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Mill, Judy E.

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# CHALLENGING LIFESTYLES: ABORIGINAL MEN AND WOMEN LIVING WITH HIV

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## ABSTRACT

The Aboriginal people of Canada are over-represented in the HIV and AIDS statistics, compared with the rest of the population. A participatory action research study was conducted in Alberta, Canada to examine the experiences of HIV-positive Aboriginal individuals in the period following diagnosis. The goals of the study were to identify factors that limited or enhanced risky behaviours, and to develop and implement an intervention to promote healthier lifestyles for Aboriginal persons living with HIV/AIDS (APHAs). Thirty-one Aboriginal men and women participated in the study. Receiving and adapting to a positive HIV diagnosis was a difficult process for most participants, and resulted in a number of potentially harmful behaviours and painful emotions. Gradually, most participants accepted the diagnosis and found ways to take better care of themselves. Nevertheless, they faced ongoing challenges, including stigma and discrimination, coping with histories of abuse, and confidentiality concerns. The intervention included the development and presentation of a skills-building workshop for individuals living with HIV, some of whom were study participants. In addition, members of the team visited several communities in Alberta to discuss the findings and the most appropriate strategies to assist individuals living with HIV to adopt healthier lifestyles.

## INTRODUCTION

HIV disease is a serious concern in the Canadian Aboriginal population (Public Health Agency of Canada [PHAC], 2005). The 3 percent of the Canadian population reporting an Aboriginal identity (Statistics Canada, 2006), represent 27.3 percent of HIV-positive test reports where ethnicity is known (PHAC, 2007). Aboriginal people living with HIV are diagnosed and initiate treatment later in the illness than their non-Aboriginal counterparts (Wood et al., 2006). In Alberta, Aboriginal people represent an increasing proportion of new HIV infections (Houston et al., 1999) and are less likely to receive therapy and to respond to treatment (Meen et al., 2004). A British Columbia study (Miller et al., 2006) found that Aboriginal youth who inject drugs were four times more likely to be HIV positive at enrolment and twice as likely to become infected during follow-up, than non-Aboriginal youth.

HIV prevention strategies have traditionally focused on the interruption of the disease prior to infection. Recently, however, the need to investigate factors that increase or limit the spread of the virus in infected individuals has been identified (Schiltz and Sandfort, 2000; Weinhardt, 2005; Wolitski et

al., 2005). Interventions with persons living with HIV to decrease the spread of infection are an important primary prevention strategy (Metsch et al., 2005) and also promote their health and well being (Wolitski et al., 2005). Despite recognition of the need for more effective strategies to prevent HIV transmission in the period following infection, there has been limited research to document the experiences of Canadian APHAs. Therefore, between 2002 and 2004, a research study was undertaken in Alberta with the following objectives: to examine the experiences of HIV positive individuals in the period following diagnosis; to identify culturally relevant HIV prevention interventions; and to design and apply an intervention to promote healthier lifestyles in Aboriginal men and women living with HIV.

## BACKGROUND

### HIV PREVENTION FOLLOWING AN HIV DIAGNOSIS

Diagnosis of a serious illness can have negative emotional and psychological outcomes, including depression (Schiltz and Sandfort, 2000). A recent American study found that adults with HIV were four times more likely to use mental health and substance abuse services than the general population (Burnam et al., 2001). Psychological problems can inhibit an individual's ability to adopt healthier lifestyles, including behaviours to limit the spread of infectious diseases to others.

The sexual behaviour of individuals, including the use of condoms and contraceptives, in the period following HIV diagnosis is not consistent, either within or among sub-groups of the general population (Schiltz and Sandfort, 2000). As many as one in three people living with HIV and AIDS will engage in unprotected intercourse after diagnosis, without disclosure of HIV status to partners (Kalichman, 2000). Researchers have reported continued sexual risk behaviours following an HIV diagnosis in homosexual men (Dodds et al., 2004), women trading sex for money or drugs, and individuals receiving highly active antiretroviral therapy (HAART) (McGowan et al., 2004). Cross-sectional research suggests that the increases in risk behaviours are associated with reduced worry about the threat of HIV (Elford et al., 2002) and with positive beliefs about the benefits of treatment (Huebner and Gerend, 2001).

