parents after she was raped at the age of 12 years: "I started drinking quite a bit [after being raped at age 12]. I really gave my parents a lot of grief after that. I really acted out and I would take off on weekends." Women also may feel discomfort with being hugged by people outside of their family, as expressed by Raven:

> Raven: I have no problem hugging my kids and stuff like that. But I do have a problem hugging people I don't know, and I don't know if that's because of the sexual abuse. For me, part of it is because there's still a part of me that I'd like to keep safe.

In summary, six of the seven women in the study had been sexually abused as children. The occurrence of sexual abuse in Aboriginal communities was thought to be an outcome of Aboriginal people's abusive experiences in residential school and the loss of traditional norms such as the "protector" role for men. Sexual abuse had a profound effect on the women's mental and emotional health, their use of drugs and alcohol, and their relationships with men and other family members.

Discrimination

The women in this study reported being subjected to various forms of discrimination. Women coped with this discrimination in various ways. The types of discrimination to which women were subjected included racist remarks, negative stereotypes, intra-racial discrimination, and systemic discrimination.

Being called a derogatory name, usually by a non-Aboriginal person, was not an unusual experience for the Aboriginal women in the study. The women identified a number of names they had been called over the years: "wag," "squaw," "dirty Indian," "wagon burner," "black bitch," "slanty eyes," and "puffy cheeks". Being called racist names led to feelings of being judged:

> Dallas: It was sad because I didn't see myself as being any colour. . . . It hurt my feelings. . . . So for me as a kid, wherever I went I always felt like I was being judged for who or who I wasn't, based on the colour of my skin, on the reserve and off the reserve.

Another type of discrimination to which Aboriginal people are subjected is negative stereotypes:

> Dallas: It was the stereotypical things that [non-Aboriginal] kids don't learn on their own—they hear [from others]. So maybe [non-Aboriginal kids heard] that [Aboriginal kids] had lice or, you know, the different things [non-Aboriginal people] say Native kids have. You know [Aboriginal kids] don't brush their teeth; their parents are drunks; their mom's probably playing bingo.

This negative stereotyping included viewing Aboriginal women as having fewer competencies than non-Aboriginal women. Aboriginal women therefore have to work harder to prove themselves:

> Raven: With non-Aboriginal women, a lot of time society looks at them and assumes they know what to do and how to do it. And with Aboriginal women, [it's] assumed that you don't know what to do and you don't know how to do it. . . . Just in life—in general: in employment, with education, with parenting. So you're always proving yourself; you have to try ten times harder to prove yourself.

Dallas, who attends a post-secondary institution with few Aboriginal students, also found that non-Aboriginal male students treat her differently from the non-Aboriginal female students.

> Dallas: People tend to not, not look to you, not think of you as intelligent, not think of you as professionals, not think of you as somebody who they can rely on. And I get that; I get that all the time. I feel that all the time.

Intra-racial discrimination occurs when Aboriginal people discriminate against other Aboriginal people:

> Courtney: Native people would call me 'Nigger Lips' and all kinds of stuff.

> Raven: My grandmother was adopted by non-Natives when she was young. . . . She lost her Treaty rights because she was adopted. My mom was actually Treaty [Indian], but [she and her siblings] were labeled 'half-breeds' because they didn't have their Treaty status.

Intra-racial discrimination may be a coping strategy to deal with inter-racial discrimination as Aboriginals internalize the stigma from others. Alternatively, it may be a response to "survivor's guilt".

> Raven: It happens almost daily, and it happens with our own people against our own people sometimes. There's so much discrimination that some of our own people are starting to absorb that. The more low self-esteem and unhealthier ones have learned to deal with it, [by] dishing it out. "If you can't beat them, join them" is a phrase that a lot of people use. . . . "You're not Indian enough." . . . It's like a survivor's guilt also too, where some of our people say, "You've made it up to that ivory tower. What are you doing to help us?" that kind of thing.

Systemic discrimination was also evident in the experiences of Aboriginal people as they accessed services from a variety of systems. One woman believed that institutions reflect the values and norms of the dominant White male society—certainly not the values and norms of Aboriginal communities: "Institutions as they exist now reflect the values and norms of a society that [is] mostly centered around men, centered around White people, centered around a certain religion like Protestant or Catholic" (Lulu). Another woman spoke of the discrimination experienced by mothers at the hands of health professionals:

> Courtney: Moms feel discriminated against by lots and lots of systems. . . . If [the mom] delayed immunizations for three shots [they are asked], "Why haven't you come in?" or [told], "Your baby needs these." . . . The moms know that they need them, but there's all kinds of reasons why they [haven't come in].

There were many consequences resulting from the discrimination the women experienced. Women who were Métis found that they did not "fit" within the Aboriginal or the non-Aboriginal communities as a result of their experience of discrimination: "I'm Métis, [and] the difficulty for me has been around not feeling totally a part of either [the Aboriginal or non-Aboriginal] culture" (Lulu). Dallas also spoke of being "stigmatized" and called an "apple" on her reserve, and not fitting in the White community:

> Dallas: I wasn't really considered Aboriginal by the other [Aboriginal] students. They always said that I was an apple—white on the inside and brown on the out, red on the outside. . . . I was stigmatized because my mom was White. . . . My mom decided she would move me to a White school. Well, that wasn't any better. There I really stood out. . . . So there again I was teased. I was called 'brown bear.' I was called a bunch of names.

Vanessa also spoke of her conflicting feelings in relation to her Aboriginal heritage. Hearing her mother called a "filthy squaw" by her paternal grandmother fueled her internal conflict about being Aboriginal. Vanessa felt fortunate that she could "pass" as a member of the Spanish community, because this minimized the discrimination she experienced:

> Vanessa: You're taught to respect the culture, to take pride in the traditions and the Elders. Yet, on the other hand, society is showing you drunken Indians, violence, abuse; and it alienates you from both aspects. You're not sure where you are in this place. . . . I've been fortunate that, depending on my hair color, I can pass for Spanish or something; I'm fortunate that way, so it helps so much with [discrimination].

Discrimination led to a loss of friends and a sense of isolation:

> Dallas: It kind of affected me because I only had maybe one or two friends. . . . People just chose not to make friends with me. But as you grow and people mature, they actually took that opportunity to talk to me and get to know me.

> Raven: I went to schools that had a high majority of non-Aboriginal people. . . . As a result of that, there was a lot of racism. I knew that I was different, and there was a lot of racism, so I never had a lot of friends. I just had the few that accepted me all the time. And plus it didn't really matter, because we would move within about a year, so I never really was stable to really meet a lot of friends and stuff.

Another consequence of the discrimination experience is its impact on accessing services. Aboriginal people may prefer to access services that employ Aboriginal staff because people feel more "trust" for Aboriginal staff:

> Starr: A lot of Aboriginal people go to Social Services or whatever and have problems with the social workers. But when they come for services [with] all Aboriginal social workers, [the people] feel they can trust [them] more it seems. It shows that way.

Aboriginal women require "self-esteem" and "support" in order to cope with this type of continual discrimination, but as Raven suggested, "They don't have the coping skills to handle that ongoing discrimination and pressure." Two of the women spoke of the difficulty that Aboriginal people had understanding the systemic nature of discrimination, rather than internalizing it as a personal issue:

> Raven: [Aboriginal people tend not to be able to handle discrimination]; they don't have the coping skills to handle that ongoing discrimination and pressure. And it's so underlying that sometimes [Aboriginal] people don't recognize [discrimination]. . . . They take [discrimination] personal[ly] because they think it's a personal thing. They don't understand that [discrimination] is a reflection of society's views.

> Dallas: I'm not assertive in the sense that if somebody says something, I don't stand up and say, "Was that a racial comment?" But if I notice that maybe it's ongoing, maybe I'll say something, but generally not. I don't like to say that it's racial. I always say that it's got something to do with me. Is it me?

Raven also spoke of the negative way in which she used to handle discrimination in her past. Today she handles discrimination by bringing it to the person's attention in a respectful way:

> Raven: I've been personally discriminated against, or I see people being discriminated against. I bring it to that person's attention so that they'll learn, and I do it in a way that's respectful too. But back in my old days I would have probably said "Fuck you" and walked out the door, and I would have drank. . . . And [today] I wouldn't have said it in a violent tone; I would have said it in a very humbling tone and allowed you to fully express what you meant by that. And then I would have expressed how that made me feel. Now, whether you go away with learning something or you don't, the ownership would have been on you; it wouldn't have been on me; I wouldn't have carried it.

Another woman focused on sharing the uniqueness of Aboriginal culture with non-Aboriginals as a way to manage discrimination:

> Dallas: Everybody's different. Everybody's unique. . . . I teach [my children] that they are Native and that their Native culture has certain qualities and certain values and customs that they can share with other [non-Aboriginal] people. . . . So I teach my kids that. Everybody's different, whether you're brown, you're white, you're purple, you're orange—you're different. And it's what's inside that counts. It's the type of person that you are.

In summary, all of the women in the study had experienced discrimination. The women had been subjected to racial remarks, derogatory stereotypes, intra-racial discrimination, and systemic discrimination. Consequences resulting from the discrimination the women experienced included feelings of not belonging in either the Aboriginal or the non-Aboriginal communities, experiencing conflicting feelings about being Aboriginal, having few friends, and hesitancy in accessing services.

Sexuality and Relationships

The women in the study had varied experiences in relation to their sexuality and relationships. A woman's sexuality and her personal power within the context of her relationship have an impact on her risk for HIV infection. In this section, I discuss the women's experiences during puberty and the nature of their intimate relationships over time. The women's intimate relationships are characterized by a greater tolerance of negative behaviours from their partners.

Experience of Puberty

Puberty was perceived as a positive experience for Aboriginal women in traditional times. Aboriginal women received affirming information and preparation about puberty from women in their community. Menstruation was viewed as "good and powerful and natural":

> Lulu: In more traditional First Nations Society a woman or a young girl was prepared and taught about [puberty] from when she could first begin to understand it and that it was something that the whole community of women came together and discussed and prepared [women] for. It was something that was seen as good and powerful and natural and part of the whole cycle of nature.

However, the residential school experience changed how Aboriginal women viewed their menses and this had an impact on their sexuality. These negative messages about menses have been passed to successive generations of Aboriginal women:

> Lulu: Like my grandmother, for example. [She] talked about when [she lived] in a residential school. [Menses] was looked upon as something dirty and nasty. She had problems because of that. . . . Just not being connected to her own sexuality, to her own womanhood and feeling like there was something wrong with being female.

The sexuality education that the participants received during puberty did not always incorporate information about all aspects of sexuality. Several of the women indicated that they would have liked additional information about sexuality as they were growing up. For example, one woman would have liked information about sexual intercourse and conception:

> Starr: I never really had sex education from my mother or my sisters. I kind of had to learn those things on my own. [For example,] if you have sex you're going to have a baby. Like, I remember in Grade 5 [sexuality educators] came to school and [gave us] sex education. They kind of showed us the pictures of the private parts and stuff. But none of my sisters explained that to me.

Another woman who had received information on STD and pregnancy control expressed a need for information on the emotional aspects of sexuality. This additional information would allow women to cope more effectively with their "feelings" within the context of relationships:

> Raven: My mom told me about STD and about not getting pregnant. She really didn't tell me about the feelings that go along with [being in a relationship]. All that kind of stuff that really matters. I think that's because she didn't really know herself.

Yet another woman would have liked information and skills about making decisions within sexual relationships. Lulu believes she made decisions within her relationships in an attempt to please her partner instead of meeting her own needs or wants:

> Lulu: When you're in a situation where you have the opportunity to have sexual relations with someone, I don't think that I was given the skills or the tools to be able to really make that choice, to say "No" or "Yes" for myself—for my own reasons. I made 'choices' based more on my lack of self-esteem or wanting to please that other person so that they'd like me more rather than because it's something I wanted. One of the things that [Aboriginal women] are not really told is we have the choice to say "No."

Intimate Relationships

The Aboriginal women had also received contradictory messages about women's roles in intimate relationships. In traditional times women had "equally important and valued roles" to play. Men were the "providers" and "protectors" for the community, whereas women were involved in parenting their own and the community's children. Men also participated in child rearing, provided role models for the young boys and men, and protected the female children and women. One of the women told a story that exemplified the different roles that Aboriginal men and women had in traditional times:

> Raven: There's a room full of people, men and women, Aboriginal women, and there's food, and the women are made to sit on the ground instead of the chairs. The men eat first, and then the women eat. Now, when people from society would look at that, they'd think it would be disrespectful, but the reason why the women sit on the ground is because we're worthy of sitting closer to Mother Earth because we're bearers of children. And the men are not yet as worthy to sit on Mother Earth because they are not bearers of children, so they sit on the chairs; there's the barrier between them. And the reason why the men eat the food first is because they're protectors, and they make sure that the food is good enough for the women to eat, so that's why they are fed first, and then the women eat after. If it's safe enough for them, then it's safe enough for us because we are the ultimate providers of emotional strength and leadership. So that's sort of the role that we play in our culture.

Today, Aboriginal women's intimate relationships are less egalitarian. The study participants believe there are four major factors that have created "unhealthy" relationships between Aboriginal men and women. These factors include a *loss of traditional teachings*, *patriarchy*, *derogatory stereotypes of Aboriginal women*, and *discrimination*.

The women perceived that the traditional Aboriginal teachings about healthy relationships had eroded as a consequence of the colonization process and the socialization that occurred through residential school experiences and other assimilation practices. Aboriginal children were forced to learn the cultural values of a dominant, non-Aboriginal society instead of their own traditional egalitarian values:

> Raven: So I think a lot of Aboriginal women . . . want things to be equal, so equal in the consensus of everything—equal parenting, equal power, that kind of thing. That's how it was traditionally. So this was a value and a moral that we had embedded in us, but without our teachings and without the direction, we don't know where that belongs. It's displaced and distorted into unhealthy scenarios. . . . The biggest cause was residential school.

Patriarchy also influenced the shift in power that Aboriginal women have in their relationships today. Women in the study spoke of Aboriginal men having more power in their relationships because they are the "breadwinners": "I was taught that men are the 'breadwinners' of the family; [therefore men] make decisions because, ultimately, [men] make money [and men] make the decisions" (Dallas). Aboriginal men and women also were taught that "women were the property of men." A consequence of not complying with their partners' demands resulted in the women being physically, sexually, or emotionally abused:

> Raven: I had a couple of uncles who used to sit with me and tell me what guys will expect [from me] and that kind of thing. Of course, [my uncles] were kind of from the 'old school.' [My uncles told me], "Don't bother [with men]" or "If you're going to bother with [men], be expected to play your part the way you're supposed to, or you're going to end up hurt." . . . [My part was] the obligation [to have sex]. . . . So when I was twenty-three I still felt that women were [the] property of men and they deserved to get hit once in a while if they [were] disrespect[ful]. So even though it didn't feel right, that's the way [it was]. My first relationship when I was seventeen was very abusive.

> Dallas: How do you say 'No'? . . . I mean, 'no' is nothing. And that was the thing with him: He had the ultimate power, ultimate. For me to say "No, you're not having sex with me" wasn't even a question. Okay, so you lay down on the bed and you have sex, you know. . . . And I find that all the Aboriginal relationships I see, the men always seem to have that 'one up' in terms of power. . . . [Aboriginal] men seem to have a lot of power.

Aboriginal women's power within their intimate relationships has been further reduced as a consequence of derogatory stereotypes relating to their sexuality. Aboriginal women feel like "sexual objects" and are viewed as a "squaw," "promiscuous," or "easy":

> Lulu: I think that Aboriginal women are viewed as objects, sexual objects, like the dichotomy in European culture with the virgin and the whore or Pocahontas and the squaw type of thing. I've seen Aboriginal women idealized as this sort of maiden of the forest and also looked upon as a woman on the streets who's available if you want her.

> Courtney: I think [Aboriginal women] have been labeled, you know, [as being] promiscuous. Especially with the younger people you hear Native girls are easy anyway.

> Vanessa: White men [believe] that a Native woman is easier, sluttier, willing to do basically anything. They have a very low opinion [of Aboriginal women], yes, the way they look at you.

Discrimination towards Aboriginal women has also had a negative impact on Aboriginal women's power within their intimate relationships. Aboriginal women have been encouraged to date other Aboriginal people. This practice of intra-racial dating is thought to increase the women's personal comfort and to minimize intra-racial discrimination towards potential children from this union. Discrimination by non-Aboriginal males towards Aboriginal females has further reduced the likelihood of entering into inter-racial relationships and perhaps has introduced the notion that Aboriginal women were not good enough to date non-Aboriginal men:

> Dallas: It was strictly Native boys that I dated. I always just felt more comfortable with that. Plus the fact that the White boys didn't seem interested in me anyway. . . . My mom always said, and never really maybe said it directly, but kind of something like, "I would like you to be with a Native man." . . . For [her daughters] to be with a Native man would just make it easier on all of [us]. So [if] our kids would be Native [they would] not have to face the discrimination.

<u>Tolerance of negative behaviours.</u> Aboriginal women's intimate sexual relationships are often typified by their tolerance of negative behaviours from their partners. This tolerance included alcohol and drug abuse, unprotected intercourse outside of their primary relationship, and various forms of abuse. The women believed that this tolerance may result from being raised in chaotic environments, characterized by displays of violence.

By giving their partner a "second chance" after these behaviours occur, Aboriginal women's risk for HIV infection from their partner increases. Courtney explains:

> Courtney: We have a higher tolerance for negative behaviours [from our partners]. There's hope the [negative behaviour] will change, that it'll go away. But I really think from the way people are raised, and I can speak for myself, it's just, you become more tolerant of behaviours against you, and you're more willing to stay and wait it out than I think other people would. . . . [The partner's

> behaviour] puts [Aboriginal] women at risk for HIV. Aboriginal people have a very high tolerance level for all kinds of behaviours. It's probably the way a lot of us grew up, you know, in that really chaotic environment.

One example of the negative behaviour that Aboriginal women tolerate in their relationships is the use of alcohol or drugs by their partner. Courtney believed that few Aboriginal women engage in injection drug use (IDU) compared to their use by Aboriginal men. When there is a pool of HIV infection within a community, and needles or drug paraphernalia are shared with each other, the potential to bring HIV infection into intimate sexual relationships increases:

> Courtney: It's not a whole bunch of women that actually do the needle use that I'm aware of. It's their partners who do it, and they can bring [HIV infection] back [into the relationship]. . . . [Aboriginal women] have been put at risk [for HIV infection] because of their partners, and there's nothing [Aboriginal women] can do about that.

Another negative behaviour tolerated by Aboriginal women was their partner's unprotected sexual intercourse outside of their primary relationship. By then having unprotected intercourse within the primary relationship, their partner increased the woman's risk for HIV infection. The Aboriginal woman may have no choice about having intercourse, protected or otherwise. This is illustrated by Dallas' experience when her partner engaged in unprotected sex outside their relationship and then proceeded to sexually abuse her:

> Dallas: And so, I mean, we just had no sexual relations, and that's when he decided he was going to have sexual relations with all of [city named]. So—and then he came back to me, nine months after I had the first [baby], and he just had sex with me, just laid me on the bed and that was it. . . . I told him, I said, "No." I would say it was rape. I still tell him to this day.

Physical abuse by their partners was another behaviour tolerated by the women. Physical abuse was described as a "common" experience for Aboriginal women in their relationships. Five of the seven women in this study had been in an abusive relationship. Courtney spoke of a pregnant Aboriginal woman whose partner had physically abused her and had sexual relations with other people outside of their relationship. As a result of this behaviour, this woman was at increased risk for HIV infection:

> Courtney: I know of a mom [who] is pregnant. There's all kinds of rumours [she and her partner are] HIV positive. He beats on this girl. He's cheated on her I don't know how many times throughout her pregnancy, and she's close to [giving] birth now. . . . I tell her it is possible that maybe [her] partner contracted the [HIV] virus and infected [her] during the pregnancy. . . . She can see that's really risky with what's been happening, but she thinks she needs to stay with him and she won't leave him. Some of the situations are pretty scary.