### THE IMPACT OF COLONIALISM ON ABORIGINAL SEXUALITY

Sexuality in Aboriginal men and women must be viewed within the broad context of the history of marginalization and discrimination that Aboriginal

peoples have faced from government and society as a whole. The colonial legacy experienced by Canadian Aboriginal communities contributes to the economic, social, cultural, and political marginalization of Aboriginal peoples (Adelson, 2005). Marginalization contributes to serious health inequities and an increased burden of ill-health among Aboriginal peoples (Adelson, 2005; Spitzer, 2005). Poverty, one of the central features of marginalization, is associated with increased HIV transmission (Mill and Anarfi, 2002).

The operation of residential schools in Canada between the years 1863 and 1984 is one example of marginalization experienced by Aboriginal peoples (Brasfield, 2001). The overall policy of the residential school system was to reinforce a sense of cultural and spiritual alienation among Aboriginal children in order to accelerate their assimilation into Canadian society. The Aboriginal Healing Foundation (2003) found that the denial of language and subsequent loss of traditional culture led to psychological disorientation and spiritual crisis among the Aboriginal survivors of residential schools. The high levels of psychological problems facing Aboriginal people, including depression, mental health problems, and self-destructive behaviours such as suicide, are the direct result of the abuse suffered by Aboriginal people in the residential school system (Grant, 1996). Residential school experiences have directly affected the adult lives of survivors (Brasfield, 2001; Kirmayer et al., 2000) including increases in high-risk behaviours for HIV infection and subsequent lack of coping mechanisms to deal with an HIV positive diagnosis.

There is limited research on the sexual behaviour of Canadian Aboriginal peoples during the period following HIV infection; however in one qualitative study, Aboriginal women reported an increase in “self destructive” or “high risk” behaviour (Mill, 2000). Many complex and interrelated factors, such as low self-esteem and a history of sexual abuse, may increase women’s vulnerability to HIV infection, influencing their abilities to adopt “safer” health behaviours post infection (Mehrabadi et al., in press, 2007; Mill, 1997; Neron and Roffey, 2000).

## RESEARCH DESIGN

Participatory action research<sup>2</sup> (PAR), adopted by this study, is a socially and culturally adaptable framework for working with Aboriginal communities (Macaulay et al., 1999). One of its principle tenets is a concern with power

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2. Participatory action research shares many similarities with community-based research which has been advocated for use with Aboriginal communities (Burhansstipanov, Christopher, and Schumacher, 2005; Strickland, 2006) and in HIV and AIDS research studies (Harris, 2006).

and powerlessness. PAR is congruent with the principles of ownership, control, access, and possession (OCAP) (Schnarch, 2004), community-controlled collaboration (Smylie et al., 2004) and culturally appropriate methodologies (Dion Stout et al., 2001) that are foundational to research with Aboriginal communities.

Members of Kimamow Atoskanow Foundation, a community-based AIDS service organization in Alberta, worked with researchers at the University of Alberta to provide guidance for the management of the project. Prior to implementation, a Community Advisory Committee (CAC) was formed to provide advice and guidance for the project. In addition to the six members of the research team, four of whom were Aboriginal, the CAC included eight individuals and representatives from Aboriginal organizations. The CAC members were selected by the community research partners based on their knowledge of HIV in Aboriginal communities, and included an Elder and two APHAs. Ethical approval was obtained from the Health Research Ethics Board at the University of Alberta. The CAC provided guidance to the research team throughout the project to ensure the study upheld OCAP principles and was ethically sound from a community perspective.

The study was carried out in two phases. The first phase explored the experiences of HIV sero-positive individuals following diagnosis. In-depth interviewing, which conforms with traditional Aboriginal storytelling methods of sharing information (Battiste and Henderson, 2000), was the primary data collection method. Several Aboriginal community organizations and HIV clinics in Alberta recruited participants. The interviews lasted between one and three hours. Guiding questions were developed by the research team, and vetted by the CAC, to ensure that similar areas were explored with all participants. Participants were invited to tell their stories and to speak freely about their lives after receiving their HIV diagnosis. Following analysis of the participant interviews, the second phase designed, applied, and evaluated an intervention to promote healthier lifestyles for APHAs. A research coordinator assisted with project management, data collection, and analysis and an Aboriginal research assistant helped with the recruitment of participants, conduct of interviews, and data analysis.

## POPULATION AND SAMPLE

The sample was drawn from Aboriginal men and women living in Alberta. The term Aboriginal, as used in this study, included individuals who identified themselves as Métis, First Nation, or Inuit. The inclusion criteria for

the participants were: over the age of 14 years, not currently an in-patient, English speaking, and HIV sero-positive. A total of 31 individuals, 16 male and 15 female, were interviewed. The Aboriginal background of the sample represents the tribal background of Aboriginal groups in Alberta, despite the use of convenience and network sampling (Brink and Wood, 1994). Table 1 summarizes the participants' characteristics.

**Table 1. Demographic Profile of Study Participants**

Age		Location		Aboriginal Group		Time since Diagnosis		Mode of Infection	
27-36 years:	17	Northern Alberta	5	Métis	6	<1 year	2	Sharing needles	15
				Cree	18	2-3 years	7		
37-46 years:	10	Central Alberta	18	Blackfoot	5	4-5 years	8	Sexual partner	13
						6-7 years	4		
				Inuit	1	8-9 years	2	Blood transfusion	2
47-57 years:	4	Southern Alberta	8	Mohawk	1	10-11 years	4		
						13-19 years	4		

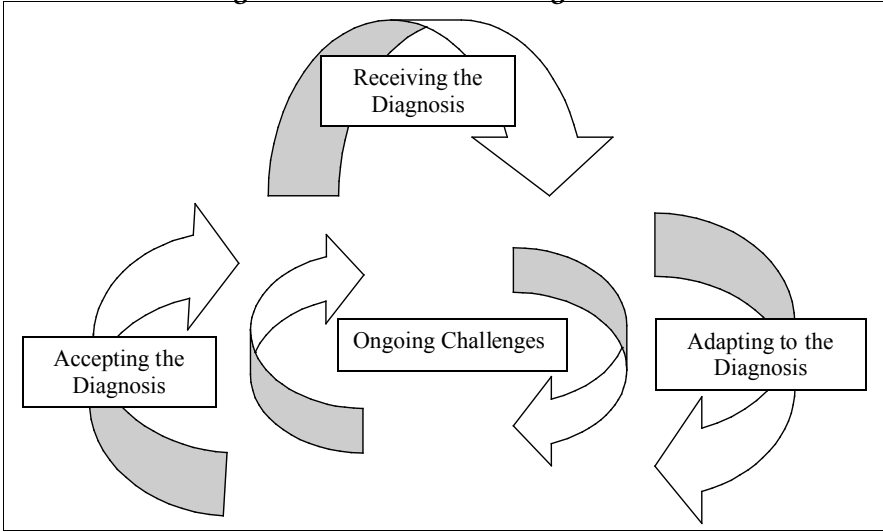
## DATA ANALYSIS

Data analysis occurred simultaneously with data collection, using techniques described by Miles and Huberman (1994). First level analysis assigned a descriptive code (label) to a segment of the data to give it meaning. As the research team became more familiar with the data, pattern coding was used to label emerging themes. The qualitative software program QSR N6 was used to assist with the labeling, revising, and retrieving of codes and memos during analysis. Members of the research team met early in the analysis to identify concepts in the interviews that were relevant to the objectives of the study and to highlight the themes emerging from the data. The identified themes provided the framework for data organization.

## FINDINGS

After receiving a diagnosis of HIV, each participant embarked on a unique journey toward acceptance. The journey is described under the following themes: receiving the diagnosis; adapting to the diagnosis; accepting the diagnosis; and ongoing challenges. Although each theme is discussed separately the adaptation process was dynamic and cyclical. Pseudonyms have been used for the participants. Figure 1 illustrates the journey that the participants experienced following their diagnosis and, consequently, the themes under which the findings are organized.

**Figure 1: The Process of Living with HIV**



## RECEIVING THE DIAGNOSIS

### WHY GET TESTED?

Participants often began the interview by describing the time surrounding their diagnosis, the process of being diagnosed, and the time immediately after their diagnosis. Many shared their feelings about, and reasons for, initiating an HIV test. Some were concerned about symptoms they were having; some just needed to know; some were concerned about their activities or their partner's activities, that they knew put them at risk for HIV infection. One woman had been tested as part of a medical examination for an insurance policy. Jake made the decision to get an HIV test because his partner was using IV drugs and sharing needles with others. Like many other study participants, Ivan's HIV diagnosis was followed by the news that he was also co-infected with Hepatitis C. Bill decided to get tested once he knew there was something he could do about it if he was positive:

I just needed to know. And one of the other motivators was that there was this new drug called AZT. Prior to that, there was no reason to be tested.... But I had actually heard that now you could intervene with something....