Being physically abused by their partner had major consequences for Aboriginal women as they attempted to cope with the relationship. They found that their ability to seek support from others was challenged. For example, one woman's ability to seek support from other people while in an abusive relationship was restricted by the partner:

> Raven: I was very isolated. And when I look back now, he helped that isolation. He would take the phone when he would leave the house so I couldn't call others. He'd have his family come and check to see if I was home, or his friends. And he would take off. He would say he was going to the garbage, and then I wouldn't see him for days. So the only time I was allowed out of the house was when I got my welfare cheque at the end of the month, to go cash it and get groceries.

Raven also found that she imposed isolation on herself as a means of coping and staying in the relationship, although this strategy did not enhance her "mental stability":

> Raven: I just didn't want outside interference [or] opinions. If anybody said, "You need to leave him," I [would] shut [the person] out of my life. And so I just was not mentally stable. There'd be times I sat in a corner with my son to make sure he was quiet with me so that [my partner and his friends] wouldn't think we were home. I'd live in my little fantasy [world imagining a different] life [than what I had] in that basement apartment.

The physical abuse experience had an impact on the women's future relationships, in that they sought similar relationships that led to abuse:

> Raven: [Aboriginal women move into abusive relationships] because it's what they're used to. It's familiar territory.

> Vanessa: It's just like a vicious cycle. You stick with what you're used to without even realizing it.

> Courtney: The man I was engaged to . . . was mentally abusive, and I knew I had to get out [of the relationship]. The first time he tried to be really cruel to my daughter, I kicked him out. It was pretty bad. He'd chase me to work and kick in my windows and stuff like that. It was pretty bad. . . . And [my] next relationship after that was physically abusive.

When the abusive relationship with their primary partner ended, some of the women engaged in sexual intercourse with multiple partners. Having intercourse with various partners was viewed as a means of increasing self-worth:

> Dallas: I had many sexual relations, many sexual relationships. Because of my own insecurities about who I was, I thought sex was the way to show everybody that yeah, I was okay. But that's why I'm scared now about [being HIV positive].

> Courtney: I became very promiscuous. . . . That's how I got lots of my self-esteem back then, was people thinking I was pretty, and the way I thought to express that was to go ahead and have sex with people. Not that I ever prost[ituted]. I never was anything like that, but I know I ended up with lots and lots of people, and lots of [my behaviour] was because of drinking too.

For other women, multiple partners led to a feeling of being desirable and being in control:

> Raven: I was very, very sexually active [after my first relationship ended]. And this time it was full [vaginal-penile] intercourse. I was being very sexually active—two straws short of a hooker I'm sure, but didn't get paid. . . . [My ex-partner] had really beaten up my self-esteem, so I needed to prove that I was desirable to other men and that I had control. A lot of these men that I had met did want to be in relationships, but I had control. . . . I said "No" by not even knowing their names sometimes and telling them to go. It was very self-destructive.

Sometimes, sexual activity was a payment for drugs or other favours:

> Raven: I engaged in sexual activity. . . . It felt like an obligation . . . because either the guy supplied me my drugs that night or supplied me a play to stay, . . . or they made me feel guilty. Like, either it was going to be my choice or it wasn't going to be my choice, and I'd rather have it be by choice [so I engaged in sexual activity].

However, one of the negative consequences of engaging in sex with multiple partners was the risk of contracting HIV infection:

> Courtney: I've had unprotected sex, and that was my fear [that I would get HIV infection]. And then I really think about do I really know where my [partner] has been? And that becomes such a big fear to me because you just think, Holy cow! [My partner] has slept with so many other people when you're sleeping with that one person, and I know that.

In summary, a woman's sexuality and her personal power within the context of her relationship have an impact on her risk for HIV infection. The women stated that traditional Aboriginal norms had a positive influence on Aboriginal women and their sexual relationships. Aboriginal women's relationships today are less egalitarian as a result of a loss of traditional teachings, patriarchy, derogatory stereotypes of Aboriginal women, and discrimination. Within their relationships, Aboriginal women exhibit a high tolerance for negative behaviours from their partners such as alcohol or drug abuse, promiscuity, and abuse, all of which increase the woman's risk of HIV infection.

Summary

The women's life experiences of childhood sexual abuse, discrimination, and intimate relationships provide a context for understanding their risk and response to HIV infection. Childhood sexual abuse had a profound impact on the women's mental and emotional health. The women who were sexually abused used alcohol and drugs to help them cope with these experiences. As a result, some of the women engaged in unprotected sexual intercourse with various partners while under the influence of alcohol or drugs. Four women developed addictions, and two of these women acquired Hepatitis C or HIV infection. The experiences of sexual abuse also affected the women's relationships with men and family members. Discrimination had a further impact on the women's self-esteem. This lowered self-esteem may have negatively influenced their intimate relationships.

The women believed that their intimate relationships were less egalitarian today because of a loss of traditional teachings, patriarchy, derogatory stereotypes of

Aboriginal women, and discrimination. These relationships are also characterized by a greater tolerance by women of negative behaviours from their partners, including alcohol and drug use, unprotected sexual intercourse outside of their primary relationship, and various forms of abuse. All of these behaviours have the potential to increase Aboriginal women's risk for HIV infection.

Aboriginal People's HIV Testing Experiences

The second major category relates to the HIV testing experiences in the Aboriginal community. This section includes the women's perceptions of their own and other's actual testing experiences, the response of testing HIV positive, and the barriers to seeking HIV testing.

The HIV Testing Experience

Five of the seven women in the study had had HIV testing. Testing occurred for one of three reasons: engaging in risk behaviour on the part of the woman or her partner; pregnancy; or being identified by public health officials as a contact of an HIV-positive individual. Testing was sought from either a physician or a nurse specialist. Physicians were accessed through their family practice site or within a medi-centre environment. Nurse-specialist services were accessed through an STD clinic in a large urban setting or in an Aboriginal agency offering outreach STD services. Of the two women who had not been tested, one had lost her "resolve" to go through with it, and another had no reason to go for HIV testing. This woman had, however, accompanied her daughter when she went for HIV testing.

Counselling prior to HIV testing was an issue for four of the seven women in the study. Guidelines on HIV pre-test counselling recommend that the counselling include information about HIV infection, options and limitations of HIV testing, and a personalized HIV risk assessment to facilitate behaviour change (Canadian Medical

Association, 1995; Holtgrave et al., 1995; Norton et al., 1997; Valdiserri, 1997). This was not the women's experience of HIV pre-test counselling. Instead, the women found that they were asked why they wanted testing for HIV, told how they should prevent HIV infection, or instructed to have a blood test because they were pregnant. Being asked why the women wanted an HIV test was identified as a barrier to HIV testing and is discussed in more detail later in this section.

> Lulu: I had one friend who told me she had requested the [HIV] test and was asked why she wanted the test. . . . I don't think [the person seeking HIV testing] should have to . . . tell [the tester] exactly why they want to [have the HIV test].

Pre-test counselling for Starr's daughter consisted of her family physician telling her daughter to "protect" herself: "All [the doctor] said to [my daughter] was, 'You young kids have got to protect yourself when you're having sex, with condoms'". Another participant, who was pregnant when tested, indicated that her pre-test counselling consisted of her physician providing her with a requisition for the necessary lab work—not exploring with her what she was being tested for, whether she would have the testing, nor the ramifications of the test results. She concluded that HIV testing was mandatory:

> Dallas: I got a [requisition form] when I first found out I was pregnant. I didn't notice until I actually went to go get my blood test, but on the back of the [requisition form] it said HIV, Hep B, and a couple other things. It surprised me 'cause I thought, Whoa, regardless if I want this [test] or not, I have to get this [HIV test].

Waiting for the test results was a difficult part of the HIV testing process for four of the five women who had testing. They experienced a variety of feelings during the waiting period, including being scared, as indicated by Dallas: "It was kind of scary for me. As she's filling the vials of blood, I'm thinking, I'm being tested for HIV. Right now, I'm being tested". The women also felt anxious as they waited for their HIV test results. One woman described her anxiety waiting for her test results as being similar to that when she knew her partner was going to physically abuse her. Her description conveys a sense of impending doom, including the potential for death:

> Raven: Knowing that your ex is mad at you and that he's going to hit you and that you may die because he's beaten you. It's sort of the same kind of comparison [to waiting for HIV test results]. The feeling, the anxiety is the same. So I've been there before; I've had that anxiety.

This same participant also felt regret for not taking precautions to minimize her risk for HIV infection. Concern surrounding the test results is all consuming, as expressed by Raven and Courtney: "Things really play like a record in your brain twenty-four hours a day, a lot of sleepless nights." (Raven) and "The waiting period's like terrible. You just can't sleep; you can't do anything." (Courtney).

The women used a variety of strategies to cope while waiting for their HIV test results. Dallas, who was pregnant, put getting her test results to the back of her mind so that she could enjoy the moment:

> Dallas: I will wait till February 2nd to find out [my HIV test results]. . . . I mean, right now I want my pregnancy to be just happy and fine, and I'm enjoying it. And I think, Okay, if I really had HIV tomorrow, what would my life be like? I would be totally devastated. So I think, Okay, another month of just enjoying this [pregnancy].

Three of the women focused on evaluating their risk by recalling past behaviours and events:

> Raven: I reflected [on my previous experiences that increased my risk for HIV]. You go over and over and over scenarios where you could have got [HIV infection].
>
> Courtney: I've [had] unprotected sex, done it, and that was a fear. And then I really think about [my sexual experiences]. Do I really know where [my partners have] been? And that becomes such a big fear to me because you just think, Holy cow, they're sleeping with so many other people when you're sleeping with that one person, and I know that.
>
> Dallas: And I'm thinking back to, Okay, so who did I sleep with? Who did I have unprotected sex with? Did those people seem like they can be HIV positive? And you can never tell. So I'm thinking this over in my mind, I'm thinking great, you

> know, I think I'm safe; but, you know, there's that chance, blah, blah, blah. So that's going through my mind right now, and that's stuff that I always keep to myself; I don't really share that with anybody else.

Courtney concentrated on feeling "in the clear" and hoping that she would be HIV negative. She framed her test results as an opportunity for a "fresh start" in changing her HIV risk behaviour:

> Courtney: Once you get [your test results] back and it's negative, then you're in the clear, you know, and it's like a new chance. I guess [negative HIV test results] give you hope, you know. It gives you time to—an opportunity to change.

In the past, Raven would have used alcohol or drugs to cope with the uncertainty of the results of her HIV test, while today she relies on her spirituality:

> Raven: I just deal with [waiting for my HIV test results] a little bit different, whereas [before] I would have a nervous breakdown, go drinking, resort to drugs [as] a coping skill. . . . [Today] reflecting on my spirituality is a big part [of my coping]. Just having the trust in the Creator that whatever path He chooses is for a reason, so whether I am [HIV positive] or not, there is a purpose.

Four of the seven women hypothesized how they would feel or what they would do if they tested HIV positive. One woman believed that an HIV positive diagnosis would be "a punishment" because of the lifestyle that she had led. Another woman mentioned that she would not share the results with others for fear of rejection. The third woman believed that she would go "into shock," become depressed, and think of committing suicide if she tested HIV positive: "If [my HIV test] came back positive, I would automatically go into shock. . . . I would become extremely depressed. I might even think of suicide" (Vanessa). The fourth woman predicted that her behaviour would depend on how she felt at the time of her HIV diagnosis. If she felt "positive," she would spend time with her children, getting her "affairs in order." If she felt negative, she believed that she would "give her kids away" and "finish [her] partying and live that long, suicidal kind of life" she lived as a teenager. Unlike other participants, she would share her diagnosis with others.

Testing HIV Positive

The testing experience for the HIV positive woman in the study was similar to and yet different from the other women's testing experiences. Maureen tested HIV positive in 1997. Her testing, unlike that of the other women, was initiated by public health authorities who notified her by mail to contact a local STD clinic in a large urban setting. When she contacted the clinic she was told that she needed an HIV test because she had been identified as a sexual contact of an HIV positive individual. She went for HIV testing that day. Similar to the other women's experiences, Maureen felt judged when she went for the testing:

> Maureen: When I was going to be tested, I felt like everybody was looking at me. . . . I thought, another Native girl being sick. That's how I felt. . . . Yeah, I was worried about being judged. [It was] just the way I was feeling.

Maureen remembered crying "lots" while she waited for her test results and preferring to be alone. Similar to the other women's anticipation of receiving HIV positive results, Maureen thought of committing suicide when she was told that she was HIV positive:

> Maureen: Yeah, I was positive, and that was . . . well, I was so scared. I wanted to kill myself right there, and [my partner and I] lived right beside each other. I locked myself in the apartment. He looked after the kids for me. I don't know; he thought I'd kill myself.

Maureen coped with her diagnosis in a variety of ways. She sought out information about the disease, but also reframed the diagnosis as being similar to "cancer". She also coped by not talking about being HIV positive:

> Maureen: The only time I talk about [HIV infection] is when I have to go see the doctor. And that's about it. I need to live with [HIV infection]. [Not talking about HIV] makes it easier for me. But it's there every day. I think about [being HIV positive].

Indeed, Maureen was reluctant to convey this information to her own family physician. Maureen had gone to her family physician for investigation of the headaches she started to have. When her physician decided to test Maureen for HIV and Hepatitis, she felt "scared to tell her" she was HIV positive. Instead, Maureen phoned her specialist's office and asked the nurse to tell her family doctor about her infection.

Maureen also investigated and exercised her options about where she could access HIV follow-up care. The potential threat to her anonymity served as a catalyst for her to change follow-up settings. Maureen used to visit her specialist at a local STD clinic in a large urban setting. She felt "scared" while waiting to see her specialist because she worried that she would be seen by someone she knew. Maureen dealt with her concerns relating to anonymity by switching to a multipurpose health care delivery environment:

> Maureen: That's why I don't go to [a local STD clinic in a large urban setting] any more. I was so scared going there all the time [because somebody I know might see me]. I've seen [my specialist] there for, I think, about a year or maybe longer. [I switched] to [a clinic in a large multi-purpose facility because of anonymity].

Confidentiality is an ongoing issue when a person is diagnosed HIV positive. It was four years after being told that she was HIV positive that Maureen finally told her family about her diagnosis. However, Maureen believed that her family knew of her infection prior to this, because they kept telling her, "Oh, [we] heard that you have AIDS." Unfortunately, Maureen believed that her family learned of her diagnosis from a previous partner who remained in contact with her family.

Barriers to HIV Testing

The women identified a number of barriers to seeking HIV testing. These barriers were categorized as internal barriers, experiential barriers, and broader, systemic barriers.

Internal Barriers

Internal barriers refer to the women's feelings or perceptions that prevent them from physically accessing an HIV test. These barriers include cultural norms about *disclosure to outsiders*, *lack of internal motivation* or readiness, *feeling ashamed*, *perceived lack of anonymity*, *fear of testing HIV positive*, and *fear of being judged by Aboriginal people*.

Disclosure to outsiders. Seeking HIV testing means the Aboriginal woman or her partner have engaged in unprotected sex or needle sharing. Aboriginal women have been socialized not to disclose their problems to "outsiders". In seeking testing, however, the Aboriginal woman would need to disregard this cultural norm:

> Dallas: Aboriginal women are taught that you don't go out there [in public] and tell people what your problems [are]. Going for a[n] [HIV] test is saying [you] have a problem. . . . My generation of women and men have learnt from their parents and their parents' parents you don't say anything [about your problems]; you keep it to yourself.

Lack of internal motivation. A lack of internal motivation or readiness to confront their risk behaviours created a barrier to seeking HIV testing. Even after an initial attempt has been made to secure testing, initial resolve can be reversed if conditions for immediate testing are not available:

> Courtney: So many of the men and women that I talk to know that they should be [HIV] tested. They know that there's so many behaviours that they've probably done that's going to put them at risk. But it's finding that motivation or acceptability to get that done.

> Raven: [Aboriginal] people who aren't yet ready to disclose [their HIV risk behaviours] and realize they're at the point where they have to admit their mistakes [will not go for HIV testing].

> Lulu: I asked once to get [an HIV test], and the doctor I saw wrote it down and I had to go some place else to get [the HIV test], and it just didn't happen after that. I sort of lost my resolve. And I had to walk around all over the place with this little piece of paper that said 'HIV' on it. That didn't really work for me. . . . And there was nothing wrong with me; there wasn't any real reason to be concerned. I thought, It's probably a good idea, but it's not on the top of my list of priorities.

Feeling ashamed. Feeling ashamed about active participation or forced exposure to HIV risk behaviour created another barrier to seeking HIV testing. Women may feel ashamed about engaging in the risk behaviour or that they had no control over the exposure. This barrier was especially significant when women perceived that they would be asked about the risk behaviours in the testing situation:

> Courtney: You feel very ashamed. Lots of people will stop at that point [and not get HIV tested] as they'll say, "Okay, I just can't go there, you know."
>
> Vanessa: [People going for testing] shouldn't have to share [their HIV risk behaviours]. Sometimes I feel shame; sometimes I don't. . . . [Perhaps] I could have been [sexually] abused [and have had no control].
>
> Lulu: [Perhaps] they don't want to say to some doctor they've just met that "I was raped last week."

People may deal with their feelings of shame by providing more socially acceptable reasons for accessing testing. Raven indicated that she would provide reasons such as getting life insurance or wanting a test because she is pregnant: "Because [Aboriginal people] are ashamed of their [HIV risk] behaviour, they try to pick [an HIV risk behaviour] that seems OK, that's easier to deal" (Courtney).

<u>Perceived lack of anonymity.</u> A lack of anonymity may be perceived relative to the name of the testing site, assumptions made by others who observe the person accessing that testing site, and the size of the Aboriginal community. These factors in combination create the perceived lack of anonymity that served as a barrier to HIV testing. Many of the women said that they would not seek testing at a local STD testing clinic in a large urban centre because the name of the clinic informs others of their concern:

> Raven: Not somewhere where it has "AIDS testing" written all over it. So the STD clinic is the last place I'd go.
>
> Starr: If you changed the name of [the STD Clinic] to something else. . . . Maybe if you could use [the word] *community* [instead of STD].

Anonymity was considered important because of the judgmental attitude and assumptions about people's past behaviour that may be present when accessing services at a local STD clinic:

> Starr: Probably the thought of somebody seeing me, you know, and thinking, She must be fooling around on her husband or something if she needs one of those tests.
>
> Raven: [Walking into a local STD clinic, the person seeking HIV testing experiences] more pointing—the [index] finger kind of stuff. An [HIV testing] setting where a lot of different services are offered [is important].

This issue is accentuated when the urban Aboriginal community is small and people have various connections to each other:

> Courtney: I think a lot of their fear is that they're going to see somebody [at a local STD clinic] that they know. Somebody else will be in the waiting room that they know. And even in the urban Aboriginal population, everybody still knows everybody who knows everybody. I mean, you can always connect to someone. Um, you know, it's still a smaller community.

Fear of testing HIV positive. The fear of testing HIV positive served as a barrier to seeking HIV testing. The women spoke of feeling fearful about finding out that they were HIV positive. This fear was related to the fatal consequences of a positive HIV test, but may also include potential rejection, suicide attempts, and depression, as identified by the women previously.

> Raven: Just the thought of death, the thought of death. . . . Even though I've tested negative three times in the last ten years, it's still a fear; it's a fear all the time.
>
> Courtney: I wasn't very HIV aware, so I thought you get the virus [and] you're going to die, right?
>
> Starr: I think they're afraid that they're going to die, right?
>
> Lulu: If I had the fear that I was positive, that would probably be a big reason not to get tested, because then I would find out I was positive and everyone would know, of course.

Fear of being judged. Aboriginal people also may not seek HIV testing because they fear being judged by Aboriginal people for engaging in the risk behaviours. This judgment results in being stigmatized and treated differently in their communities:

> Dallas: Because I know who's HIV positive and I can guess who maybe could be HIV positive. . . . So then you look at the people they associate with, and then you think, Okay, well, maybe they've had sexual relations with these people.
>
> Starr: I don't know why people look down on [you if you go for HIV testing] so much. It seems like they still do, in the sense you are a drug addict or something. . . . [People] never think that you could have got [HIV infection] from blood.

Stigmatizing behaviour may include Aboriginal people being stereotyped or even expelled from their community:

> Dallas: I think now on our reserve there's people coming up HIV positive. You really get stigmatized after that. . . . [The women are] stigmatized as being sluts. I don't know some of the other words that people use, but that's what they're stigmatized as. That could have been her first sexual relationship, but still, she's a slut.
>
> Lulu: [She] hasn't heard of anything recently, but within the [past] two years, people have been expelled from [their] communities because of their HIV positive status.

Experiential Barriers

Experiential barriers refer to the barriers to accessing HIV testing related to the previous experiences that the Aboriginal women or significant others have had with HIV testing, or that she perceives may occur in the HIV testing situation itself. These barriers include an actual *previous negative experience*, *questions about HIV risk behaviours*, *perceived judgement by the tester*, *preaching or pressuring by the tester*, *lack of confidentiality and anonymity*, *perceived lack of sensitivity on the part of the tester*, and the *gender of the tester*.

A previous negative experience. A previous negative HIV testing experience the individual or another significant person had experienced created a barrier to seeking further HIV testing:

> Courtney: [Aboriginal people] may have had a bad experience [when seeking HIV testing]. They don't want to be judged, or there is a fear [that they will be judged]. Or just knowing their father had a bad experience or their sister or their friend. And it gets back to [other people]. "Well, I'm not going there. I know they can do the [HIV] testing, but I'm not going there," you know.

Questions about HIV risk behaviours. Anticipating that the tester may ask women questions about HIV risk behaviours served as a barrier to seeking testing for many of the Aboriginal women. Women do not want to disclose previous HIV risk behaviours for a variety of reasons, related primarily to the feeling that they might be judged by the tester:

> Lulu: Maybe [Aboriginal people] don't want to tell [the tester] exactly why they want that [HIV] test. . . . [The tester] is full of judgments, and I think that's a real barrier. I know it's a barrier for me. . . . When [the tester] asked why [I wanted the test], immediately that makes me feel like I'm being judged. Puts me on the defensive. It makes me feel like I have to justify myself.
>
> Vanessa: I didn't want to reveal that I'd used drugs or shared needles.
>
> Raven: I wouldn't want to be asked [about] my sexual background. Obviously, I'm there for a reason, getting testing for a reason. It doesn't matter how I [might have] contracted it. . . . Quite frankly, if I had to make a list [of who I've had sex with], it would be a scary thought. I wouldn't want to do that reflecting [on my past HIV risk behaviours]. I've dealt with that, and I wouldn't want to continually [do this each time I go for testing].

Over and above their reluctance to share their risk behaviours, some of the women were unaware of why it is necessary to ask about HIV risk behaviour:

> Vanessa: Why do the [testers] need [to ask] the questions [about HIV risk behaviours]? Is it the [tester's] business really?
>
> Starr: I wonder why [the tester] wants to know that information [about HIV risk behaviours]. . . . Is it for stats?

> Courtney: Some people I know ask why [the tester] is so nosy. . . . I think [I would prefer] no questions. . . . I think there's still that fear of being judged.

The women identified the negative effects of being questioned about their HIV risk behaviours. Questioning by the tester may lead to distancing, concealing the truth, or not going for testing:

> Vanessa: [The tester] is distancing the person right there immediately. [The person] may even walk out of the [tester's] office.
>
> Courtney: You know, this might sound off the wall, but [the tester asking questions about HIV risk behaviours] gives [the person seeking HIV testing] the opportunity to tell the truth or to lie. I know people who have lied when they go in for testing because they're ashamed of [their HIV risk] behaviour.
>
> Lulu: When [a tester] asks you questions [about HIV risk behaviours] that you don't really want to answer, you're probably inclined to lie or avoid being asked the questions in the first place [by not going for testing].

On the other hand, one woman thought that it was important for the tester to ask questions about risk behaviours for HIV infection. Asking questions was perceived as conveying concern and giving the woman permission to ask for help:

> Dallas: I would prefer to be asked questions [about my HIV risk behaviours] 'cause I think it's like going to see a counsellor. You're going there for a reason. There's obviously something that's bothering you. . . . Because to me [maybe] it's [my] cry for help. Maybe I'm afraid to say something, and all it'll take is one question [from the tester] to break me right down. . . . Yeah, [it's about] permission. I think if I walked into a room and said, "I'm here for an HIV test" [and the tester said] "Okay, ma'am, sit down. Give me your arm," take some blood and walk[ed] away, inside I'm thinking to myself, I'm really hurt. Something did happen to me. You don't care, so why should I care? Just give me the results. If I'm HIV positive I'll go somewhere and suffer the pain.

Perceived judgement by the tester. Most of the women believed that they were treated differently when they accessed health services. They spoke of being more aware that they are "Aboriginal" and feeling judged by the health care provider when they sought services. Judgement was perceived to result from lack of understanding of the context of Aboriginal women's life experiences:

> Vanessa: The tester was biased because of my nationality. I was more Native, and [my] body language. Nothing verbal really.... It's that people automatically make assumptions about you based on being an Aboriginal. And with that, personally, I feel a bit of shame, a bit of guilt, for no reason whatsoever.

> Lulu: [Doctors] may not care, and they're full of judgements just like everyone else, and I think that's a real barrier. I know it's a barrier for me. I don't want to be asked those kinds of questions in that kind of way, by some guy I don't know—who is invariably White, who's invariably older, who's, you know, just is so far removed from my experience and has no comprehension of who I am or where I'm coming from. I found it really uncomfortable.

> Courtney: I mean, there's all kinds of [reasons] that contribute to unprotected sex. The morning-after pill is an [example]. [Aboriginal women] know they've had unprotected sex, and [if] they go back twice in the same month [for the morning-after pill], the doctor says, "What is wrong with you?" . . . [Doctors] are very judgmental. That's why Aboriginal people tend to be very mobile with their health care, going to family doctors and medi-centres.

Preaching or pressuring by the tester. Lack of appreciation of the woman's life experiences may lead to the tester "preaching" or "pressuring" women to reduce their HIV risk behaviours without exploring or understanding the multiple reasons for engaging in these activities. This behaviour may create further barriers for Aboriginal people seeking HIV testing:

> Raven: It's an acceptance of me as an individual, my family dynamics, to all Aboriginal people. [My family doctor is] not much of a preacher. He says, "Okay, this is what we'll do," and he does it, and we get it done and there's not a lot of the yadda-yadda kind of thing, . . . the preaching, the judgment. God knows, [Aboriginal people] preach and judge ourselves enough. We know what's wrong and right.

> Courtney: A lot of people think their family doctor is going to pressure them . . . 'cause lots of doctors have that attitude, [if] you come back and you were just tested last month, why are you still having unprotected sex? And there's lots of reasons why this might be.... Some people haven't gotten to the point where they're going to use protection all the time. [Perhaps] they get pressured into having sex and it's hard for them to say no. [Maybe the person can't afford] the price of condoms. I mean, there's all kinds of stuff that contributes to unprotected sex.

Lack of confidentiality or anonymity by the tester. Indiscreet actions on the part of health care providers working in the community may directly or indirectly identify a person who is at risk for or who has HIV infection. This lack of confidentiality or anonymity may create further barriers to HIV testing:

> Courtney: The family doctor is not seen as confidential as they probably should be, [and] some people are even afraid their parents might find out through their family doctor that they've been for HIV testing.
>
> Lulu: I heard of one case where a person tested positive and they were getting a visit from a nurse, and through contract tracing [the nurse] visit[ed] someone who [the HIV positive person] had sexual contact with. [These two people] happened to live very close [to each other], so [the identified] person knew who they had come in contact with . . . [and] threatened [the HIV positive person with] physical violence.

The provincial government's decision to keep statistics on people who are HIV positive could be a barrier to people seeking testing, because they may fear a lack of anonymity. A strategy to counter this is the availability of anonymous HIV testing where only the patient knows their identifying code (Matiation, 1998c):

> Lulu: The availability of anonymous testing is very important. . . . I would hate to see that go. . . . I think that especially since [the government] is keeping statistics on HIV diagnosis [the keeping of statistics] shouldn't be a barrier. . . . [When] a person can go in [for testing] without having to give their name, it gives protection to the person who comes in.

Perceived lack of sensitivity on the part of the tester. HIV testers may be perceived to be less sensitive to Aboriginal people seeking HIV testing because they feel that Aboriginal people "know how to deal with HIV" given the high prevalence of HIV infection in Aboriginal communities. A lack of sensitivity may limit the types of support provided to Aboriginal people. This perception may create a barrier for Aboriginal people seeking HIV testing:

> Raven: It's almost expected that [Aboriginal people] have [HIV infection] . . . because you're Aboriginal, because we have those multi[ple] issues. . . . The odds are that you have [HIV]; [the] stats say we have it. [The testers] treat us [with]

> less sensitivity because they think that we're used to dealing with [the HIV] issue by now. . . . We've had relatives die of [HIV infection]; we've had friends die of it; we've had maybe our own kids die of it, so it's something that society thinks we know how to deal with HIV already. They think we're used to it. . . . And we're no more [desensitized] or educated on the issue [of HIV infection] than anybody else. So they don't think we're surprised.

Gender of the tester. Having a male HIV tester was identified by six of the women as a barrier to HIV testing because of the non-egalitarian nature of women's intimate relationships. This barrier will be discussed in greater detail later in this chapter.

> Lulu: If an Aboriginal male was [HIV testing] an Aboriginal woman, . . . there's so much wrong in that relationship right now. I don't think they'd be able to connect. . . . I think that might be a barrier. I would prefer an Aboriginal woman [HIV tester].

Systemic Barriers

Systemic barriers refers to the broader barriers to HIV testing that prevent individuals from accessing an HIV test. These include *lack of trust* resulting from the colonization experience, *institutionalized discrimination*, *Child Welfare involvement*, and *transportation/childcare concerns*.

Lack of trust. Many Aboriginal people "feel helpless" and "weary" of trusting health care providers based on their own or other Aboriginal people's experiences with non-Aboriginal policies and discriminatory treatment since European settlement in Canada. These experiences, filtered down through different generations of Aboriginal people, may create barriers for Aboriginal people seeking HIV testing:

> Lulu: Every time Aboriginal people come up against those kinds of institutions we lose, and we lose big. There not being a trust of the medical community within the Aboriginal community is a real barrier [to HIV testing], and I think the onus is on the medical community to fix that.

Institutionalized discrimination. Discrimination by service providers working within various institutions has created numerous barriers for Aboriginal people, which affect their access to these services. Institutionalized racism is believed to be an "unintended consequence of a system of racial inequality" (Abercrombie, Hill, & Turner, 1994, p. 342). Institutionalized discrimination may serve as a barrier to accessing HIV testing for Aboriginal people:

> Courtney: Just from [hearing] from tons of moms, I think they feel very discriminated against by lots and lots of systems. . . . They've had bad experiences with it, and it's hard.
>
> Raven: I don't want to say [the reason Aboriginal people are discriminated against] is the [fault] of the tester. I want to say it's the way the whole system is set up as a whole [including] the government and how it's passed down to the tester maybe.

Child Welfare involvement. Previous Child Welfare involvement may lead some Aboriginal women who are at increased risk for HIV infection not to access health care during their pregnancy. If the woman does access prenatal care, she may be encouraged to have an HIV test done. If the woman tests HIV positive, she may fear that Child Welfare will apprehend her baby at birth as a result of the circumstances that led to her testing HIV positive. Women who have had children previously apprehended by Child Welfare may have even greater fear. As a result, previous or potential Child Welfare involvement may create a barrier for some Aboriginal women in accessing HIV testing and prenatal care:

> Courtney: [Aboriginal women are] scared they're going to lose their kids [to Child Welfare, and] if they've already lost their kids, they're scared there's gonna be even more restrictions placed on them [by Child Welfare]. So if they disclose any [HIV risk] behaviours or they think they might be pregnant again, they don't even want to get [HIV] tested because they're scared that, you know, their children have already been apprehended. . . . Do they continue on with their pregnancy? Do they let their worker know? Do they try to hide [the pregnancy] for seven months?

Transportation and childcare concerns. Some Aboriginal people may lack the transportation and/or childcare support to access HIV testing: "And I think [another] barrier to [Aboriginal] people get[ting] [HIV] tested is [their lack of] transportation [and] childcare" (Courtney). However, this concern was voiced by only one woman.

Summary

The women's HIV testing experiences were varied and occurred for one of three reasons: risky HIV behaviour on the part of the women or her partner; pregnancy; or being identified as a contact of an HIV-positive individual. HIV pre-test counselling did not provide the information recommended by current practice guidelines. Waiting for HIV test results was a difficult part of the HIV testing process, as the women felt scared, anxious, and regretful for not having utilized HIV precautions. One of the women in the study was HIV positive. There were both similarities and differences between her experiences going through HIV testing and those of the other women in the study.

The women identified a number of barriers to seeking HIV testing—internal barriers, experiential barriers, and systemic barriers. Internal barriers included cultural norms about disclosure to an "outsider", lack of internal motivation or readiness, feeling ashamed, perceived lack of anonymity, fear of testing HIV positive, and fear of being judged by Aboriginal people. Experiential barriers were identified as a previous negative experience, questions about HIV risk behaviours, judgement by the tester, preaching and pressure from the tester, lack of confidentiality and anonymity, a perceived lack of sensitivity on the part of the tester, and the gender of the tester. Systemic barriers include mistrust of health providers, institutionalized discrimination, Child Welfare involvement, and transportation/childcare concerns. Many of the identified barriers to HIV testing focus on some aspect of being judged unfairly by others, due in part to a lack of understanding of the context of Aboriginal women's past and present lives. However, the women's identified barriers also reflect perceptions of judgement from their own Aboriginal communities.

The Ideal Testing Situation

The third category focused on the ideal testing situation. A number of guiding principles were identified that would redress the barriers to HIV counselling and testing, and that would facilitate "culturally appropriate" HIV testing situation for Aboriginal women. These guiding principles included *Aboriginal determination in the development of HIV policy and programming*, using a *harm reduction approach*, adopting a *"present" orientation*, and *providing opportunities for choice*. The women identified specific *characteristics of the ideal tester*, as well as specific steps that comprise the *ideal testing process*.

Guiding Principles of the Ideal Testing Situation

Aboriginal Determination

The first guiding principle of the ideal HIV testing situation was that Aboriginal women will play a lead role in the development of HIV policy and programming for Aboriginal communities. The experience of colonization was thought to have had a negative impact on Aboriginal women's abilities to find solutions for their issues. As Aboriginal women develop their knowledge and expertise, they will have the capacity to create "culturally appropriate" HIV counselling and testing experiences for Aboriginal women:

> Lulu: One of the problems that Aboriginal people have is that all of the really nice White people are trying to fix things for us all the time. . . . [The solutions] need to come from [the Aboriginal community]. . . . I think that the process is very important for Aboriginal people to begin to recover from the whole colonial experience, that we have the knowledge and the capability and the expertise. We are valuable; what we know is valuable. What we can do is just as good if not better for us than what's already being provided. I think that would be really important to really discover and explore.

Harm Reduction Approach

The second guiding principle was the incorporation of a "harm reduction" approach. This approach takes a value-neutral stance to HIV risk behaviour, wherein the individual adopts "safer" practices to reduce personal harm while continuing to engage in risky behaviours such as injection drug use or unprotected sexual intercourse. Four of the women valued the tester's use of this approach in their work with Aboriginal women. The women appreciated this approach because it is similar to "an Aboriginal way," is non-judgmental, and provides options for the woman engaging in HIV risk behaviour to reduce her personal harm. This approach also recognizes more clearly the context of the women's life experiences, which may prevent them from abstaining from high risk behaviours. For these reasons, a harm reduction model works better for Aboriginal women than an abstinence model:

> Raven: Harm reduction is a good philosophy, and it's the closest technical term and philosophy that follows sort of an Aboriginal way.
>
> Starr: I think using a [harm reduction model] would be good because then the tester wouldn't seem to be judging the person—"You shouldn't be doing drugs"—because it's really none of [the tester's] business. But [the tester] could help in the sense of giving [the person] needles or condoms.
>
> Lulu: It would be absolutely ridiculous for a tester, after the [person] has disclosed that [she has] been involved in unprotected sex and intravenous drug use or whatever, for the [tester] to say, "Oh, don't do that." That's just stupid. Of course [the tester] would have to have the approach of giving people options, again saying "If you want to engage in this behaviour, there are ways you can do it where you're safer" and providing that information: . . . "Are you aware of the needle exchange program? Are you aware that you can get free condoms here? Are you aware that this treatment facility is available if you want it?" Just letting people know exactly what they have available to them so they can make the choices.

Present Orientation

The third guiding principle was the adoption of an orientation to the "present" by the HIV tester when working with Aboriginal women seeking HIV testing. The tester ideally would not focus on the woman's past HIV risk behaviours but on her immediate HIV risk behaviours from "this minute forward". This focus on the present would also convey a more positive approach:

> Raven: Obviously I'm getting testing for a reason. It doesn't matter how I [might] have contracted [HIV]. . . . I'm there for the testing; I'd want to work with the [tester] counting this minute forward. . . . "Are you in a current relationship? Does your partner know you're here? How are you going to deal with that?" . . . More stuff in the future-wise, not reflecting on the past. . . with a very positive, 'Go forth,' triumphant kind of attitude.

Providing Choices

The fourth guiding principle provides Aboriginal women seeking HIV testing with multiple opportunities to make choices prior to and throughout the HIV testing situation. Having opportunities to make choices in the HIV testing situation was valued by all of the women in the study. One of the women spoke of *choice* as sacred within the Aboriginal community, although it may not be easy for the tester to be supportive of the choices made by the woman seeking HIV testing:

> Lulu: I've heard Aboriginal Elders and Aboriginal people say [an Aboriginal] belief is [that people] have choice[s], that you are the person who chooses what will happen to you and that it's a sacred thing and the [testers] have to, as much as possible [be] 'hands off' and let people make choices. I mean [the tester] has obligations to fellow human beings, but people also have to [be] free to make those choices.

The Aboriginal woman seeking HIV testing in the ideal testing situation would have opportunities to make choices about her HIV tester, the presence of a support person during the testing process, participating in traditional Aboriginal practices, and the types of supports and resources she would access. For example, in the ideal HIV testing situation, Raven would have been asked the gender, ethnicity, and age of HIV tester she preferred:

> Raven: I would like to have had the opportunity [to choose my tester]. I would like someone to come up to me and say, "Okay, you want to come for [HIV] testing. Who would you like [the tester] to be? A man, woman, Aboriginal, non-Aboriginal, younger or older [tester]?"

In addition, Raven would like an opportunity to bring a support person with her when she meets with the HIV tester:

> Raven: One of the things that I know that some of the people that have gone for testing have always wanted to bring someone as a support. There are some places not comfortable with you doing that. I would encourage that to be allowed.

Some of the women identified the importance of choosing whether to participate in traditional Aboriginal practice such as smudging when they accessed HIV testing:

> Courtney: If [the person seeking HIV testing] was given the opportunity and [asked], "Do you want to smudge, or do you want to just continue talking?" . . . [and] not having [smudging] as part of testing practice but more of an opportunity.

> Raven: As long as there's options so they have the opportunity to do things on their own or be shown how to do [traditional practices such as smudging].

Further, some of the women would like to be made aware of the various traditional and nontraditional resources available to them in the community:

> Lulu: And no push in any direction, but letting people know what [community resources] are available to them. And making sure that the links between [the person and the resource] are strong and people aren't left in limbo. [The tester] doesn't have to fix [their problem] for them, but has to make sure that the doorway doesn't lead to an elevator shaft or something.

> Courtney: [The tester would be knowledgeable about mainstream and traditional resources] so women would have the option.

Ideal HIV Tester

The fifth guiding principle of the ideal HIV testing situation for Aboriginal people outlines key characteristics of the tester. These characteristics include the tester's *personal attributes, skills, knowledge, gender*, and *ethnicity* as well as how the tester would work to *develop relationships* with individuals seeking HIV testing.

Personal attributes. Personal attributes of the ideal tester included being sensitive, compassionate, intuitive, respectful, respected, accepting and nonjudgmental, trustworthy, and having a sense of humour. Sensitivity to the Aboriginal woman's life experiences, intuition, and compassion were illustrated by the following quotes:

> Dallas: But [the tester] just [is] sensitive to [the] issue [of sexual abuse and Aboriginal people's discomfort with touch]. That [the tester] doesn't get too close [physically] but talks to the women and says, "Okay, how can I make this easier for you?"
>
> Vanessa: As well [the ideal tester] is compassionate. After the testing, I really think it's important [whether] you're [HIV] positive or negative that the [tester] would be able to talk with you compassionately and show some concern about your lifestyle.
>
> Raven: Good intuition is being able to read body language, being able to read facial structure, being able to read between the lines. Good intuition is watching and observing that person in the waiting room before they come in [for HIV testing] and as they go out, just knowing the right things to say at the right time and that good intuition to know that this is a good question to ask now, kind of thing.