### RECEIVING THE DIAGNOSIS DURING PREGNANCY

Some female participants discovered they were HIV positive as a result of a pre-natal HIV screening test. There was urgency among these women to be-



gin HIV medications to prevent the transmission of the HIV virus to their unborn child. Michelle emphasized the importance of having health care providers (HCPs) follow and support women during pregnancy, especially when they are HIV positive. Admitted into hospital with pregnancy complications, a nurse wanted to induce labour in Michelle. She refused, and the health care team that had been following her provided the medical rationale she required to support her decision:

... they're not allowed to [induce labour] because the fluid will get to the baby, and the baby will take that fluid. ... I did tell her, yeah. I told her I'm positive. Just — I don't know; I guess she was probably panicking, and they didn't know what to do and that. But the public [health] nurse phoned her. ... Like, they did phone the hospital and tell them, "No, you can't do this," so she did come back in and apologized. But yeah, it was scary thinking that she was going to do this. [pause] But everything turned out for the best. I had a natural birth.

### THE ROLE OF HEALTH CARE PROVIDERS

HCPs had a major effect on the experience of participants receiving their diagnosis. About one third of the participants reported very positive treatment at the time of diagnosis. Participants mentioned that the HCP was supportive, nurturing, in tune with them, and took time to answer their questions. Bill, who had known his diagnosis for 14 years, described his relationship with his family physician; the physician let Bill take the lead in deciding when to have an HIV test and was supportive after Bill received a positive diagnosis:

So, he was really trusting and he did a lot of post-counseling. He never pushed me to be tested for HIV, but always encouraged me that, when that time came around he would be there. ... When I came in he spent a good deal of time with me. He told me as soon as I came into his office that I was HIV positive. ... He grabbed me and gave me a hug and had a cry with me at the same time. ...

About half of the participants reported negative experiences with HCPs following their diagnosis. They were questioned about their lifestyle and the source of their infection, and felt that they had not received any support or help from the HCP. Ingrid felt that the physician was not able to relate to her and provide support because he lacked any real life experience:

They put me down into the psych ward and locked me in there. They didn't tell me right away about my results ... so the doctor just came down and he said "there's no easy way to tell you this so I'm going to tell you straight out, you're HIV positive. Do you have any questions?" And that was it.

Following his diagnosis, Henry described the lack of confidentiality and professional ethics that a community AIDS support worker displayed while he was hospitalized. Mark explained his frustration with seeing different physicians and the need to disclose and discuss his HIV illness at each visit. As a patient, he viewed this as insensitive and uncompassionate.

## ADAPTING TO THE DIAGNOSIS: "IT TAKES TIME"

Despite the range of participants' social and economic backgrounds, they described common feelings and behaviours directly following their diagnosis. These included isolation from family and friends, viewing the diagnosis as a death sentence, having suicidal thoughts or behaviours, and increasing the use of drugs and alcohol. Diagnosis was sometimes followed by periods of risky behaviour and secrecy concerning their HIV status. Eventually, most of the participants were able to accept their illness and to be open about their HIV status by sharing their story with others. This period was often paralleled with better care of themselves and a desire to confront the disease and encourage friends and family to be tested.

Many of the participants felt isolated after their diagnosis or tried to isolate themselves. Henry stated that his self-imposed isolation was related to his fear of infecting others with the disease and the lack of knowledge in others about HIV transmission. Elizabeth was a 30 year old woman who had known of her diagnosis for three years. At the time of her diagnosis, her mother wanted her to come and live with her, but Elizabeth wanted to be alone.

It was common for participants to equate their HIV diagnosis with a death sentence. This belief was mixed with thoughts of suicide, increased use of drugs and alcohol, and high risk behaviour. Catherine discussed her scepticism about a nurse's suggestion that she might live a long life:

She [nurse] explained to me, she said, "This doesn't mean you're going to die in the next year." That's all I could think of at first, eh. It took me quite a while to believe her.... Because I thought, "Screw it all. If I'm going to die, I'm going to have fun while I'm at it."

About half of the participants recalled considering or attempting suicide after receiving their diagnosis. They wanted to numb the pain, to help along the inevitable, or to avoid going through what they had seen others experience. Catherine explained that she was scared to start taking HIV medications because of the side effects she had seen her friends suffer. She preferred to

have the control to take her own life, rather than allow the disease to run its course. Ingrid recalled her thoughts of suicide right after receiving her diagnosis:

Right after I found out, I wanted to die right there. I just — before my first appointment — I was sitting out in the field with a rope and I was thinking “OK, which one [tree] am I going to hang myself from?”

Many participants received support services from inner city agencies. These agencies were concerned about their clients after their diagnosis, as they would often disappear for long periods of time. During this time, participants were vulnerable, susceptible to other diseases, and in danger of inflicting further harm upon themselves and others under the influence of drugs and alcohol. Ivan described his opinion of risky behaviour on the street:

And I knew I had it. Some of the people are wondering. Sometimes I'd use protection, sometimes I wouldn't. But some of these were girls on the street and I already knew they had it, so what's the use of telling them? They already have it.

### EMOTIONS: “IT’S AN EMOTIONAL DISEASE”

About two-thirds of the participants had difficulty accepting their diagnosis and experienced a range of emotions after receiving it that included: shock, denial, depression, fear, guilt, shame, anger, loneliness, confusion, and stress. These emotions often culminated in feeling overwhelmed. Anna recalled:

That's what I'm having a hard time dealing with, too, right now. [sobs] It's an emotional disease, I think.

For some participants, the shock following diagnosis caused physical symptoms. Some described their reaction as hysteria. One man remembered feeling a sense of panic at the idea of having contracted an incurable disease. Jessica recalls the numbness she experienced:

I remember distinctly walking out of there, and all I could feel was the top of my body. I don't know how I was moving, but honest to God, I couldn't feel my legs. I felt like everybody was going slow.... I couldn't hear things; I could see their mouth moving like they were talking to each other. But just the top of my body was moving, and I couldn't feel my legs.

Most of the participants experienced some sadness or depression following their diagnosis. Some were very afraid of dying and adopted a fatalistic

approach to their life. Many gave up hope and made comments like “I’m going to die anyway, so I’m going out the way I want to.” Anna recognized the connection between her lack of motivation and her diagnosis:

Like today I was OK. But then there are some days I just lay there and think “Oh my goodness, I don’t even want to get out of bed.”... Like I said, an emotional disease. I get my ups and downs and there’s times when I think I’m giving up.

About half of the participants expressed guilt or self-hatred over their role in contracting the virus and concern that they might have infected someone else with HIV. Some participants tried to direct the blame and focus their anger.

Others mentioned the shame they associated with the disease, both for themselves and for their families. Many participants described feeling anger following their diagnosis. Some were angry that they had not protected themselves from the virus, some with judgmental or nonconfidential care from HCPs, others that they would not be able to fulfill their dreams. Christopher believed that some Aboriginal individuals were very angry about HIV disease, believing that “white” individuals introduced the virus into Aboriginal communities.

Loneliness and confusion were also common emotions. A few participants were concerned that they would be alone if there was any change in their current relationships. They worried that their HIV status would make new relationships impossible. Two male participants vividly described their sense of loss and loneliness when they realized the burden that HIV placed on their relationships with women, including their ability to father children. About half of the participants were confused or unsure where to turn for help. Catherine was a mother of eight children who worried about dying alone:

Sometimes it really scares me, though. Sometimes I’ll sit alone and I’ll cry; like, “God, what am I going to do? I’m 43 years old, and this could kill me in the next year.... What if I’m alone?” I think being alone is something that’s hard when you’re sick, and think about being alone or dying alone from this.

## ACCEPTING THE DIAGNOSIS

Most of the participants in our study had accepted their diagnosis by the time they participated in an interview, although this process had taken several years for some. They had resigned themselves to their HIV diagnosis

and were trying to get on with their lives. For example, Amy had found that talking and writing helped her deal with her problems, while Mark recalled that he had focused on the hopeful aspects of his life to help him accept his diagnosis. Some participants, who were very comfortable with their diagnosis, shared their stories within the HIV community or with their Aboriginal communities in the hope of contributing to a better future for all. Andrew recalled that being involved in the HIV community had helped him build a better life for himself:

I do as much as I can almost on a monthly basis.... I guess it's not for everybody, but I have a lot of good friends in the HIV community. Generally, being on committees and working in the HIV community helps me a lot; it helps me build a better life for myself.

A positive outcome of the HIV diagnosis was that most participants took better care of themselves as they became more aware of their health status. It was very interesting, and somewhat ironic, that many of the participants believed that their illness was a gift, had triggered positive changes in their life, or had inspired a greater purpose in their life. Participants implemented various healing strategies, such as abstaining from drugs and minimizing stress, often motivated by a desire to parent their young children for as long as possible. About half of the participants commented that returning to activities (e.g., visiting friends, talking on the phone, gardening, going out for coffee) that they had done before their diagnosis with HIV helped them feel normal. For Mark, this process interrelated with coming to terms with his HIV diagnosis.