In addition, the tester would be respectful, and respected by people in Aboriginal communities:

> Courtney: [The ideal tester] has to be well-respected and trusted.
>
> Lulu: Respect is a two-way street too, and you can't give respect to someone who doesn't have respect for you or doesn't respect your rights to be and that sort of thing.

The ideal tester was described by a number of the women as being accepting of Aboriginal women and their issues, and being able to convey that acceptance. Sensitivity to the context of Aboriginal women's life experiences was an important element in conveying this acceptance. Being nonjudgmental and trustworthy were also important in making women feel comfortable to disclose their issues. Again, confidentiality was considered important:

> Raven: [The tester demonstrated] an acceptance to me as an individual. It's an acceptance to my family dynamics, and it's acceptance to all Aboriginal people. . . . I think one of the biggest things that Aboriginal people [experience] when they tell their story, [the people they told their story to] are surprised, and that makes [Aboriginal people] feel like [their experience] is not normal by their surprise and that it's out of place. So [the ideal tester would] say, "Oh, yes, okay. I can relate to that [experience]" or "I can understand that [issue]. Yes, I've heard it before, You are not any different. You and how many other women have been through this scenario." . . . "Oh my God!" kind of stuff just makes [the person seeking HIV testing] feel [like] more of an outcast.
>
> Vanessa: I think a lot of women have gone through [prejudice] and all that stuff, so [the ideal tester] would have to [be] a bit nonjudgmental.
>
> Starr: [The tester] needs to be honest with [the people seeking HIV testing], open and honest. Direct eye contact shows that you can be trusted. Reliable—say something and do it and not go back on it, that type of thing. . . . I suppose [the person seeking HIV testing] tells [the tester] stuff that they wouldn't tell other people. Say if [someone] told me something about [their] boss, they trust me not to go say anything to the boss that they've said, right?
>
> Dallas: Trust [is] number one, [a] big issue [for Aboriginal people].

Further, Raven would have liked the HIV tester to possess an Aboriginal sense of humour. In this context, Raven described Aboriginal humour as being dry and perhaps involving body language and sound:

> Raven: [The ideal tester] would have a little bit of Aboriginal sense of humour; they understand it, they know where it's coming from. . . . Aboriginal humour is really dry humour; it's very simple humour. It's facial, it's a sound, it's a tease that's meant in good spirit.

Skills. In addition to the above attributes, the women in the study identified that the ideal tester would have good communication and counselling skills. The ability to listen and to ask open-ended questions were identified as important skills in eliciting responses from the women seeking testing. Counselling skills would enhance comfort and confidentiality:

> Starr: [The ideal tester has the] ability to listen. I think [that] is important.
>
> Lulu: Asking open-ended questions as [much as] possible. That gives the person [seeking HIV testing] the opportunity to talk and say what they are prepared to say.
>
> Vanessa: If the [ideal tester] were to have some counselling skills as well, I would feel more comfortable around her, and the same with confidentiality.

Knowledge. The ideal tester would possess specific knowledge about HIV infection, determinants of health (e.g., poverty), and the issues that Aboriginal women experience (e.g., sexual abuse), as well as their feelings about these experiences. The ideal tester would also be knowledgeable about mainstream and traditional resources for HIV-positive or HIV-negative Aboriginal women:

> Lulu: [The ideal tester] that I [would speak] to would be really knowledgeable about not just HIV but some of the factors around it, especially in the Aboriginal community. I know that [HIV infection] is slightly different the way the virus is travelling [in the Aboriginal community]. It's more likely [transmitted] through intravenous drug use, more likely that women are testing positive, . . . and the women are younger [in the Aboriginal communities]. . . . Also [the tester would have knowledge] of the health determinants around poverty, education and other background things. . . . The [tester] would also be able to connect the [HIV-positive Aboriginal person] to Aboriginal services and mainstream [services] 'cause you would need both.

Others spoke of the tester being aware of Aboriginal people's history, which has perhaps led to many of the issues that Aboriginal women experience today such as sexual abuse, poverty, and addiction issues. It was also important that the tester be aware of the negative consequences of these issues. This knowledge can be seen as enabling the non-judgmental, sensitivity attributes identified above:

> Raven: [The tester knows] the possibility that I had been sexually abused before I walk in there. . . . [The ideal tester needs to] know about [Aboriginal] history, what types of Aboriginal people there are. There's urban Aboriginals; there's reserve Aboriginals. [The tester needs to know] how we react to certain things and the issues that we face on a daily basis, . . . the finances, the addiction issues.

> Courtney: The tester [needs to be] aware, really aware of that chaos and what that hurt and that shame is. Having the [ideal tester] aware of that, knowing that [these are the people they] might be looking at when [Aboriginal people] come [in for HIV testing].

Developing relationships. The ideal tester works in a specific way, not only with the individual seeking testing but also in the larger Aboriginal community. The tester is consistent in her behaviour at work and at social events within the community, advocates on behalf of Aboriginal women, and works to create relationships with women who come for testing by finding a balance between being personal and professional. For example, Raven spoke of the tester's consistent behaviour at work and at community events: "People who are going to do [HIV] testing would have to be consistent not just within their working style, but taking the opportunities to attend some of these round dances, getting to know the culture [or community issues]" (Raven).

Courtney described the ideal tester as a strong advocate who is willing to "go up in arms" for Aboriginal women. She continued by saying that Aboriginal women "need someone who's going to say, 'You know what? I believe in you' and 'We're going to [face this together], I'll [be] with you.'"

The ideal tester works to create relationships with Aboriginal women coming in for HIV testing by "getting on the same level". This may be accomplished when the tester achieves a balance between being personal and professional:

> Lulu: I know that [HIV testers] have this thing about their professionalism. But [the testers] are talking about people's very intimate [experiences], and [the tester] needs to be on the same level [as Aboriginal people] to really get [the person

> seeking HIV testing] to talk about [her intimate concerns], right? and to feel comfortable talking.

> Raven: [The ideal tester builds] a relationship on more of a personal level. I know a lot of non-Aboriginal have a hard time with that personal-professional line. . . . It's a balance.

Appropriate disclosure of experiences that are similar to those of the Aboriginal women seeking HIV testing was another strategy the tester could use to connect with her client. Appropriate disclosure "normalizes" the behaviour and feelings the woman may be experiencing, and therefore may decrease anxiety and encourage disclosure of concerns and issues:

> Courtney: It's easy [for the tester] to say, "[I've] been there [and] done that. You know, I did the same thing." . . . I think that's helped me connect with people. They start disclosing [when the tester] says "I've been there" or "I was just tested three months ago, I know what that's like." . . . "I know exactly how you're feeling." [This strategy] is very powerful. . . I think [the tester would] start off with some 'small talk' as it helps people . . . get to a level where [the tester and the Aboriginal person seeking HIV testing] can start.

However, it is critical that the tester's personal issues be resolved; otherwise her issues may "interfere" with the issues of the person seeking HIV testing:

> Raven: The [ideal tester] can be very personal and still be very professional. . . . [I've seen testers, though, who] don't know their own boundaries and haven't looked at themselves. So [the ideal tester's are] very in tune with themselves [and] don't have a lot of their own issues that interfere. . . And we can tell right away; we are very intuitive that way. We can tell right away [when professionals] are dealing with their own issues and make it ours.

Gender. A female tester was preferred by six of the women in the study for a variety of reasons. The women believed that a female tester would understand their emotional and biological needs, and have a greater understanding of their issues as women. In addition, the women believe a greater potential exists for them to be nurtured by the tester if the tester is female.

> Dallas: I would prefer to [speak] with a female [HIV tester]. . . . But just emotionally, I think that women understand each other more on that level than a man does. Even if you've lived in the same house with a man for fifty years, I still believe that my female neighbour would know more about how I feel than [my partner] would.
>
> Starr: I really prefer a woman [HIV tester] just because maybe I'd feel closer to her instead of closer to a man.
>
> Lulu: If the [tester] was female, that would be the thing for me. I don't know how it would be the other way around, like if an Aboriginal male was [providing HIV testing] to an Aboriginal woman, . . . because there's so much wrong in that relationship between Aboriginal men and Aboriginal women right now that I don't think they'd be able to connect [during the HIV testing situation] . . . [given] the levels of domestic violence in Aboriginal communities and the abuse.

However, one woman believed that the gender of the tester is less important than the possession of certain attributes: "But now I would have to say, now that I've had a little more self-esteem for myself and stuff, as long as [the tester] is someone who is sensitive, intuitive [and] respectful" (Raven).

Ethnicity. In the ideal testing situation the majority of women in the study preferred an Aboriginal HIV tester. An Aboriginal tester was viewed as incorporating many of the characteristics of the ideal tester already identified. More specifically, having an awareness of the issues that Aboriginal women might experience was used to support an Aboriginal-tester preference. Not only would an Aboriginal tester have an awareness of the issues that Aboriginal communities experience, but she may also have had similar experiences herself. This similarity may result in a non-judgmental attitude on the part of the tester, and a greater feeling of trust and comfort in the testing situation:

> Vanessa: Being Aboriginal [the ideal tester] would be aware of the prejudice in her life. . . . She would know the lifestyle, and she would maybe know the culture, hopefully. And she would, either through her [own experience] or from associations with her friends or a cousin or something, know of the bad [experiences within] the Native culture. . . . Yes, she would [know about the abuse]. That's how I could identify with her because ask almost any Aboriginal woman and sometime, somewhere in their life, youth or whatever, they are aware

> of [abuse]. Just [the tester] knowing that would make me feel more comfortable because she'll know where I'm coming from.

Aboriginal people may feel "safer" speaking with an Aboriginal tester, especially if the person has experienced racism. On the other hand, Aboriginal people who are "used to mainstream" would likely accept HIV testing from a non-Aboriginal tester:

> Starr: I would probably be willing to answer those questions [about HIV risk behaviour] if the [tester] was Aboriginal. . . . I think I would feel safe[r]. . . . I think it would depend on who the Aboriginal person is that's being tested. If they've been through a lot of hardships or racism as an Aboriginal, then it's going to be easier to speak to an Aboriginal [tester]. If they had a fairly good life, you know, [and] are used to mainstream, then it wouldn't matter, I think, to have a White person do the [HIV] test.

For some women, an Aboriginal tester was preferred because she was viewed as a role model for Aboriginal women and had legitimacy working with Aboriginal communities:

> Raven: An Aboriginal [tester] would be doing a lot of things: being a role model, being a mentor, that kind of thing.
>
> Lulu: Non-Aboriginal people who have been involved in working with Aboriginal people run into difficulty when it comes to cultural things. . . . You almost have no legitimacy if you're not Aboriginal.

Having an Aboriginal tester, however, raised a major concern pertaining to confidentiality. Aboriginal health workers may also live in their communities. Conflicts may arise if confidential information is known that could protect a friend or family member. For example, Lulu would be inclined to disclose this confidential information, as her friend or relative's health is considered to be more important than maintaining client anonymity and confidentiality:

> Lulu: The [Aboriginal] health worker who's [in Aboriginal communities] now is usually not only a member of the community they work in, but they probably [have] relat[ives] in the community. . . . What if [the Aboriginal health worker] finds out that someone is [HIV] positive because they have that access [to confidential information]. The [health worker] also knows [who] the [HIV positive] person is in a sexual relationship with [and if the relationship is with] their sister. . . . What is the [health worker] supposed to do? I mean, we know what they're supposed to do ethically, but there's something above that as well,

> like, "My sister is at risk and does she know? and can't I tell her because it's her life? And is preserving [the HIV positive] person's anonymity more important than my sister's life?" "Well, no, but I could lose my job."

In order to preserve confidentiality, therefore, a number of women in the study specified that the Aboriginal tester needed to be someone they did not know or who was not connected to their specific community:

> Starr: For Aboriginals, it might be easier if [the tester] was Aboriginal, [but] I kind of think [the tester] would be someone that you didn't know, . . . just because . . . there's always that little, how do you say—like when my brother died of AIDS, he didn't want people to know that he died of AIDS.
>
> Raven: [The tester] would have to be an Aboriginal person. . . . It would have to be someone I know that's not connected to my community because of confidentiality.

Nevertheless, one of the women in the study preferred a non-Aboriginal tester, given the concern about confidentiality in Aboriginal communities. Courtney summarized the advantages and disadvantages of having an Aboriginal tester:

> Courtney: I think Aboriginal people are kind of funny, because it'd be perfect to say an Aboriginal nurse, of course. But you know, at the same time that doesn't jive for lots and lots of people because the [Aboriginal tester] is almost a threat. . . . That also might go against her. . . . [It would be positive that the tester is Aboriginal] because she's one of us and just being from the same culture, you know. . . . I think that's what the plus would be. I think people would, could connect with [an Aboriginal tester]. At the same time there's always that risk of confidentiality with just [Aboriginal] people knowing people knowing people. There's always that fear, and I don't think it's ever gonna go away. . . . I think [being non-Aboriginal] gives the [HIV tester] an edge [because of the confidentiality concerns].

HIV Testing Process

The final guiding principle relates to a number of characteristics of the ideal HIV testing process. Previously discussed guiding principles provide the foundation for the ideal HIV testing process. For example, the HIV tester would incorporate the use of a harm reduction approach, operate from an orientation in the present, and provide the Aboriginal woman seeking HIV testing with multiple choices throughout the testing process. Also, the tester would strive to develop a trusting relationship with the woman as previously described.

The women in the study identified specific sequences of the ideal HIV counselling and testing process. The women felt that the Aboriginal woman seeking testing should not have to complete paperwork when she arrived at the testing site; rather, the tester could complete all paper work after the woman leaves her office. Paper work was viewed as interfering with the tester's ability to focus on the woman, as well as being a barrier for Aboriginal people:

> Courtney: Paperwork scares people, like if I took out my [paperwork] and said, "I'm just going to ask you some questions." . . . Actually, charting things scares [Aboriginal] people, like when they're actually still there. . . . Yup, no paperwork, I think, would be [best].

In the ideal testing situation, the waiting period to speak with the tester after arriving at the testing site should be kept to a minimum. Reducing the waiting time was thought to prevent the woman from changing her mind about having the testing done and to reduce anxiety and "superstition" that the HIV test results would be positive:

> Raven: The other thing too is that I wouldn't want to be sitting waiting. I'm feeling insecure enough about going; . . . I wouldn't want to do a lot of waiting. I wouldn't want to wait there more than two or three minutes because I might just walk out. . . . And a lot of times Aboriginal people are very superstitious. They look at little signs [like having to wait for HIV testing], and if things don't go good right off the bat, it's a sign; it's a superstition; it's a sign that this testing isn't going to go good at all.
>
> Starr: Maybe not having to wait too long. Like, you know, you go to [the] doctor's office, maybe you have to wait ten or fifteen minutes. Maybe if you got an appointment at ten, then you are in and out. You know, not have that anxiety to wait for a test that would be good.

One of the women spoke of the importance of the tester welcoming the woman seeking testing, validating her decision to be tested, and stressing confidentiality. These measures would help the woman feel "secure":

> Dallas: [The tester would say to the person seeking HIV testing], "I'm glad you came in for an HIV test. I'm glad to see you here. . . . I'm just glad you're here to get this. And the test results, you can come in and see me. [The HIV test results] won't be mailed so your husband gets them or your boyfriend. This is totally confidential." And I think, just a real secure feeling.

Two of the women explained that the tester should proceed with HIV testing by providing information about the process of testing rather than asking questions about the woman's HIV risk behaviours.

> Raven: [The tester would say], "Okay, let's do [the HIV test]. And [then the tester] would start building rapport. [The tester] would start by bringing me in and sitting me down and explaining how the [HIV] testing goes and what to expect and how long it takes [to get HIV test results back].

The tester then would provide an opportunity for the woman seeking HIV testing to ask any questions of the tester after the HIV testing process had been explained. This would allow the woman seeking testing a chance to identify additional concerns. The following quotations provide examples of questions the tester may ask:

> Courtney: "Is there anything else I can do for you today?"

> Lulu: "Is there information that you have that you're not sure about? Is there something you want to discuss about that issue?"

The tester also would assess the supports available to the person seeking HIV testing:

> Raven: "What kinds of supports do you feel you need? Are you okay with this?. . . Are you in a current relationship? Does you partner know you're here? How are you going to deal with that? Do you have kids? How are you going to deal with that?"

Two of the women believed that support should be available immediately if a woman seeking HIV testing learns that she is HIV positive. Support should incorporate a realistic appraisal of the situation, options, and future steps.

> Vanessa: [If the person] was HIV positive there [should be] support people there right away to speak with them, not just the [tester]. Yeah, have the support or counselling or something [available immediately].

> Lulu: I think that a person only needs counselling around HIV probably when they first are diagnosed, and that's the most important time. . . . [The HIV positive person needs to] understand that [she is not] going to die tomorrow, what [her] options are, explore how [she became HIV positive] and how [she] can move on from there. It's really important that a person can connect with that [support] really quickly.

After assessing the support required and available to the person seeking HIV testing, the tester would discuss other services available within the building in which the HIV testing site is situated. A few of the women believed that the tester could ask new questions about HIV risk behaviours, but only if the tester had developed a relationship with that person:

> Courtney: I think once someone has gone in and had the HIV test, if there's an opportunity for [the tester] to do some more personal—like, if [the tester] gets at more of a personal level with [the person seeking HIV testing], . . . I think there would have been a time there where you would have to ask them, "Is there any reason why you're being tested?" And I think it would be okay [to ask this question of the person seeking HIV testing]. Once [the tester has] gotten to that level, it's okay to ask that.

> Vanessa: [The tester] needs to show some concern, and perhaps [if that person] opens up, then it would be fine to ask questions. . . . Yes, unless the [person seeking HIV testing] is comfortable. The tester needs to just show concern if the person seeking HIV testing opens up.

Summary

Six guiding principles were identified and described to realize the ideal HIV testing situation. These six guiding principles would redress the barriers of HIV counselling and testing, and influence the development of the "ideal" HIV policy and programming for Aboriginal women. The guiding principles are:

1. Aboriginal self-determination
2. Harm reduction approach
3. Present orientation
4. Providing choices

5. Ideal HIV tester

   Attitudes - sensitivity, compassion, intuition, acceptance, and nonjudgmental, trustworthiness, respect, respectfulness, a sense of humour

   Skills - communication, counselling

   Knowledge - HIV infection, determinants of health such as poverty, issues Aboriginal people experience such as sexual abuse, mainstream and traditional resources

   Developing relationships - role model, advocate, on "same level" (balance between personal and professional, appropriate disclosure, tester's personal issues resolved)

   Gender - tester is female

   Ethnicity - may or may not be from the Aboriginal community

6. Ideal HIV testing process
   - no intake paperwork
   - minimal waiting period to speak with the tester
   - multiple opportunities to make choices throughout the testing process
   - welcome and validate the person's decision to have HIV testing while stressing confidentiality
   - explain the HIV testing steps
   - provide opportunity for questions
   - obtain the blood sample for HIV testing without assessing the person's HIV risk factors
   - assess the person's level of support
   - make referrals to nontraditional and traditional community resources
   - ask questions about HIV risk factors only after a trusting relationship has been developed

Dimensions of "Culturally Appropriate" HIV Testing in Aboriginal Communities

Culture and *culturally appropriate* are words used to describe health services for various populations, including ethnic groups. Often when this word or phrase is used, the listener presumes the intended meaning. In the fourth and final category, the women explicated these words in an effort to improve HIV policy and programming for Aboriginal women. Important dimensions of "culturally appropriate" HIV testing services in Aboriginal communities include *sensitivity to and knowledge of the issues that Aboriginal women may experience*; *inclusion of traditional teachings, practices, and Aboriginal spirituality*; the *physical environment of the services*; and *Aboriginal staff and approaches*.