Participants shared their perspectives on spirituality, including their views about Aboriginal traditions. Many believed that their connection to their Aboriginal spirituality had been very helpful in accepting their diagnosis. For some, the guidance from Elders in their community had been helpful. Some participants reconnected to their Aboriginal traditions, while others stated that they did not follow traditional practices and beliefs. While Christopher found that Aboriginal traditional ceremonies helped him come to terms with his diagnosis, Amy combined her Christian beliefs with Aboriginal traditions:

It's helped me a lot. I'm a very spiritual person. I'm a Roman Catholic, but — like, I pray every night, but I also believe in the old — with the sweetgrass and the sweats, I agree with it; I totally agree with all that.

Almost all of the participants mentioned the importance of a strong support system to assist HIV-infected individuals to adapt to and accept their diagnosis. Several of the participants were surprised by the amount of support that was available once they knew where to find it and were able to ask for it. Participants differed in the type of support they found comfortable. Some participants preferred individual support while others attended support groups. For the most part, the participants found it very helpful to talk with other Aboriginal men and women who were HIV positive. Most of the participants had at least one family member, such as a parent or sibling, who provided support following their diagnosis; however a few felt that their families had not provided the support they needed at the time of, and following, their diagnosis.

## ONGOING CHALLENGES

About half of the participants, both men and women, experienced physical, sexual, or emotional abuse both before and after their diagnosis with HIV. A few of the participants attributed the abuse, experienced or witnessed, to the impact of residential schools. Dealing with the effects of abuse was an ongoing challenge in the lives of participants as they adapted to their illness. After his diagnosis, Norman joined a support group for male survivors of sexual abuse:

I started going to therapy ... that's been a real big help, and there, I've been learning a lot more about myself and a lot more about a lot of things that happened to me, and why I drink so much because of the loneliness. ... 'Cause I never realized that I was still hurt from what was going on in the past. I drank all that pain away; for 10 years, I drank.

Prior to their diagnosis, almost all of the participants used drugs or alcohol; a few lived in an environment of drug abuse. For some participants, an ongoing involvement with drugs and alcohol affected their ability to parent, adding additional stress to their lives. Many participants had children and spoke about the impact of their HIV diagnosis on their relationships with their sons and daughters. Participants spoke of their love for their children and their desire to protect them from suffering; they often worried that their illness would cause undue burdens on their offspring. Parents struggled with the decision of telling their children of their diagnosis, and in some cases they decided to keep it a secret. Michelle had unknowingly passed the virus to her son during pregnancy and recalled the resulting pain and guilt:

My mom was living with me, staying with me, so I'd leave my son with her. I guess I was just trying to escape from all that because waking up to it every day and seeing my son like that it was hurting, it was hurting me.

Almost all the participants spoke about experiencing, or were worried that they might experience, discrimination due to their HIV status. A few participants related the discrimination to changes in their physical appearance. Henry provided a very poignant description of how he was treated on his reserve after his diagnosis became public:

I was pulling an oxygen tank around the reserve and people walked around me ... like I was a disease — like I was a cold or something. Something deadly. Like I was a bum or something, they'd walk right around me.... But when they see me pulling this oxygen tank around, from being a really big person going down to being a small one real fast, that will make you think. Like it would make me think if I'd seen a really healthy person, all of a sudden he's just skinny like that....

The stigma and prejudice experienced by the men and women resulted in difficulties with disclosure. Fear of negative reactions from family, friends, and the community resulted in a period of secrecy for many participants. This was sometimes felt to be necessary despite believing in positive benefits associated with being more open about the disease. One repercussion of keeping the diagnosis secret was that it limited the support available to the participant. Mark recognized the importance of support, but had not shared his diagnosis with his family. He was also not interested in sharing his diagnosis with individuals who had not shared his experiences:

... and it's hard from my perspective because I didn't tell my family, or I didn't tell anyone close to me. Why go to somebody that knows nothing about what I'm experiencing or what I'm going through? What help could they possibly be to me?

About half the participants discussed disclosing their HIV status to friends and their relationships with them following disclosure. A few participants found that relationships with friends had changed, while others still felt accepted by their friends. One male participant did not feel that he had any friends to tell because they were "all drug addicts." Catherine believed that sharing diagnosis with her friends enabled her to identify her true friends:

I found that if I told people right away, I'd find out who my real friends are.... I'd say, "Oh, by the way, I'm" — and see the reaction. And either that's a friend or it's not. Their loss, 'cause I could be a pretty good friend.