Sensitivity to Aboriginal Issues

Women used the word *culture* in reference to the multiple issues and hardships that Aboriginal women have experienced or continue to experience within and outside Aboriginal communities. Women believed the ideal HIV tester would be sensitive to this aspect of their "culture". Raven contrasts this aspect of culture with the more conventional use of the term to refer to traditional practices:

> Raven: That's what I was talking about, not that [the ideal HIV tester] needs to be 'culturally sensitive' in knowing how [Aboriginal people] smudge and how we do all that stuff. [The ideal HIV tester] is culturally sensitive about our history . . . and the issues that we face on a daily basis, . . . housing, finances.
>
> Vanessa: Being Aboriginal [the ideal HIV tester] would be aware of the prejudice in her life, . . . know the [Aboriginal] lifestyle, . . . would maybe know the culture . . . and would . . . know of the bad aspects of the Native culture [such as abuse of Aboriginal women].

These issues were described in detail in the first section of this chapter on Aboriginal women's life experiences. The importance of sensitivity to the women's historical and present life experiences is reflected throughout these findings, and is viewed as essential for the provision of non-judgmental care.

Traditional Teachings, Practices, and Aboriginal Spirituality

The second way the women used the word *culture* was in reference to traditional norms, practices, and Aboriginal spirituality. As discussed previously, the women in the study spoke of the erosion of traditional Aboriginal teachings through the experience of colonization. A return to these traditional teachings was thought to result in a return to "healthier," more egalitarian experiences within Aboriginal communities.

Raven spoke of a *teaching* or norm "embedded" in the Aboriginal culture. She spoke of Aboriginal people being a "proud people," regardless of the hardships they have experienced:

> Raven: [Aboriginal people] are a proud people. Even though we're living on the streets and shooting up and living in garages, we're still proud people. Again, that's something that's been embedded in us. You can raise me on Mars and I'll still have those same feelings; it's something that's in our blood, something that we live.

Aboriginal *traditional practices* were considered an important component of culturally appropriate HIV testing. Examples of traditional practices included sharing circles, healing circles, and smudging. The women in the study would also have liked the opportunity to access Elders within the HIV testing context.

Sharing circles could be developed to explore the multiple issues that increase Aboriginal women's risk for HIV infection. Women interested in participating in the circle would come together at a designated time with a tester and an Elder. Both these staff members would facilitate the confidential session. Lulu believed that the sharing circle could provide information, support, and referral similar to mainstream pre-test HIV counselling. After the completion of the sharing circle, the women could explore individual concerns with the tester or the Elder, such as concerns about HIV sero-conversion due to their partner's needle-sharing practices:

> Starr: For women who need education on [HIV infection], you could have a retreat or a circle that would explain what HIV is all about and how it goes into AIDS or how to protect [yourself]—the whole educational thing.

> Lulu: This is kind of a 'way out' there idea, but it might be of interest to develop a sharing circle around the issues [that Aboriginal people experience, such as sexual abuse] and HIV [infection] that people who are concerned [can attend]. Almost like a session, a pretest session. . . . We sort of sit in a circle. . . . A confidential session where Aboriginal people can talk about these issues. . . . Maybe have an Elder present [and] have [the circle] facilitated by someone who is trained to provide counselling and has information on HIV and other issues that come up around it, like sexual abuse or drug addiction. And from that [circle] also provide information . . . on treatment for addiction, even HIV or other STD and just, you know, have a sharing circle. . . . The most intimate things come out, and people get the support and the help that they need, and after that they get all the information they need to address [HIV prevention].

Healing circles could be made available for Aboriginal women who are HIV positive, where they could come together for information, support, and referral regarding their infection and related concerns. A tester and an Elder could facilitate the healing circle. Although a lack of anonymity was expressed as an issue, it was not viewed as insurmountable. Starr explained:

> Starr: You could have a women's healing circle, you know, with smudging. . . . I don't know of any healing circles right now, [but] that's what I really want to do, . . . have an Aboriginal healing circle for women with AIDS. . . . [Perhaps the healing circle] would cause a stigma where [the Aboriginal women] won't want to come to [the circle] because then [their attendance] shows they have AIDS. . . . So I think if you got their trust, then [HIV positive Aboriginal women] would come.

Smudging is an Aboriginal cultural practice that involves the burning of dried grasses while saying a prayer. People may inhale or cup the smoke in their hands and spread it over different parts of their body as they pray. It is believed that when a person smudges, her prayers are carried to her Creator. Women in the study held various beliefs about what smudging was, how to smudge, and when to smudge:

> Courtney: A smudge is a prayer but it's also—some people like to use it for cleansing [and] purifying. And once you've gone through [HIV testing, smudging] really does [purify] you.

> Vanessa: [Sweetgrass] to cleanse your spirit. I would think that [smudging] would be really useful. Okay, I'm just trying to visualize this. . . . I think sweetgrass would be nice . . . [and] inviting because it's like a medicine itself. Except it's for the spirit. I think [smudging] should be incorporated into [the HIV testing session].
>
> Dallas: [Smudging] is a personal choice. But I mean, . . . the smell of smudge is soothing.
>
> Raven: I smudge on my own time; I don't smudge with other people. That's a personal thing; that's my own personal, private thing. When I go to gatherings or meetings or whatever, I never smudge with other people's stuff, because that's something I do for me, when I need to do it, when the time is right for myself. And if my family wanted to be there, they'll smudge with me. If they don't, then that's my journey, my learning path, my growth.

Regardless of the different beliefs about smudging, the women in the study indicated that culturally appropriate HIV testing would incorporate the option to smudge.

Aboriginal spirituality was also considered as an important component of culturally appropriate HIV counselling and testing:

> Raven: As an Aboriginal person it would be good to have someone at the [HIV testing site] who can talk about that cultural spirituality part of [HIV testing] to enforce that "Even though this is a difficult time, you have the support of [Elders]."
>
> Lulu: An Elder who . . . not only has the cultural knowledge, but has the knowledge around HIV. . . [I know an Elder who has] gone out and learned the cultural stuff.

Seeking the support of an Elder was considered important for people seeking HIV testing, especially if they were HIV positive. Elders would provide the cultural spirituality within the context of HIV testing. According to Raven, Elders provide very individualized support, relevant to the person's particular situation. Generally, an Aboriginal person could seek support from an Elder in the form of "doctoring," prayers, or a sweat lodge on their behalf:

> Raven: [Elders] would offer me a sweat lodge or offer to pray for me in a sweat lodge. Also some 'doctoring' from [the Elder], . . . offering me the traditional medicine, what that looks like, the different ways of doing it, the healing for my

> whole family kind of thing. . . . Elders work so differently with each individual, so it would be up to the Elder's discretion. But I'll give you an example. Okay, say I'm HIV positive . . . and I go to an Elder and say, "I've been Indian medicined; I'm HIV positive." . . . It wouldn't be just, "I need to smudge because I'm HIV positive." It's not just that.

The Physical Testing Environment

The physical HIV testing environment was an important characteristic of culturally appropriate HIV testing services for Aboriginal people. Most of the women in the study agreed that HIV testing services should not be located on the reserve communities but be located in a large urban setting due to concerns relating to anonymity:

> Starr: If I was living in my little community [in rural Alberta] and had to go for HIV testing, I would leave the community and come to [a large urban setting] because . . . there's people there [in my community] I've gone to school with that work in the hospital. So I would probably leave that area and come to the city.
>
> Vanessa: [I] would not [have HIV testing] in my own community, most definitely. . . . I wouldn't get testing done on the reserve. I'd go to the neighbouring town or maybe even further because [towns] have close connections.
>
> Courtney: The thing about reserves is that everybody knows everybody who knows everybody.

In addition, the HIV testing site would be situated within a multipurpose building that provides various health care services for Aboriginal people. The women in the study believe that this would ensure anonymity for Aboriginal women seeking HIV testing. Two of the women spoke of the anonymity they experience when accessing HIV testing in a medi-centre or doctor's office, which would be similar to a "multipurpose" building:

> Raven: [The HIV testing site] should be in a multipurpose kind of building [because of anonymity].
>
> Courtney: There's still a part of me that wants anonymity [when going for HIV testing], and that would bring me to medi-centre [a multipurpose office] again.

> Dallas: Like I go to my doctor's, nobody knows why you're walking into that room. . . . Nobody has to know. . . Privacy is a big thing for me, any kind of testing. More so for HIV because that's a very personal thing.

Four of the women in the study envision HIV testing within an Aboriginal women's health centre. One of these women believes that the ideal centre would provide HIV testing solely for Aboriginal women because "women feel comfortable with each other":

> Dallas: I think that if a man walks in the room, it automatically sets a different pace or sets a different mode. . . . It creates tension, so I think it would be a place where there would be just women. . . . Not a clinic setting but more of just a community type of an area where, you know, you would just feel comfortable. . . . A woman's centre, . . . just Aboriginal women.

Three of the women support the concept of an Aboriginal women's health centre attached to an existing Aboriginal agency. This arrangement would be more likely to "incorporate" the Aboriginal culture:

> Lulu: I think that in an ideal situation, there would be an Aboriginal women's health centre that would be attached to an Aboriginal agency so that the management and the administration and all that incorporated the Aboriginal [culture]. . . . It would include mostly Aboriginal staff.
>
> Vanessa: I like the [idea of] an Aboriginal women's centre. For one thing, it's for Aboriginal women. They'd have every [service] there. But it's the culture; it's everything there.

Another reason cited for having the women's health centre connected to an Aboriginal agency was that people would be more likely to seek HIV testing if they had already developed a "trusting" relationship with staff from the attached Aboriginal agency.

> Courtney: [The person seeking HIV testing] has developed a relationship with staff [in an Aboriginal agency]. . . . I spend lots of time [as a counsellor] with [people seeking HIV testing]. I answer their questions, and eventually they'll say, "Well, yeah, I am a bit concerned, you know, as I have [engaged in] risky behaviours." Or I'll say, "Well, do you think you'd feel okay if you went and saw [an HIV tester] on [Tuesday], you know, and I could come with you." . . . So they kind of disclose a little bit to me, and then . . . they'll either go to see [the tester] or they'll come back and talk to me about it.

Nonetheless, one woman questioned the creation of a women's health centre because she believes Aboriginal children and men also have health issues. She also wondered whether enough women would come to justify a centre for Aboriginal women only. Instead, she preferred an Aboriginal health centre for all:

> Starr: Why would the [health centre] be for women? . . . Let the children [attend] maybe. Then the men would feel probably left out, I don't know. Men have issues too, you know what I mean? . . . I wonder if there would be . . . enough women to come to that health centre?

Several of the women described the interior space of the culturally appropriate health centre as being similar to a home environment, including comfortable furniture, Aboriginal art and symbols, and refreshments.

> Dallas: The place would be set up [so] that it is invitational in a sense. . . . The room would have Aboriginal [symbols] in it. And you have chairs and you have a couch. . . . Yeah, a home setting, not an office setting, but more of a home [or] invitational kind of setting.

> Starr: Perhaps the [interior space] not be so sterile. . . . Maybe couches, you know, nice pictures or Native hangings, something like that. . . . It makes me feel good when I walk into a place like that because then . . . [the staff] care [about] Aboriginals because the cultural things [are in the interior space].

> Vanessa: [The interior space would be] something inviting, . . . just for Aboriginals, like with the art and stuff.

A number of the women would like to see Aboriginal art and pictures on the wall, but two of the women caution that the art must not be "cheesy" or the "Hollywood version of Indianness" in order for the interior space to look "respectful":

> Raven: You don't want to have Hollywood's version of 'Indianness,' . . . keeping in mind that [Aboriginal] spirituality and [Aboriginal] culture is a very sacred thing for us. We are what we live, so when that's being presented, it's got to be done in a very respectful manner.

Courtney and Starr would like to see dream catchers and other Aboriginal symbols throughout the health centre. Courtney describes a dream catcher as something that helps to alleviate the fears Aboriginal people may experience when seeking HIV testing:

> Courtney: A 'dream catcher,' . . . symbols like that in the [Aboriginal] culture are very powerful. So things like dream catchers or sweetgrass or a smudge bowl or even an Indian blanket. It just brings you—it calms you down if you're scared . . . The dream catcher is all about taking the fear away at night, . . . so having something like that would just take away some of bad feelings. You know, there's something there to catch [the person's fear].

Starr spoke of having a ceremonial table, covered with a Native blanket and a seashell for sweetgrass:

> Starr: You could have the testing room maybe set up with Aboriginal art . . . and then have a . . . ceremonial table with a Native blanket over top, and have a seashell there with the smudge inside and just tell that they are free to smudge if they want to before the test.

A balance between Aboriginal and non-Aboriginal culture was considered important in accommodating various levels of acculturation. Achieving a balance in the use of Aboriginal art and symbols would decrease barriers for Aboriginal people who are "removed" from their culture or culturally unaware:

> Raven: If you're talking about an urban Aboriginal person who knows nothing [about her culture], yes, [the interior of the health centre] could throw them off. [The interior] would have to have a really good balance. . . . The designing of the front office would have to be balanced, just like the person who was doing the testing. They have to have a certain amount of professionalism mixed with a certain amount of being able to be personable.

Many of the women spoke of having food and coffee available to people as they waited for their HIV testing. They believe that these amenities would enhance the "home environment" and serve to welcome people, thereby increasing their comfort levels. Easy access to a smoking area would also be important for Aboriginal people attending the testing site:

> Dallas: It would be important to have coffee and a place to smoke.

> Lulu: Of course. The first thing that happens when you go into an Aboriginal person's home is, they offer coffee and food. . . . Access to smoking—yes, absolutely. Just out the front door would be fine.

Music and burning smudge were seen as providing a calming atmosphere in the waiting area, and as being congruent with the holistic view of health:

> Raven: [While waiting for HIV testing] the person's mind [needs to be] occupied with positive thoughts . . . because . . . Aboriginal people, when they talk about their health and if you look at what they believe in, they believe in their selves as a holistic being. And if their mind is healthy and their spirit is healthy, then their [body] will be healthy. . . . So then it's making a positive atmosphere. Some good, soothing music in the background; you're working with them mentally and spiritually from the whole atmosphere. . . . [Burning smudge also] mellows people out. . . . It represses them to something nice, something positive, and their attitudes drop a little bit.

Aboriginal Staff and Approaches

The presence of friendly Aboriginal staff within the health centre was another dimension of culturally appropriate HIV testing services. The receptionists and the majority of the staff in the health centre, with the possible exception of the HIV tester, would be Aboriginal. Perceiving a shared experience of the context of Aboriginal women's life experiences was thought to enhance the comfort level of the woman seeking testing:

> Lulu: I think in the ideal situation there would be . . . mostly Aboriginal staff . . . because there's the shared experience, [and] it would increase [my] comfort level being able to talk about certain things [like issues within the Aboriginal community].

> Starr: And to see Aboriginal [people] on staff is good too. . . . I think it [makes the person seeking HIV testing] feel safe maybe. . . . Being an Aboriginal person, it's going to be easier to speak to an Aboriginal [HIV tester]. . . . A lot of Aboriginal people feel they can trust [Aboriginal staff] more it seems. . . . Maybe the tester wouldn't have to be Aboriginal, but an Aboriginal greeter or a receptionist or something like that.

Staff providing HIV testing could use a "team approach" in their work with Aboriginal women seeking HIV testing. This approach could utilize a physician or tester working in concert with either an Elder or an Aboriginal service provider. Raven and Courtney had similar, yet different, ideas about this approach. Raven would like to see her physician or the HIV tester provide HIV testing as part of a team. This team approach would mean that the HIV tester works with an Elder, with the Elder providing the "cultural spirituality" portion of HIV testing:

> Raven: It would be good to have [an Aboriginal person] on site who can talk about that cultural spirituality part of [the HIV testing] to enforce that "Even though this is a difficult time, you have our support." Knowing that someone's there that'll say "I'm going to pray for you" and that kind of thing; knowing that helps. . . . An Elder who is knowledgeable about [Aboriginal] culture, . . . the spiritual part [of Aboriginal culture]. . . . And [the HIV testers] work well with the Elders, and the Elders are just as respected as the doctors. They work together as a team. You can see the team.

The Elder could be male or female; however Raven believes that a female Elder would better understand women's issues: "It would be nice to have a female Elder, but then again, it really doesn't matter. . . . [The female Elder] understands the issues and the biological kind of stuff as a woman just naturally". Minimally, Raven prefers counselling from an Aboriginal person because they understand the issues within the Aboriginal community:

> Raven: If the doctor was going to do some counselling on top of things [during the HIV testing], I would prefer it be an Aboriginal doctor. That's right. But if it's just going to be a [non-Aboriginal] doctor, then [I'd go] to get counselling elsewhere; then I prefer the Aboriginal counsellor.

As discussed previously, Courtney believes the ideal approach would place a non-Aboriginal HIV tester as a staff member at both the health centre and the Aboriginal agency. Aboriginal staff members in both agencies would work to develop relationships with the Aboriginal women who access services from the two agencies. Staff members would look for opportunities to refer the Aboriginal woman for HIV counselling and testing, either in the health centre or in the Aboriginal agency. Not only would the staff members be able to share their personal HIV testing experiences, but they would also be able to advocate and increase the likelihood of a "safe" and more "positive" experience for the person accessing HIV testing services.

Although an Aboriginal tester would have knowledge of the issues and Aboriginal culture, Courtney was concerned about a potential lack of confidentiality if the tester was Aboriginal. She cites the experience of a non-Aboriginal nurse who currently works in an Aboriginal agency providing outreach health services. Courtney believes this nurse has an "edge" working with Aboriginal people seeking HIV testing because they perceive a non-Aboriginal nurse as ensuring more confidentiality than an Aboriginal nurse.

Summary

Culture and *culturally appropriate* are often used with the listener presuming the intended meaning. The dimensions of *culturally appropriate* HIV counselling and testing emerging from this study included sensitivity to the multiple issues and hardships that Aboriginal women have and still may experience; traditional teachings, practices, and Aboriginal spirituality (smudging, sharing circles, healing circles, use of Elders); a physical testing environment that incorporates Aboriginal symbols and offers multiple services; and the presence of Aboriginal staff working in a team. Health services that actualize the identified dimensions and are constructed on the foundation of the ideal HIV testing situation's guiding principles would encapsulate culturally appropriate HIV counselling and testing.

CHAPTER 5

DISCUSSION

In this chapter, I will highlight the major findings of this study and relate them to the existing research literature. The major findings are organized around the four research sub-questions: the factors influencing Aboriginal women's risk for HIV infection, the barriers to HIV counselling and testing for Aboriginal women, the factors that facilitate culturally appropriate HIV counselling and testing, and the characteristics of culturally appropriate HIV counselling and testing. This chapter will conclude with the limitations of the study, directions for further research, and implications for policy and programming.

Factors Influencing Aboriginal Women's Risk for HIV Infection

Aboriginal women's risk for HIV infection may increase as a result of their past and current life experiences. Three major factors influenced their risk of HIV infection: childhood sexual abuse, discrimination, and sexuality and relationships.

Childhood Sexual Abuse

Six of the seven Aboriginal women interviewed were sexually abused repeatedly during their childhood. Sexual abuse had a negative impact on their self-esteem and mental health, including the development and expression of their sexuality. Consequently their personal power in their intimate relationships may decrease, while potentially increasing their likelihood of engaging in behaviours of their partner's choice—some of which may be unprotected intercourse or needle sharing. Childhood sexual abuse also led to alcohol and drug abuse, resulting in impaired judgement and unprotected intercourse with multiple partners. Clearly, all of these factors increase the risk for acquiring HIV infection.

The incidence of childhood sexual abuse in Canadian Aboriginal communities is considered to be higher than in the general population (Neron, 1998). McEvoy and Daniluk (1995) suggested that the incidence of sexual abuse is as high as 80% in Canadian Aboriginal communities. Mill's (1997) study of Aboriginal HIV positive women in Alberta found that six of the seven women interviewed had experienced childhood sexual abuse, while DuBois et al. (1996) reported that 75.7% of their Aboriginal sample in Montreal had experienced some form of abuse.

Childhood sexual abuse has been strongly correlated with women acquiring HIV infection. Low self-esteem, chronic depression, phobias, and an overwhelming sense of shame have been identified as sequelae of sexual abuse. In addition, sexual abuse sequelae may lead women to believe they are responsible for the sexual abuse, and as punishment, they may engage in HIV risk behaviours (Amaro & Raj, 2000; Davila, 2000; Denenberg, 1997; Goma, 1997; He et al., 1998; McEvoy & Daniluk, 1995; Mill, 1997; Miller, 1999; Neron, 1998; O'Leary & Martins, 2000; Pharris, Resnick, & Blum, 1997; Zierler et al., 1996). These findings from the literature support the findings from the women in this study.

Increased alcohol and drug use, along with unprotected sexual activity with more lifetime partners, are additional sequelae of sexual abuse reported in the literature (Denenberg, 1997; He et al., 1998; Sherman & Steckler, 1998; Zierler et al., 1996). Although alcohol and drugs are readily available and immediately effective in mitigating the negative effects of past sexual abuse (Davila, 2000; Denenberg, 1997; Klein, Williams, & Witbrodt, 1999; McCormick, 1996; Mill, 1997; Miller, 1999; Pharris et al., 1997), their use may impair judgement leading to HIV risk behaviours such as unprotected intercourse and needle sharing (Baldwin et al., 1999; Hines & Caetano, 1998; Weaver, 1999a).

A useful summary of the effects of childhood sexual abuse and HIV infection is provided in Miller's model (1999), which suggests that the relationship between sexual abuse and HIV infection is negotiated through various sexual abuse sequelae or causal pathways. These pathways include drug use, increased sexual risk taking, psychopathology (such as depression and low self-esteem), and social networks. The first three pathways refer to the individual's feelings and behaviour while the final pathway reflects the broader social context in which women's risk for HIV infection occurs, such as gender and cultural dynamics.

Discrimination

Aboriginal women's risk for HIV infection may increase as a result of discrimination, according to the women in this study. They were subjected to racist remarks and negative stereotypes about Aboriginal people, specifically about Aboriginal women, beginning in their childhood. These women's experiences of discrimination were of various types and occurred in a variety of contexts such as employment, parenting, education, and health care delivery. Of particular note is the presence of both intra-racial and inter-racial discrimination, which can lead to a feeling of disconnection with either culture. The participants identified the negative impact that discrimination had on their self-esteem, and consequently on the development and expression of their sexuality and relationships. Similar to their experiences of sexual abuse, discrimination may reduce the women's personal power in their intimate relationships. Given that self-esteem is an integral component of healthy sexuality, lowered self-esteem acquired by discrimination experiences may increase the women's risk of acquiring HIV infection.

The sequelae arising from discrimination have been found to increase the potential for HIV infection among people from minority communities. Sequelae include: lower self-esteem (Fullilove, 1998; Postl, 1997); self-hatred (Amaro & Raj, 2000); hopelessness; physical or emotional violence (Sandhu & Brown, 1996); and oppression or marginalization by the dominant culture (Fullilove, 1998; Hamby, 2000; Sandhu & Brown, 1996; Watts, 1993). These researchers conclude that discrimination interferes with minority people's abilities to reduce their exposure or risk of HIV infection. An oppressed minority woman with lower self-esteem may be less likely to discuss condom use with her partner due to her experiences of discrimination coupled with her reduced power within her relationship (Choi & Coates, 1994; Gorna, 1997; Klein et al., 1999). As a result, minority women's risk of acquiring HIV infection increases. This literature supports the findings from the women in this study. No literature, however, was found that identified the effect of discrimination on HIV risk behaviours among Aboriginal people.

Sexuality and Relationships

As previously discussed, Aboriginal women's sexuality and the expression of their sexuality within their intimate relationships may be negatively impacted by their experiences of sexual abuse and discrimination. In addition, the women in this study identified the loss of Aboriginal traditional teachings and patriarchal influences as factors that may further negatively impact the development and expression of Aboriginal women's sexuality. These four factors may reduce Aboriginal women's personal power within their intimate relationships, thereby increasing their risk of acquiring HIV infection.

Colonization by European settlers changed the nature of relationships between Aboriginal women and men, according to the women in the study. Aboriginal norms or their traditional teachings were replaced with values of the dominant non-Aboriginal culture. For example, in traditional times, Aboriginal women and men experienced equal power in their relationships and were equally valued for their contributions in their communities. However, with adoption of the dominant norms of patriarchy, women experienced a loss of social status and power in their relationships.

Perhaps as a result of these shifts in status and power, Aboriginal women tolerate such negative behaviours from their partners as alcohol or drug abuse, unprotected intercourse outside of their primary relationship, and various forms of abuse. By giving their partner a "second chance", Aboriginal women may further increase their risk of acquiring HIV infection. Some of the women attributed this tolerance to their childhood experiences, which were often fraught with violence. This socialization with violence as a norm also may explain the women's continuing involvement in abusive relationships.

According to relevant literature, Aboriginal women's reduced social status and power within their relationships has been attributed to colonization policies and practices that limited or abolished traditional Aboriginal teachings, such as egalitarian relationships within Aboriginal communities (Hanson & Hampton, 2000; Kirkmayer, Brass, & Tait, 2000; Malone, 2000; McCormick, 2000; Poonwassie & Charter, 2001). In addition, patriarchal influences, discrimination, and derogatory stereotypes of Aboriginal women, also introduced through colonization, further reduced Aboriginal women's status and personal power (Hamby, 2000; Kirkmayer et al., 2000; Shain et al., 1999; Wingood & DiClemente, 2000).

The literature identified many consequences of European colonization that may negatively impact Aboriginal women's ability to adopt HIV risk reduction behaviours in Aboriginal communities. Adopted cultural and gendered norms through the colonization process may interfere with Aboriginal women's ability to negotiate safer sexual practices (Amaro, 1995; Bajos & Marquet, 2000; Baldwin et al., 1999; Fenaughty, Fisher, & Cagle, 1998; Irwin, Scarlett, & Moseley, 1998; Klein, Bullock, Calzavara, Cockerill, & Marshall, 1999; Myers et al., 1997; Shain et al., 1999). In addition, the process of colonization may have had a negative impact on the role of Aboriginal men. As a result, Aboriginal men may also experience internalized oppression and reduced self-esteem, which may contribute to domestic violence in Aboriginal communities (Hamby, 2000; Malone, 2000; McCormick, 1996).

The literature also supports the study findings that Aboriginal women's risk for HIV infection may increase because of their tolerance for their partner's HIV risk behaviours. The partner's alcohol or drug abuse (Baldwin et al., 1999; Cattarello et al., 1998; Duke & Omi, 1991; Fenaughty et al., 1998; McCormick, 2000; Sherman & Steckler, 1998; Wingood & DiClemente, 2000), unprotected sexual activity outside of the primary relationship (Baldwin et al., 1999; Calzavara et al., 1998; Duke & Omi, 1991; Wingood & DiClemente, 2000), and all forms of violence, including sexual assault (Baldwin et al., 1999; Hamby, 2000; Neron, 1998; Zierler at al., 1996), increase Aboriginal women's risk for HIV infection.

Remote Aboriginal communities are not insulated from the spread of HIV infection, as a consequence of Aboriginal women's tolerance of their partner's HIV risk behaviour (Calzavara, Bullock, Myers, Marshall, &Cockerill, 1999). Calzavara and colleagues found that some Aboriginal people had sexual partners within and outside of their communities. As a result, a sexual pathway or "sexual bridge" importing or exporting HIV infection was created, which again increased Aboriginal women's potential for acquiring HIV infection—this time in remote Aboriginal communities.

In summary, the study findings, supported by the literature, provide an important understanding of the context of Aboriginal women's life experiences. This information is crucial to understanding not only the factors that increase women's risk for HIV infection but also to the multiple challenges Aboriginal women may experience when attempting to reduce their risk for HIV infection. Furthermore, these data provide insights into the women's perceptions of barriers to HIV testing and their understanding of what is needed in "culturally appropriate" HIV counselling and testing.

Barriers to HIV Testing for Aboriginal Women

A number of barriers to HIV counselling and testing were identified by the women, and were organized into three major categories: internal barriers; experiential barriers; and systemic barriers.

Internal Barriers

"Internal" barriers refer to the women's feelings or perceptions that may prevent them from physically accessing HIV testing. These barriers include cultural norms that prevent women from disclosing HIV risk behaviour to an "outsider", lack of internal motivation or readiness, feeling ashamed, perceived lack of anonymity, fear of testing HIV positive, and fear of being judged by Aboriginal people.

There is a paucity of literature describing internal barriers to HIV counselling and testing generally, and for Aboriginal women in particular. However, one qualitative study of HIV-positive African American, Puerto Rican and non-Hispanic white women in the United States (Siegel, Raveis, & Gorey, 1998) revealed that fear and denial of potential HIV infection were the principal barriers the women experienced towards HIV testing once they acknowledged their HIV risk. The participants spoke of being overwhelmed, perhaps even suicidal, and ill equipped to deal with the fall-out from an HIV positive diagnosis (Siegel et al., 1998). These findings support the internal barrier the women in the study identified as fear of testing HIV positive.

Some literature has described Aboriginal people's internal barriers when accessing health care services generally (Watershed Writing and Research, 1997) or mental health services specifically (Manson, 2000; McCormick, 2000). Evidence from these studies support the following internal barriers identified by the women in this study: feeling ashamed (McCormick, 2000; Watershed Writing and Research, 1997); a lack of anonymity (Watershed Writing and Research, 1997); potential community judgement (Manson, 2000); and stigmatization (Watershed Writing and Research, 1997).

Experiential Barriers

The women in the study identified a number of "experiential barriers" relative to HIV counselling and testing. This category of barriers relates to previous experiences that Aboriginal women or their significant others have had with HIV testing, or what the women perceive may occur in a testing situation. Experiential barriers identified by the women included: a previous negative experience; questions about HIV risk behaviours; judgement by the tester; preaching and pressure from the tester; confidentiality and anonymity issues; a perceived lack of sensitivity by the tester regarding the impact of HIV infection on Aboriginal communities; and the gender of the tester (gender discussed in next section). Many of these barriers relate to the women's perceptions of being judged unfairly.

Once again, there is little research describing experiential barriers to HIV counselling and testing generally, or for Aboriginal women in particular. In one study conducted in Latvia, HIV positive men and women identified history taking by the HIV tester as a potential barrier for individuals seeking HIV testing (Sauka & Lie, 2000). The researchers concluded that a trusting relationship might not be developed if the HIV tester inquired about the sexual relationship or orientation of the individual seeking HIV testing, creating a barrier to HIV counselling and testing.

Another group of researchers questioned dispensing with HIV pre-counselling in a genitourinary medicine clinic for women and men (Munday & Mullan, 1999). After reading an information sheet on HIV infection, female and male study participants assessed their level of personal HIV risk. If the individual concluded that their risk for HIV infection was low, s/he received HIV testing without counselling. The researchers concluded that HIV pre-counselling was not a barrier for people accessing HIV testing. Further research on this practice is warranted, given the limited design of this study. Moreover, it is not known whether Aboriginal women would view such a self-assessment form as acceptable or less intrusive than questioning by the tester.

Two Canadian studies identified Aboriginal women's barriers to health care services in general (Browne, Fiske, & Thomas, 2000; Clarke et al., 1998). Aboriginal women in the Browne et al. qualitative study identified invalidating and validating encounters with health care providers. An invalidating encounter included the health care provider's disregard for the women's personal circumstances (e.g., long waiting, charging for missed appointments, lack of transportation). This study also found that women transformed their appearance and behaviour when attending the mainstream clinical services in order to enhance credibility with, and minimize discrimination from, the health care provider (Browne et al., 2000). Similarly, Clarke et al. (1998), in a study to identify barriers that Canadian Aboriginal women experience when accessing pap smear testing, found that fear of being judged by physicians and having had a previous negative experience with health care providers were barriers to seeking screening. Once more, this finding would support the experiential barrier the women in the study identified relative to a previous negative experience and feeling judged by the HIV tester when accessing HIV counselling and testing.

A third Canadian study identified experiential barriers for Aboriginal injection drug users accessing health care services in general (Watershed Writing and Research, 1997). This study revealed that injection drug users were subjected to racist stereotypes, in addition to being stigmatized as drug users. Health care providers operating from an abstinence model of drug use were more likely to direct or "pressure" individuals to cease their drug behaviour. The pressure or potential preaching by the health care provider may create a barrier for individuals with regard to access to health care services. Participants in this research also identified confidentiality as a barrier for Aboriginal people accessing health care services, especially on reserves (Watershed Writing and Research, 1997), as many health care providers may be related to the Aboriginal person seeking health care services. These barriers are similar to the barriers the women identified regarding pressuring by the tester and the potential lack of confidentiality when Aboriginal people are accessed in their communities for HIV follow-up.

Systemic Barriers

"Systemic" barriers refer to the broader barriers to HIV testing that prevent Aboriginal women from physically accessing an HIV test. These include lack of trust resulting from the colonization experience, institutionalized discrimination, Child Welfare involvement, and transportation and childcare issues.

Because of Aboriginal women's experiences of discrimination since European colonization and extending to the present, many Aboriginal women may feel disempowered when accessing services such as HIV counselling and testing. Previous or anticipated Child Welfare involvement may have particularly grave results for pregnant women, as it may pose a barrier not only to HIV testing, but also to accessing prenatal care.

HIV infected women are at risk for transmitting their infection to their unborn child. A high proportion of HIV infected women who deliver are Aboriginal women, based on recent data from some sites in western Canada. One study of deliveries by HIV infected women in northern Alberta and the Northwest Territories between 1996-98 found that 91% of the women were Aboriginal (Birse, Shokoples, & Houston, 1999).

Once more, there is limited research describing systemic barriers to HIV counselling and testing in general, and for Aboriginal women specifically. However, one Canadian study on Aboriginal women's experiences accessing health care services in general provides support for some of the findings from this research. Browne et al. (2000) identified the negative judgement and discrimination that Aboriginal women experience when accessing health care services in general, including discriminatory assumptions that Aboriginal women may be abusive mothers. This may lead to Aboriginal women's reluctance in accessing and trusting health care providers. Access to transportation and a telephone were also identified as important resources enhancing Aboriginal women's capacities to access services.

Further, Browne et al. (2000) this study identified a number of recommendations to improve Aboriginal women's access to mainstream health services. One of the recommendations from the study was to develop policies to "protect Aboriginal women from institutional discrimination in mainstream post-colonial health care systems" (p. 28). Another recommendation identified the importance of having Aboriginal health care providers working within mainstream health care systems in order to minimize Aboriginal women's experience as "outsiders or intruders" (p. 29). These recommendations are pivotal in reducing barriers for Aboriginal women in accessing health care services and may be similar for Aboriginal women accessing HIV testing.

Several conclusions can be drawn from the literature and the findings of this study. First, the women's experiences point to the lack of adherence to the HIV testing and counselling guidelines established by the Canadian Medical Association (1995). While nurse specialists working in publically funded STD clinics operate from these standards, physicians working in private practice may not be spending sufficient time on the pre-test counselling, as evidenced by the women's comments. As a result, Aboriginal women's access to HIV information and the testing process are compromised, which may further impact the woman's capacity to provide fully informed consent to HIV testing. There are clear practice implications arising from the lack of adherence to the Canadian HIV counselling and testing practice standards.

Second, it is important to note the three different contexts in which the women experienced judgement when accessing HIV counselling and testing: intra-racial, inter-racial, and systemic discrimination. Perhaps least acknowledged or recognized is the intra-racial judgement and discrimination, which contributes to barriers related to anonymity and confidentiality, and the perceived repercussions of testing HIV positive. This fear of being judged by one's own community is added to the fear of being judged by others outside of the community, particularly in the testing situation. Conceivably it is for reasons relating to discrimination that Aboriginal women would like to bring a supportive relative or friend with them when they access HIV counselling and testing. This practice is currently frowned upon at some STD clinics, due to a potential power differential should the woman bring her partner or her pimp. Unfortunately, this practice may prevent Aboriginal women from accessing quality STD/HIV testing services - services that are grounded in current, Canadian standards of practice for HIV counselling and testing. Some physicians appear to accept women bringing a support person with them, as evidenced by the women's comments, which may reduce the discrimination experience, or minimally provide them with immediate support if the HIV tester is judgmental.

Third, the perceived lack of anonymity the women anticipate or have experienced when accessing services at a STD clinic is somewhat surprising. In this city, STD services are provided within a multi-purpose building, which would supposedly afford some anonymity. Unfortunately, this barrier may encourage women to seek other sources of HIV counselling and testing, where practice standards may not be adhered to but anonymity enhanced.

Another important consideration relates to the pre-test assessment of HIV risk behaviours. Being asked questions about HIV risk behaviours created an enormous barrier for Aboriginal women in accessing HIV counselling and testing, a finding that was rarely mentioned in the literature. I was overwhelmed by the sense of judgement the women experienced when asked about their risk behaviours. If the HIV tester utilizes the Canadian guidelines, the women would understand the purpose of the HIV risk assessment. However, knowing the purpose of the HIV risk assessment may not reduce the women's sense of judgement by the HIV tester. This is an important issue, given that there is also a need to obtain epidemiological data regarding HIV infection in the Aboriginal community so that appropriate interventions can be developed. Perhaps there are different ways that the HIV risk assessment could be completed, while honouring the women's concerns about this issue. Clearly, research and practice implications arise from this particular barrier to HIV counselling and testing.

Closely related to this issue is the perceived lack of sensitivity on the part of the HIV tester about HIV infection in Aboriginal communities. Even though there is an increased prevalence of HIV infection in Aboriginal communities, the women cautioned that this does not mean that Aboriginal women require less support. On the contrary, Aboriginal women may require enhanced support given the impact this disease has on their communities, and their community's capacity to prevent HIV infection and to support infected and affected individuals and families.

A final issue is reflected in the experience of Aboriginal women with Child Welfare. Given that a high percentage of pregnant women with HIV infection are Aboriginal, Aboriginal women need to be able to access prenatal care without fearing the potential apprehension of their baby at birth, should they test HIV positive. If this systemic barrier is not corrected, there may be an increase in the number of HIV positive Aboriginal babies delivered, and a faster progression for Aboriginal women from HIV to full-blown AIDS.

The limited evidence in the literature on HIV counselling and testing barriers, especially for Aboriginal women, suggests the need for further research in this area. Some research identifies the barriers Aboriginal women face when accessing health services in general; however, further research is required to determine if these barriers are different for Aboriginal women seeking HIV counselling and testing. The stigmatizing and fatal nature of HIV infection may present different barriers. Further, Aboriginal women's life experiences, their reduced social status, and their reduced personal power in their intimate relationships may create different barriers to HIV counselling and testing than the barriers experienced by non-Aboriginal women seeking HIV testing. While the findings from this study advance empirical knowledge on Aboriginal women's barriers to HIV counselling and testing, these findings need to be considered as a beginning data set.

Factors Facilitating Culturally Appropriate HIV Counselling and Testing

The women in the study were able to identify six characteristics or principles that underpin the "ideal testing situation" and in many ways address the barriers previously identified. These guiding principles include (a) Aboriginal women determining HIV policy and programming, (b) incorporating a harm reduction approach, (c) utilizing a present orientation, (d) providing multiple choices, (e) utilizing an ideal HIV tester, and (f) incorporating an ideal HIV counselling and testing process.

The literature supported many of the recommendations made by the women. Involvement in HIV policy and programming for Aboriginal communities is in keeping with the paradigm shift to self-determination for Canadian Aboriginal peoples, wherein Aboriginal people would develop HIV policy and programming to best address their identified needs at a local level (Baldwin et al., 1999; Crown et al., 1993; Dufrene & Coleman, 1994; Hamby, 2000; Hanson & Hampton, 2000; Poonwassie & Charter, 2001; Royal Commission on Aboriginal Peoples, 1996; Watershed Writing and Research, 1997; Weaver, 1999a). Active community participation would not only ensure that the intervention is timely and appropriate but also would build on the strengths of the community, fostering increased empowerment (Clarke et al., 1998; Klein et al., 1999).

The Canadian Aboriginal AIDS Network recommends that Aboriginal communities in Canada adopt a harm reduction model to minimize the spread of HIV infection based on results from a survey of 126 Aboriginal injection drug users across Canada (Watershed Writing and Research, 1997). A harm reduction philosophy is generally applied to drug-use interventions and other HIV risk behaviours such as unprotected intercourse (Duke & Omi, 1991; Duncan, Nicholson, Clifford, Hawkins, & Petosa, 1994; Klein et al., 1999; O'Leary & Martins, 2000).