## INTERVENTION AND DISSEMINATION

As the Aboriginal participants in this study shared their journeys toward acceptance of and adaptation to a life with HIV, it became clear that their experiences were layered on individual and community histories characterized by trauma. Childhood experiences of abuse, poverty, discrimination, and violence laid the foundation for high-risk lifestyles that provided a fertile environment for HIV infection. The trauma continues, and the infection rate among Aboriginal people continues to be alarmingly high. Although the statistical data is disturbing enough, it was the participants' powerful stories that inspired us to work with Aboriginal colleagues and communities.

Following identification of the major themes in the interview data, the research team and CAC focussed on creating appropriate responses to the issues raised by participants. Consensus was reached that, due to the sensitivity in many Aboriginal communities to HIV and AIDS, the most appropriate intervention was to disseminate the findings to Aboriginal communities in Alberta. At the time of writing, presentations had been made to HCPs, community members, and leaders in eight communities. The purpose of the presentations was to discuss findings and share the research process. In addition, a pamphlet was developed to assist with the dissemination of the results and the findings were presented at several academic venues, including national and international conferences.

The involvement of APHAs was integral to the intervention. Several of the participants expressed their desire to assist the research team in sharing the findings, but lacked the necessary skills for community presentations. Therefore, the research and advisory teams developed and presented a skills-building workshop to give individuals living with HIV, some of whom were study participants, the presentation skills required to share their experiences with a range of audiences. At least one of those participants has since presented at a variety of functions and locations across the province, bringing the experience of HIV and AIDS to many communities and individuals. The development of knowledge translation strategies with Aboriginal community members is consistent with the approach recommended by Smylie and colleagues (2004).

## DISCUSSION

Findings from this study illustrate the journey that APHAs undertake following diagnosis. In another Canadian study (McKay-McNabb, 2006),



Aboriginal HIV-affected women described their experience following an HIV diagnosis as a *journey* in which they integrated acceptance, risk factors, and everyday challenges in their healing path. Some of the participants in the current study continued to engage in high-risk behaviours, including the use of drugs and alcohol, to help them cope following their diagnosis. Following a meta-analysis, Weinhardt (2005) concluded that the first year after HIV diagnosis is a critical period of higher levels of risk behaviour. Recognizing the multiple traumas with which HIV positive individuals are often dealing, high-risk behaviours can be seen as survival techniques (Mill, 1997). This perspective shifts the dialogue away from individual "risk behaviour" to the broader concept of "risk environment" (Mill and Anarfi, 2002; Rhodes et al., 2005), and acknowledges the broad social, political, and economic determinants of HIV risk. Following an extensive review of the social and structural factors that shape HIV risk among IV drug users, Rhodes and colleagues (2005:1026) argued that "HIV risk environment is a product of interplay in which social and structural factors intermingle but where political-economic factors may play a dominant role." They concluded that social structural change is critical to globally addressing the AIDS pandemic.

Findings from the current study demonstrate the critical need for support for Aboriginal individuals receiving a diagnosis of HIV. Ongoing support from peers who are Aboriginal and HIV positive is a key element in the acceptance of an HIV positive diagnosis (Kang et al., 2005; McKay-McNabb, 2006). This support must be available in different forms (e.g., individual, group) for clients in different stages of readiness to acknowledge and deal with their diagnosis. HCPs must be aware of the wide range of places and people where newly diagnosed clients can find support.

AIDS stigma and discrimination was problematic for APHAs in the current study, and has been documented in several recent studies (Carr and Gramling, 2004; Kang et al., 2005; Mwinituo and Mill, 2006). Stigma and discrimination negatively affect access to health care generally (Link and Phelan, 2006), and mental health care specifically (Reece, 2003). Most of the participants living with HIV in a recent Canadian study (Mill et al., 2007) experienced a layering or double burden of stigma that varied depending on the social and environmental context in which health care was provided. HCPs must be sensitive to AIDS stigma and work to develop interventions to decrease or eliminate it.

The development of culturally sensitive approaches to health care has been advocated (Majumdar et al., 2004), including training for HCPs to

ensure that their care demonstrates cultural humility (Juarez et al., 2006; Tervalon and Murray-Garcia, 1998). Based on the current findings, we urge researchers and practitioners involved in HIV prevention and care activities with Aboriginal communities to move beyond the concept of culturally sensitive care to the more comprehensive approach of *cultural safety* (Kirkham et al., 2002; Smye and Browne, 2002). Cultural safety examines the broad social, political, historical, and power-related factors that influence HIV infection and reveals traditional beliefs about the meaning of health and illness (Browne and Varcoe, 2006; Dion Stout and Downey, 2006). For example, the integration of traditional healers and Elders into prevention and treatment services for HIV positive Aboriginal individuals may ensure culturally safe care. While Aboriginal peoples are diverse in their perspectives on health, a culturally safe approach might include a holistic view of health that respects traditional views of illness and maintains the balance between the physical, spiritual, emotional, and mental aspects of health.