Support for the principle of adopting a present orientation was found in the literature that described Aboriginal people's time orientation to the present (Garrett &

Garrett, 1994; Garrett & Wilbur, 1999), with a focus on wellness (Hanson & Hampton, 2000; Strickland, Squeoch, & Chrisman, 1999). This orientation would frame the interaction in a positive light while working towards reducing the individual's risks for HIV infection.

Support for the guiding principle of providing choices to women was found in the health care delivery and counselling literature on Aboriginal people. Respect for personal choice is considered important when counselling Aboriginal people and is more consistent with Aboriginal cultural practices (Garrett & Wilbur, 1999; Heilbron & Guttman, 2000; Malone, 2000). Having a choice not only increases personal satisfaction but also serves to increase personal power and community empowerment (Clarke et al., 1998; Poonwassie & Charter, 2001). In one Canadian study of Aboriginal women accessing pap screening services, all aspects of care were based on the participant's choice (Clarke et al., 1998). For example, if an Aboriginal woman wanted to have a support person present during her exam, then she was encouraged to do so. Service providers are cautioned not to assume that all Aboriginal people engage in traditional practices (Garrett & Wilbur, 1999; Mill, 2000; Poonwassie & Charter, 2001). Rather, it would be incumbent for the tester to assess the Aboriginal woman's level of cultural commitment and to offer her options to engage in traditional Aboriginal practices throughout the HIV testing process (Clarke et al., 1998; Garrett & Garrett, 1994; Heilbron & Guttman, 2000; Weaver, 1999a).

There is also ample evidence in the health care and counselling literature on Aboriginal people to support the attributes of the HIV tester, as identified by the women in the study. *Compassionate*, *caring*, *trustworthy*, *respectful*, *accepting*, and *nonethnocentric* were descriptors used in various studies (Clarke et al., 1998; Garrett & Garrett, 1994; Klein et al., 1999). Aboriginal humour, described as dry exaggeration, was identified as a useful tool to foster connection between the individual seeking HIV testing and the HIV tester (Garrett & Garrett, 1994; Garrett & Wilbur, 1999). Weaver (1999b) identified important communication and counselling skills when providing health care services for Aboriginal people, highlighting the need for listening skills. Also, the HIV tester should be knowledgeable about Aboriginal culture, including the issues that Aboriginal women may experience within their communities (Klein et al., 1999; Malone, 2000; Weaver, 1999b).

Assessing for learned powerlessness and the use of a feminist approach would also be important for the HIV tester to incorporate in her work with Aboriginal women. One research study involving HIV positive Aboriginal women stressed the importance of assessing for learned powerlessness because survival mechanisms for Aboriginal women may oppose HIV prevention strategies (Mill, 1997). Using a feminist approach, Malone (2000) stressed the value of helping Aboriginal women to realize that they are their own experts in their experience, building on their strengths. This approach would suggest that the counsellor relinquish her personal control and adopt a role as student first, followed by a professional role, in order to facilitate client and personal growth of the tester in the ideal HIV testing situation (Garrett & Garrett, 1994).

Support for the development of an egalitarian type of relationship between the tester and the woman was found in the health care and counselling literature. Relationship building is enhanced by the tester using statements rather than questions, and by modelling self-disclosure (Garrett & Garrett, 1994). The use of an egalitarian approach, awareness of Aboriginal women's circumstances, and acceptance of Aboriginal women and their reality, would strengthen the relationship between the HIV tester and the Aboriginal woman (Browne et al., 2000; Clarke et al., 1998; Manson, 2000; Smith & Morrissette, 2001), and support the findings from this study.

A number of researchers have designed their HIV intervention studies with female facilitators or interviewers for minority women, including Aboriginal women (Baldwin et al., 1999; Jemmott, Maula, & Bush, 1999; Kalichman, Williams, & Nachimson, 1999; Nyamathi et al., 1999; Shain et al., 1999). One group of researchers found that study participants, especially Aboriginal women with a history of sexual abuse, preferred female health care providers because they felt less threatened and better supported (Clarke et al., 1998). Another group of researchers working with immigrant and refugee women living in Quebec state that the quality of health care for immigrant women improves by matching their ethnicity and gender to that of the health care workers (Vissandjee, Weinfeld, Dupere, & Abdool, in press).

Numerous researchers have used ethnic matching in their research studies with various minority women, including Aboriginal women (Baldwin et al., 1999; Jemmott et al., 1999; Kalichman et al., 1999; Nyamathi et al., 1999; Shain et al., 1999). Rapport and communication are believed to be improved through ethnic matching (Dufrene & Coleman, 1994). Also, there is an assumption that the Aboriginal tester and person seeking testing may have common experiences, issues, and concerns founded on similar cultural teachings and practices (Clarke et al., 1998; Dufrene & Coleman, 1994).

However, there is conflicting evidence on the importance of ethnic matching. One Canadian study of Aboriginal residential school survivors found that not all participants identified ethnic matching as important in interviewing (Hanson & Hampton, 2000). Others caution that ethnic matching for Aboriginal health care is not always feasible, nor does it reduce value conflicts or ensure that the interaction will be culturally sensitive (Dufrene & Coleman, 1994; Kirkmayer et al., 2000; Poonwassie & Charter, 2001). Hamby (2000) states that some Aboriginal people perceive greater confidentiality when the counsellor or tester is a non-Aboriginal person, which would support the preference of one of the women in this study.

There is little literature on the HIV testing sequence for women in general and for Aboriginal women in particular. However, findings from the counselling literature on Aboriginal people provides for the presence of a support person during the interview and identifies the importance of assessing available supports for the woman (Garrett & Wilbur, 1999; Manson, 2000). In fact, one study suggested that Aboriginal people seeking health care services be provided with an opportunity to include their family in the interview, because this would be more supportive of the norms within Aboriginal communities (Smith & Morrissette, 2001).

When considering the six guiding principles in relation to the barriers identified by the women, it is apparent that many of the previously identified barriers to HIV testing would be addressed by incorporation of the principles. Aboriginal determination of Aboriginal women's HIV policy and programming is perhaps the most important principle in reducing the judgement women may experience from Aboriginal people in their communities, from non-Aboriginal HIV testers, and within the systems they access for HIV testing. A harm reduction approach would decrease judgement, as well as the preaching and pressure from the tester. Using this approach, the tester would support the woman developing HIV risk reduction strategies that she could use "right now". In addition, providing choices wherein a woman may bring a support person, may minimize judgement, with the support person acting as an advocate on the woman's behalf. Employing a tester (ideally female and Aboriginal) who is sensitive to and aware of the multiple hardships and issues Aboriginal women may have experienced would further overcome the critical barrier of "being judged".

While evidence exists for the guiding principles individually, there is little research that incorporates the use of these guiding principles as a whole in HIV counselling and testing for Aboriginal women. As a result, findings from this study advance the understanding of the factors that facilitate the ideal HIV counselling and testing for Aboriginal women and reduce Aboriginal women's barriers to HIV counselling and testing.

Characteristics of "Culturally Appropriate" HIV Counselling and Testing

In the study, the women explicated the meaning of *culture* and *culturally appropriate* in an effort to improve HIV policy and programming for Aboriginal women. Important dimensions of "culturally appropriate" HIV testing services in Aboriginal communities include sensitivity to and knowledge of the issues that Aboriginal women may experience, along with the inclusion of traditional teachings, practices, and Aboriginal spirituality in service delivery. In addition, the physical environment of the testing services and the presence of Aboriginal staff were also identified by the women as important characteristics of "culturally appropriate" HIV policy and programming for Aboriginal women. Support for these findings was identified in HIV intervention literature related to women in general, Aboriginal and minority women, and in the counselling literature related to Aboriginal people.

A critical component of culturally appropriate HIV interventions acknowledges minority women's life experiences that impact or impede their HIV risk reduction activities (Davila, 2000; Jemmott et al, 1999; Manson, 2000; Sauka & Lie, 2000; Shain et al., 1999; Smith & Morrissette, 2001), along with an emphasis on gender dynamics within the cultural context for women (Amaro, 1995; Browne et al., 2000; Clarke et al., 1998; Downing et al., 1999; Duke & Omi, 1991; Klein et al., 1999; Nyamathi et al., 1999). Unfortunately, many of the existing HIV intervention models may be inappropriate for minority women as they "fail to address the role of culture in female disempowerment or to provide cultural definitions of female power" (Amaro and Raj, 2000, p. 726). One example of an inappropriate HIV intervention model was found in a study of American Aboriginal women with the information-motivation-behaviour model of behaviour change utilized in their intervention (Morrison-Beedy, Carey, Lewis, & Aronowitz, 2001). Although these researchers identified the value of providing culturally appropriate interventions, they concluded their research by claiming that Aboriginal women lacked the motivation or skills to prevent HIV infection. This conclusion reflects a paternalistic attitude steeped further in racist assumptions.

On the other hand, some Aboriginal people worry that "culturally appropriate" interventions that acknowledge life experiences of Aboriginal people may inadvertently reinforce negative stereotyping of Aboriginal people. Participants in a study of HIV risks among American Aboriginal injection drug users did not want the issue of drug use linked to Aboriginal people (Baldwin et al., 1999). These subjects were concerned that HIV programming that connects Aboriginal people to HIV infection reinforces negative stereotypes of Aboriginal people, leading to further stigmatization. As a result, study participants had varied attitudes toward developing "culturally sensitive" HIV prevention materials for Aboriginal people.

The second characteristic of culturally appropriate HIV counselling and testing refers to opportunities for Aboriginal women to engage in traditional teachings, practices, and Aboriginal spirituality when seeking testing. Researchers from the counselling or HIV field for Aboriginal people support this dimension of culturally appropriate testing as this facilitates Aboriginal women reconnecting to their traditional teachings (Baldwin et al., 1999; Poonwassie & Charter, 2001; Weaver, 1999a). In fact, McCormick (2000) states that many Aboriginal Elders and healers believe that Aboriginal people's disconnection from traditional teachings "have made Aboriginal people unhealthy in the first place" (p. 27). However, other researchers (Garrett & Wilbur, 1999) caution that Aboriginal people's beliefs about spirituality and traditional values may vary depending on a number of factors, including their level of acculturation (Weaver, 1999a).

Other literature on Aboriginal health care in Canada suggests that cultural and spiritual practices that are incorporated into health care service delivery may reduce barriers to treatment for Aboriginal people (Strickland et al., 1999). Healing and sharing circles are powerful tools for sharing traditional values, along with emotional and spiritual healing (Garrett & Garrett, 1994; Heilbron & Guttman, 2000; Kirkmayer et al., 2000; Poonwassie & Charter, 2001; Strickland et al, 1999; Struthers & Littlejohn, 1999), and for promoting physical, spiritual, and psychological connection of participants (Heilbron & Guttman, 2000). Storytelling during the circle provides opportunities to share personal experiences and to learn more about Aboriginal traditional values (Downing et al., 1999; Malone, 2000; Myers et al., 1997; Strickland et al., 1999).

The role of Elders and spiritual leaders in health care and counselling for Aboriginal people is well supported (Clarke et al., 1998; Crown et al., 1993; McCormick, 2000; Weaver, 1999a). Elders and spiritual healers could promote traditional teachings, practices, and Aboriginal spirituality in a variety of ways, including the use of smudge and sweat lodges for individual and community healing (Garrett & Wilbur, 1999; Kirkmayer et al., 2000; McCormick, 1996).

One study on Aboriginal women provides support for the women's description of an HIV testing environment that reflects Aboriginal culture, the third characteristic of culturally appropriate HIV counselling and testing (Clarke et al., 1998). Participants in this study suggested that visible signs of Aboriginal influence such as dream catchers and other forms of Aboriginal art would help the participants to perceive the office and clinic setting as warm and inviting. In addition, the researchers learned that providing refreshments and child care was an important component of service delivery.

The fourth characteristic of culturally appropriate HIV counselling and testing identified the importance of Aboriginal staff providing HIV services for Aboriginal people. Findings from the Royal Commission on Aboriginal Peoples (1996) identified the need for integrated health and social service centres based in local Aboriginal communities, provided by Aboriginal people. The report states, "No amount of intervention from outsiders, however well meant, will help Aboriginal people achieve well-being. What outside forces cannot bring about, Aboriginal people can do for themselves" (p. 75). However, intensive education and training of Aboriginal people are required in order to fulfil this need. In summary, Aboriginal people will determine their own health needs, utilizing an integrated approach with Aboriginal staff to meet those needs (Weaver, 1999a).

These study findings, in conjunction with the supporting literature related to "culturally appropriate" HIV counselling and testing, point to several important conclusions. First, sensitivity and knowledge of the multiple hardships Aboriginal women may experience during their lives is probably one of the most important aspects of culturally appropriate HIV testing. Indeed, this issue is reflected throughout the thesis. Insensitivity to this issue is the basis of several barriers and leads to perceptions of being unfairly judged. The literature supports incorporating this characteristic in the development of HIV prevention interventions for other ethnic women. This criterion may be even more salient for Aboriginal women in that their life experiences may reflect violence, decreased social status, and reduced power in their intimate relationships.

Second, the concept of ethnic matching raises challenges. While an Aboriginal tester may enhance sensitivity and awareness of the issues Aboriginal women experience, other concerns arise about the potential challenge the female Aboriginal tester may have maintaining confidentiality and anonymity, especially if a family member of the tester is affected. Most of the women believed that an Aboriginal HIV tester would better address the needs of the women but cautioned that the tester would need to be someone they did not know, due to a potential lack of confidentiality.

There is also the more problematic consideration of the availability of Aboriginal testers. Until sufficient Aboriginal HIV testers are available and willing to work with Aboriginal women providing HIV counselling and testing, the use of non-Aboriginal HIV testers will need to be considered. Perhaps other strategies could be developed, such as training Aboriginal Community Health Representatives to perform HIV counselling and testing.

There is also the question of whether the ethnicity of the HIV tester is as important as the qualities of the ideal HIV tester described by the women. This discussion reminds me of an argument I heard when I first started my career in public health nursing. Public health nurses held different views about the qualities of the PHN prenatal instructor. Some public health nurses felt that prenatal classes could only be taught by women who had experienced pregnancy and childbirth. This issue certainly raises two important considerations. The first point is whether the tester can achieve an understanding of the women's issues "vicariously" through education and experience. Second, the tester needs to have resolved any personal issues, and clarified her/his own values, attitudes, and beliefs so that s/he are better able to support the women seeking testing.

Similar issues need to be considered regarding the presence of Aboriginal staff. Their capacity to minimize intra-racial and inter-racial discrimination, to enhance confidentiality and anonymity, and to demonstrate many of the other characteristics described for the ideal HIV tester is an asset. While the receptionist would not need to have the same level of knowledge about HIV infection and the determinants of health, her ability to welcome women arriving at the HIV testing site is critical.

Finally, incorporating Aboriginal artifacts and traditional practices may be critically important because it provides tangible evidence to Aboriginal women that their cultural norms, practices, and Aboriginal spirituality are acknowledged and supported. It is equally important, however, to acknowledge the woman's level of acculturation, and to provide her with the choice to engage or not engage in any of the Aboriginal traditions.

Limitations of the Study

This study focused on Aboriginal women's perspectives on "culturally appropriate" HIV counselling and testing. Nonprobability convenience sampling was used to reach female Aboriginal women in a western Canadian city. Because the sample size was small and obtained from only one urban area, the participants may not be representative of Canadian Aboriginal women in this urban area and others. Women who volunteered to be part of the study may be different from those women who did not participate. For example, the participants in the individual interviews were well educated and may not be representative of all Aboriginal women. It is important, therefore, to regard these findings as a beginning data set. Nevertheless, this in-depth study of a small number of participants, supported by other studies, provides many valuable insights about culturally appropriate HIV counselling and testing.

With regard to the researcher as a data-collection instrument, the quality of the interviews that I conducted reflect my skills as a novice research interviewer, and may have influenced the quality of the data obtained. As the interviews progressed, so did the quality of interview data collected, reflecting an improvement in my interviewing skills. I also wonder whether the women in the study would have discussed things differently and raised other issues if the interviewer had been an Aboriginal woman. In addition, the 18 month period between data collection and analysis may have had a negative impact on the interpretation of the data. Hopefully, the use of my personal journal and my memos worked to minimize this limitation in the study. Perhaps the time lapse allowed me to interpret and report the findings more objectively.

The focus-group strategy was useful in that it provided validation of the findings from the individual interviews. However, there was hesitancy on the part of the participants to share their thoughts freely on this topic. I question whether the women's hesitancy was a reflection of knowing each other and possible confidentiality issues, or perhaps a consequence of having two non-Aboriginal women facilitate the group. The lack of spontaneity by the focus group participants may reflect a different communication style for Aboriginal women in this particular setting, or perhaps highlights a different level of education and acculturation compared to the participants in the individual interviews.

Implications for Research

Future research should be undertaken in other contexts in order to validate, clarify, and expand the findings from this research. Further study in this area would confirm and extend present empirical knowledge of the barriers to HIV counselling and testing for Aboriginal women, factors that influence culturally appropriate HIV counselling and testing, along with the characteristics of culturally appropriate HIV counselling and testing for Aboriginal women. It would be important to learn whether these findings are similar for Aboriginal women in other urban and rural areas of Alberta and Canada, or whether there are regional differences. These studies would enhance the generalizability of these findings. It would also be useful to determine how health professionals view "culturally appropriate" care. Obtaining their perspectives on HIV testing barriers and the ideal HIV testing situation would provide a more complete understanding of culturally appropriate HIV counselling and testing.

In addition, findings from this research could play an important role in the development of culturally appropriate HIV prevention interventions for Aboriginal women—interventions that are urgently required given the increasing number of Aboriginal women affected by or infected with HIV in Canada. The potential to initiate two pilot test situations arises from the findings from this research. The first pilot would test the effect of alternative methods of assessing HIV risk behaviours. Different options to complete the HIV risk assessment may include the Aboriginal woman completing her own HIV risk assessment to support the test, or the HIV tester providing the HIV test without the HIV risk assessment information. The HIV tester would only access the woman's HIV risk information when the woman is ready to disclose. A second pilot study, generated by comments from the women in this study, would compare levels of satisfaction when HIV counselling and testing is conducted by an Aboriginal female tester versus a non-Aboriginal female tester.

Ideally, Aboriginal researchers would develop research agendas and be involved in further research on HIV counselling and testing for Aboriginal people in general, and for Aboriginal women in particular. Engaging support and direction from key leaders within Aboriginal communities is necessary to ensure relevance and to build on the strengths and capacities of Aboriginal communities. In addition, it would be strategic to utilize Aboriginal interviewers to enhance the validity of the data.

Implications for HIV Policy and Programming

The perspectives of the Aboriginal women in this study raise many questions about current HIV counselling and testing practices and provide many suggested changes. Ideally, it would be important to implement the guiding principles along with the characteristics of culturally appropriate HIV counselling and testing. Given the limitations outlined above, further research is needed to confirm major findings from this study prior to consideration of changes to HIV policy and programming in Aboriginal communities. However, the findings, supported by other studies, do point to areas for potential change.

There are a number of recommendations at the policy level. First, there is a need to explore the lack of adherence to the Canadian Medical Association (1995) practice standards for HIV counselling and testing. Furthermore, increased attention to the HIV counselling and testing practice standards is warranted to ensure that considerations related to gender and culture are incorporated. HIV policy developers also need to examine the women's concern about the lack of anonymity provided by the title of STD clinics in this province, and make the necessary changes.

Policy level working groups with the requisite stakeholders need to be established to address two of the barriers the women identified. First, the women's concern relating to the HIV pre-test risk assessment requires exploration by stakeholders, including Medical Officers of Health, medical STD/HIV consultants, epidemiologists, and female representatives from Aboriginal communities. Second, a working group needs to consider policy that will support pregnant Aboriginal women to access prenatal care and HIV counselling and testing without fear of potential child apprehension by Child Welfare authorities. Potential stakeholders for this working group would need to include representatives from Alberta Health and Wellness, Alberta Human Resources and Employment, Infectious Disease specialists, and key female Aboriginal leaders.

In addition to the policy implications arising from the study, a number of implications for practice are evident. First, there is a need to enhance current HIV pre-test counselling. HIV testers need to provide the rationale for the HIV risk assessment for women seeking HIV counselling and testing. Minimally, informed consent must be obtained prior to proceeding with the HIV test. Further, the HIV tester could normalize the range of potential feelings women may experience while waiting for their HIV test results. Exploring the feasibility of hiring Aboriginal HIV testers, and incorporating Aboriginal traditional practices, are additional practice implications for consideration.

Education for healthcare providers and particularly for HIV testers is needed to enhance sensitivity and knowledge about the life context of Aboriginal women. Professional in-servicing could provide information about (a) the multiple hardships and issues experienced by Aboriginal women both historically and in their current situations, (b) the various forms and contexts of discrimination to which Aboriginal women are subjected, (c) the nature of stigmatization especially for HIV positive Aboriginal women, and (d) harm reduction approaches appropriate for HIV prevention.

Attending to the numerous research, policy, and practice implications identified by the women in the study will increase the capacity of Aboriginal women to access culturally appropriate HIV counselling and testing.

Conclusion

The purpose of this study was to identify Aboriginal women's perspectives on the characteristics of culturally appropriate HIV counselling and testing. Aboriginal women's risk for HIV infection may increase as a result of their past and current life experiences, particularly the factors of childhood sexual abuse, various forms of discrimination, and sexuality and relationships. These factors may increase Aboriginal women's risk for HIV infection by impeding their ability to engage in HIV risk reduction behaviours. In addition, these factors provide insight regarding the women's perceptions of the barriers to HIV counselling and testing, and their understanding of what is needed in "culturally appropriate" HIV counselling and testing.

A number of barriers to HIV counselling and testing were identified: internal barriers, experiential barriers, and systemic barriers. Internal barriers refer to the women's feelings or perceptions that prevent them from physically accessing an HIV test. Experiential barriers refer to the barriers Aboriginal women or significant others have had, or perceive will occur in the HIV testing situation. Systemic barriers refer to the broader barriers to HIV testing that prevent individuals from accessing an HIV test. Many of the identified barriers to HIV testing focus on some aspect of being judged unfairly by others, due in part to a lack of understanding of the context of Aboriginal women's past and present lives. However, the women's identified barriers also reflect perceptions of judgement from their own Aboriginal communities.

The women identified six characteristics or principles that underpin the "ideal testing situation" and in many ways address the barriers discussed previously. These guiding principles include (a) Aboriginal women determining HIV policy and programming, (b) incorporating a harm reduction approach, (c) utilizing a present orientation, (d) providing multiple choices, (e) a female, likely an Aboriginal tester that has particular personal attributes, skills, knowledge, working to develop relationships; (f) and incorporating an ideal HIV counselling and testing process, that includes HIV testing without an HIV risk assessment until a relationship has been developed between the tester and the Aboriginal woman.

An important dimension of "culturally appropriate" HIV testing services in Aboriginal communities includes the HIV tester's sensitivity to and knowledge of the issues that Aboriginal women may experience. Indeed, insensitivity to the hardships and life experiences that Aboriginal women may experience is the basis of several of the barriers to HIV counselling and testing, and leads to Aboriginal women's perceptions of being unfairly judged. The inclusion of traditional teachings, practices, and Aboriginal spirituality in service delivery were also identified as important dimensions of culturally appropriate HIV counselling and testing, along with attention to the physical environment of the testing services and the presence of Aboriginal staff. Health services that actualize the identified dimensions and are constructed on the foundation of the ideal HIV testing situation's guiding principles would encapsulate culturally appropriate HIV counselling and testing.

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APPENDIX A

INFORMATION ABOUT THE STUDY

Information About the Study

Purpose

To learn what Aboriginal women think "culturally appropriate" HIV counselling and testing is.

Principal Investigator

Dawn Bucharski, BScN, MSc Candidate, Centre for Health Promotion Studies, University of Alberta

Phone 449-5175

Supervisor

Dr. Linda Reutter, Professor, Faculty of Nursing, University of Alberta

Phone 492-5909

Methods

Dawn would like to interview 5-10 Aboriginal women individually and then 6-8 different Aboriginal women for 1 to 2 group interviews. These women will be asked questions about what they think "culturally appropriate" HIV counselling and testing is. They will also be asked what things make it easy or difficult to access HIV testing. The women will be asked to describe what the "best" HIV counselling and testing experience would be like. Dawn will also ask the women to consider answering some background questions about themselves.

The individual interview will be about 1-1 ½ hours long. The first interview will be held at a time and place agreed upon by the woman and Dawn. The second interview will be shorter and may be held by phone. The women will be given either a gift or $20.00 in acknowledgement of their time and expertise.

The group interviews will take place after the individual interviews. They will be about 2 hours long and held at a time and place agreed upon by all of the participants and Dawn. The women will be given either a gift or $20.00 in acknowledgement of their time and expertise. These women will also be reimbursed for their parking expenses or provided with round trip bus fare. The women will be able to give their feedback about the findings from the individual interviews. They will also have a chance to talk about their own ideas about what things that make it easy or difficult to go for HIV counselling and testing, along with their recommendations for improving HIV counselling and testing services.

Your Role in Recruiting Study Participants

It would be great if you would tell the following women about the study:

- women of Canadian Aboriginal ancestry (First Nations, Métis, status, non-status)
- able to speak and understand English
- 18 years of age or older and
- living within 100 kilometers of Edmonton.

It does not matter if the women are pregnant, have had HIV testing or are HIV positive.

When you talk to people, it would be great if you would describe the study and ask the women if they are interested in participating. If they are, could you please pass on Dawn's name and phone number.

You might want to say something like this when describing the study to potential participants:

> *A researcher from the Centre for Health Promotion Studies at the University of Alberta is doing a study with Aboriginal women to learn what they think "culturally appropriate" HIV counselling and testing is. The researcher is interviewing Aboriginal women about this. She hopes that the study will help to improve HIV testing services for Aboriginal women. To thank you for being in the study, you will get $20.00 if you take part.*

Benefits of the Study

This study may not have direct benefits for your agency or the people you work with. The findings from this study will help health care providers create HIV counselling and testing services that are culturally appropriate for Aboriginal women.

APPENDIX B

INFORMATION LETTER

Informed Consent for Individual Interviews
Information Letter

Part 1
Title of Project:
Aboriginal Women's Perspectives on "Culturally Appropriate" HIV Counselling and Testing.
Investigator:
Dawn Bucharski, BScN, MSc Candidate, Centre for Health Promotion Studies, University of Alberta 449-5175
Supervisor:
Dr Linda Reutter, Professor, Faculty of Nursing, University of Alberta 492-5909

Study Purpose:
The purpose of this research is to learn what Aboriginal women think "culturally appropriate" HIV counselling and testing is. I also want to learn about the things that put Aboriginal women at risk for HIV. I want to ask you what things would make it easier or more difficult for you to go for an HIV test. I want to ask you to describe what the "best" HIV testing experience would be like. I will also ask you to consider answering a few background questions about yourself.

Study Background
I am a community health nurse working on a Master's degree in health promotion. I am interested in women and HIV infection. I want to learn how to make HIV counselling and testing for Aboriginal women more respectful of Aboriginal culture. Results from this study could be used to improve HIV services for Aboriginal women.

Study Procedure
I want to talk with you two times. The first interview will take about 1-1½ hours. We will talk in a quiet and private place of your choice. We will meet at a time that works best for you. The second time we talk it will be shorter and may be by phone. At this time we will review the notes from our first interview. This will provide you with a chance to check whether I have interpreted what you told me correctly. It will also be a time to make things more clear if they were unclear.

I will tape record all interviews. Notes will be typed from the information on the tapes. Your name will not be on the tape or the notes. Instead, I will use a number to identify your interview. I am the only one who will know the number used for you. I will keep the tapes and notes from our talk private (confidential). I will share the notes only with my research committee.

This form will be kept locked up. I will tear up and throw away this form five years after the study is over. The tapes and notes from this study will be locked in a different place from the consents when I am not using them. I will keep the tapes and notes for 7 years.

The notes may be used for another study in the future. The investigator must get approval from the correct ethics review committee first.

I will share what is learned from this study at conferences, and in appropriate scientific journals. Your name or any information that may identify you will not be used.

You will receive a small gift of $20.00 for being in this study. This is to thank you for your time and knowledge.

Study Participation

You do not have to be in this study if you do not want. If you do decide to be in this study, you may drop out at any time by telling me. You can refuse to answer any question. You will not be punished for quitting the study.

By being in this study, I do not expect any harm will come to you. Sometimes, talking about life experiences may be uncomfortable. If this happens, I will help you find the support you need.

I will need to report to Social Services if you tell me that a person under 18 years is being abused. Also, I will need to report if a person who provides care is abusing someone else. This information can not be kept confidential. If you would like, I could ask a community health nurse to visit you about this.

Additional Contacts

If you have any concerns, you may call Dr. Helen Madill at 492-9347. She is the Graduate Program Co-ordinator at the Centre for Health Promotion Studies, University of Alberta. Dr. Madill is not part of this study. She would want to speak with you about your concerns.

________________ Participant's Initials

________________ Researcher's Initials

APPENDIX C

INDIVIDUAL INTERVIEW GUIDE

Individual Interview Guide

The questions and probes identified in this guide were reviewed by the Advisory group for relevancy, clarity, sensitivity and completeness. The questions were pilot tested and revised before the first interview. Prior to the third interview, a couple of the questions were further refined. The questions are as follows:

Aboriginal Women & Culture

It would really help me to have a better understanding of your life if we begin by exploring

- What it was like for you growing up as an Aboriginal girl?
- What kinds of things did you learn as you were growing up?
  Describe your life around the time of your first period; . . . around the time that you started dating.
- Are there different teachings for Aboriginal women compared to the Aboriginal men? Give an example that explains the difference(s).
- How do Aboriginal women want to be treated by men?
- Are Aboriginal women treated differently than non-Aboriginal women?

HIV Testing

I imagine that over the course of time, various Aboriginal people have told you about their HIV testing experiences. . . .

- Would you describe their experiences to me please?
- Describe your testing experience(s) from the time you thought about going for testing until you got your test results.
- Where would you prefer to go for HIV testing?

Ideal HIV Testing Experience

The ideal HIV testing experience—can you describe what you believe the ideal testing experience would be like. . . .

- **Who** would provide the testing?
  Probe:
  Aboriginal/non-Aboriginal
  Doctor/Nurse/CHR
  Person you know/person you don't know
- **What questions** could the tester ask you about your possible HIV risk?
  Would you answer the questions differently if the tester were Aboriginal?
  Are there **other factors** that would make it more difficult or easier to talk with the tester?
- Do you think being an Aboriginal woman makes a difference in going for testing? Are you treated differently? If so, how?
- What things would you not like to have happen during the testing? (Ask only if not already answered)

Culturally Appropriate Testing

Health care providers are seeking ways of providing HIV testing that is more inviting. . . . This means that Aboriginal women would be able to get tested and feels comfortable about the testing process.

- What would a comfortable HIV testing process look like for an Aboriginal woman?
- What Aboriginal traditions could be part of HIV testing process?
  Probe:
  Smudging
  Speaking with Elder first
- How could the traditions be provided during the testing?
- Do you think testing for Aboriginal women should be different than for non-Aboriginal women?

APPENDIX D

INDIVIDUAL INTERVIEW CONSENT

Individual Interview Consent

Part 1

Title of Project
Aboriginal Women's Perspectives on "Culturally Appropriate" HIV Counselling and Testing

Principal Investigator
Dawn Bucharski, MSc Candidate, Centre for Health Promotion Studies, University of Alberta

Phone 449-5175

Supervisor
Dr. Linda Reutter, Professor, Faculty of Nursing, University of Alberta

Phone 492-5909

Part 2
(to be completed by the research subject)

Do you understand that you have been asked to be in a research study?	Yes	No
Have you read and received a copy of the attached Information Sheet?	Yes	No
Do you understand the benefits and risks involved in taking part in this research study?	Yes	No
Do you understand that the interview will be tape-recorded?	Yes	No
Have you had an opportunity to ask questions and discuss this study?	Yes	No
Do you understand that you are free to refuse to participate or withdraw from the study at any time? You do not have to give a reason.	Yes	No
Has the issue of confidentiality been explained to you? Do you Understand who will have access to your information?	Yes	No

This study was explained to me by: ______________________________

I agree to take part in this study.

Signature of Research Participant	Date	Witness
Printed Name		Printed Name

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of Investigator	Date

APPENDIX E

BACKGROUND INFORMATION FORM

Background Information Form

Code number______________

1. Age:_____

2. Please describe yourself:
   _____First Nations
   _____Métis

3. Where do you **mainly** live (more then 50% of the time)?
   _____city
   _____town
   _____rural community
   _____reserve
   _____settlement

4. Who do you **mostly** live with (more then 50% of the time)?
   _____myself
   _____my partner
   _____my parents
   _____my partner's parents
   _____extended family
   _____other:_________________

5. What school grade did you complete? Grade _____
   Did you complete post-secondary?
   _____Yes - In what area?___________________
   _____No

6. Describe your relationship status **at this time**.
   _____single
   _____married
   _____living common law
   _____separated/divorced
   _____widowed
   _____other:_________________

7. Do you work **outside** of your home?
   _____Yes (Please move to Question 8)
   _____Yes, but I work from my home (Please move to Question 8)
   _____No (Please move to Question 9)

8. Do you work
_____full time
_____part time
_____casual
_____seasonal (certain times of the year)

9. How old were you the first time you had sex?
_____years

Was it your choice to have sex then?
_____Yes
_____No

How many people have you had sex with?
_____partners

Were your sex partners:
_____male
_____female
_____both genders

10. **If you are sexually active:**

How many times in the past month did you have unprotected sex?
_____times

Did you have unprotected sex with a person who uses needles?
_____Yes
_____No

What stopped you from using a condom in the past month?
____
____
____
____
____

If you use needles:
How many times in the past month did you "use"?
_____times

How many times in the past month did you share a "rig"?
_____times

APPENDIX F

FOCUS GROUP GUIDE

Focus Group Guide

The questions and probes identified in this guide have been provided to the Research Committee and the Advisory group for their review, relative to relevancy, clarity, sensitivity and completeness. The proposed introduction and questions are as follows:

I have been talking with Aboriginal women about HIV counselling and testing. I want to learn how to make HIV counselling and testing more respectful of the Aboriginal culture, especially for women. I have been speaking with individual Aboriginal women about this and would now like to hear your thoughts on what they said. I would also like to hear your ideas as they may be different from what has been said so far.

- Let's start by asking you to share your name and then describe any HIV testing experience(s) you have had, or that you have heard from other Aboriginal people?

- In talking with Aboriginal women so far:
  - They mentioned several things that make it difficult to get HIV testing. These are ________. How does this fit with your ideas? Can you add others?

    Probe
    Are Aboriginal women treated differently than non-Aboriginal women when they go for testing?
    Another factor identified by women in not getting HIV testing was their previous experience with health care or social service agencies. Can you tell us more about this?
    How does this affect HIV testing?

  - The women also talked about the things that make it more comfortable to get HIV testing. these were _______. How does this fit with your ideas? Can you add others?

- In talking with Aboriginal women so far, ________ seem to be common ingredients for the "ideal HIV testing experience." How do you feel about this?

    Probe
    In talking with Aboriginal women so far, I have found that most of the women want the tester to be female and Aboriginal. How does this fit with your ideas?
    Would you like the tester to ask you any personal questions about HIV risk behaviours?
    What kind of physical setting do you prefer?

- In talking with Aboriginal women thus far, "culturally appropriate" HIV counselling and testing means that all women are treated in a respectful way, but the difference for Aboriginal women is the physical setting and the ability to access Aboriginal staff (including Elders) and traditional practices.
  - What does "culturally appropriate" mean for you?
  - Is there anything else that you would add?

- We've talked about the HIV testing experience that you and other Aboriginal women have encountered, along with the ideal HIV testing experience. Just now you shared your thoughts on "culturally appropriate" HIV testing. Given what we have shared today,
  - What recommendations for improving HIV counselling and testing would you make?
  - Who should get the results of this research?

APPENDIX G

INFORMATION LETTER FOR FOCUS GROUP

Informed Consent for Focus Groups

Information Letter

Part 1

Title of Project
What does culturally appropriate HIV counselling and testing mean for Aboriginal women living in Alberta?

Supervisor:
Dr Linda Reutter, Professor, Faculty of Nursing, University of Alberta

Phone 492-5909

Investigator:
Dawn Bucharski, BScN, MSc Candidate, Centre for Health Promotion Studies, University of Alberta

Phone 449-5175

Study Purpose:
The purpose of this research is to learn what Aboriginal women think "culturally appropriate" HIV counselling and testing are. I also want to learn about the things that put Aboriginal women at risk for HIV. I want to ask you what things would make it easier or more difficult for you to go for an HIV test. I want to ask you to describe what the "best" HIV testing experience would be like. I will also ask you to consider answering a few background questions about yourself.

Study Background
I am a community health nurse working on a master's degree in health promotion. I am interested in women and HIV infection. I want to learn how to make HIV counselling and testing for Aboriginal women more respectful of Aboriginal culture. I want to talk with a group of Aboriginal women after I have spoken with individual Aboriginal women. I would like to hear what you think about some of the things that individual Aboriginal women have said. The results from this study could be used to improve HIV services for Aboriginal women.

Study Procedure

The focus group will last about two hours and will be held in a quiet and private place. We will meet at a time that works best for the group.

I will tape-record all interviews. Notes will be typed from the information on the tapes. A number will be used to identify the tape used for each group. I am the only one who will know the code for each tape. I will keep the tapes and notes from our group private. I will share the notes only with my research committee. People who take part in the focus group interviews will be asked not to talk about the information that is shared with other people. I cannot guarantee that people won't talk outside of the group.

This form will be kept locked up. I will tear up and throw away this form five years after the study is over. The tapes and notes from this study will be locked in a different place from the consents when I am not using them. I will keep the tapes and notes for seven years. The notes may be used for another study in the future. The investigator must get approval from the correct ethics review committee first.

I will share what is learned from this study at conferences, and in appropriate journals. Your name or any information that may identify you will not be used.

You will receive a small gift of $20.00 for being in this study. This is to thank you for your time and knowledge.

Study Participation

You do not have to be in this study if you do not want. If you do decide to be in this study, you may drop out at any time by telling me. You can refuse to answer any question. You will not be punished for quitting the study.

By being in this study, I do not expect any harm will come to you. Sometimes talking about your life experiences may be uncomfortable. If this happens, I will help you find the support you need.

I will need to report to Social Services if you tell me that someone under 18 years is being abused. Also, I will need to report if a person who provides care is abusing someone else. This information cannot be kept confidential. If you would like, I could ask a community health nurse to visit you about this.

Additional Contacts

If you have any concerns, you may call Dr. Helen Madill at 492-9347. She is the Graduate Program Co-ordinator at the Centre for Health Promotion Studies, University of Alberta. Dr. Madill is not part of this study. She would want to speak with you about your concerns.

__________________ __________________

Participant's Initials Researcher's Initials

APPENDIX H

FOCUS GROUP CONSENT

Focus Group Consent

Part 1

Title of Project
Aboriginal Women's Perspectives on "Culturally Appropriate" HIV Counselling and Testing

Principal Investigator
Dawn Bucharski, MSc Candidate, Centre for Health Promotion Studies, University of Alberta

Phone 449-5175

Supervisor
Dr. Linda Reutter, Professor, Faculty of Nursing, University of Alberta

Phone 492-5909

Part 2
(to be completed by the research subject)

Do you understand that you have been asked to be in a research study?	Yes	No
Have you read and received a copy of the attached Information Sheet?	Yes	No
Do you understand the benefits and risks involved in taking part in this research study?	Yes	No
Do you understand that the interview will be tape-recorded?	Yes	No
Have you had an opportunity to ask questions and discuss this study?	Yes	No
Do you understand that you are free to refuse to participate or withdraw from the study at any time? You do not have to give a reason.	Yes	No
Has the issue of confidentiality been explained to you? Do you understand who will have access to your information?	Yes	No

This study was explained to me by ______________________________.

I agree to take part in this study.

Signature of Research Participant	Date	Witness
Printed Name		Printed Name

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of Investigator	Date