Metsch and colleagues (2005) provide a comprehensive analysis of preventive interventions with HIV positive individuals in community settings. They highlight the paucity of published, tested, and effective interventions designed for HIV positive persons. Barriers to implementing prevention with persons living with HIV include: recruitment and retention of persons with AIDS (PHAs), e.g., due to stigma and discrimination; inadequate resources; lack of effective interventions; and limited integration between care and treatment. The key facilitators for effective prevention interventions with PHAs include: bringing PHAs into all aspects of the intervention work; strong linkages with care settings; collaboration with other community-based organizations; and adopting a harm reduction approach. Our experience of successfully integrating APHAs in the current study, and our findings related to the experiences of the participants, fully endorse the importance of these facilitators.

HIV prevention interventions must acknowledge the challenging lifestyles that Aboriginal people often experience, and integrate strategies to address their root causes. For example, a few participants attributed their ongoing challenges to the impact of residential schools. A recent study of male survivors of residential schools (Aboriginal Healing Foundation, 2003) found that 100 percent had experienced sexual abuse, 90 percent physical abuse, and the majority suffered from mental health problems including post-traumatic stress disorders, substance abuse disorder, and major depression.

A comprehensive (Wolitski et al., 2005) or multiple intervention program approach (Edwards et al., 2004) is required for the design of interventions to

reduce the spread of HIV in persons living with HIV. Multiple intervention programs target multiple levels (e.g., individual, community, political) and multiple sectors of a system through a variety of channels (Edwards et al., 2004). Metsch and colleagues (2005) recommend an intensive, case management approach with HIV-positive persons to ensure that their multiple medical, social, and economic needs are met. The importance of considering the context of sexual risk, including relationship dynamics, gender, and power in the design of interventions for HIV-positive individuals was highlighted following a study with injection drug users (Knight et al., 2005).

## CONCLUSION

Many factors influence the experience of HIV and AIDS within the Canadian Aboriginal population. Despite stigma, discrimination, minimal support structures, and other social, behavioural, and physical challenges, the 31 participants in the study negotiated their way through the process of coming to terms with HIV illness and its implications. HCPs may wish to assess their level of tolerance, acceptance, compassion, support, and confidentiality in order to provide culturally safe, holistic care for Aboriginal individuals and communities. Sensitivity to the challenging journey that many APHAs may travel before, during, and following their diagnosis is essential to the development of effective, culturally appropriate interventions.

Since this study was conducted with a small sample of participants in the province of Alberta, further research is needed amongst communities in other jurisdictions. This would enable exploration of more efficient strategies for enhancing the health of communities and reducing the spread of disease. Additional interventions, developed collaboratively by Aboriginal communities and HCPs, must be evaluated for their ability to address relevant health issues in a manner that promotes self-determination and well-being. Such research will contribute to the uptake and utilization of new knowledge by HCPs and consumers.

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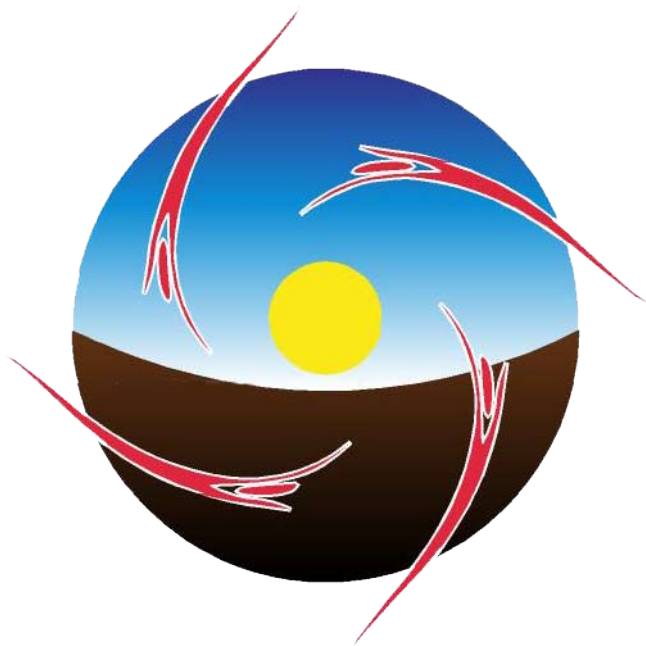
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