### OUR SEARCH FOR SAFE SPACES:

# A QUALITATIVE STUDY OF THE ROLE OF SEXUAL VIOLENCE IN THE LIVES OF ABORIGINAL WOMEN LIVING WITH HIV/AIDS



## THE CANADIAN ABORIGINAL AIDS NETWORK (CAAN)

#### **OVERVIEW**

Established in 1997, the Canadian Aboriginal AIDS Network (CAAN) is a national, not-for-profit organization representing more than 400 member organizations and individuals. Governed by a national 13-member Board of Directors and a four-member Executive, the Network provides a national forum for members to express needs and concerns. It advocates for access to HIV/AIDS information on behalf of its members and the public and provides relevant, accurate and up-to-date HIV/AIDS information.

#### MISSION STATEMENT

As a key national voice of a collection of individuals, organizations and provincial/territorial associations, CAAN provides leadership, support and advocacy for Aboriginal people living with and affected by Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome (HIV/AIDS). CAAN faces the challenges created by HIV/AIDS in a spirit of wholeness and healing that promotes empowerment and inclusion, and honours the cultural traditions, uniqueness and diversity of all First Nations, Inuit and Métis people, regardless of where they reside.

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MONTREAL: Native Friendship Centre of Montreal; Stella; Centre des Femmes; Centre for AIDS Services of Montreal; Native Women's Shelter of Montreal; Chez Doris

OTTAWA: Wabano Centre for Aboriginal Health; Minawashin Lodge — Aboriginal Women's Support Centre; AIDS Committee of Ottawa — The Living Room; Bruce House; Pauktuutit Inuit Women of Canada; University of Ottawa HIV clinic; OASIS; Pink Triangle Services; Shawenjeagamik (House of Compassion) Aboriginal Drop-In Centre (510 Rideau)



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Dr. Gail Valaskakis was an original member of the research team, and unfortunately passed into the spirit world shortly after the study began. Her guidance and strength was missed over the course of this project.

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## EXECUTIVE SUMMARY

#### INTRODUCTION

Aboriginal women are continuing to be over-represented among new HIV cases in Canada. Although Aboriginal people represent just 3.8% of the Canadian population, in 2005, estimates indicated Aboriginal people were about 7.5% of all prevalent HIV infections. Since 2004, at least 50% of newly reported HIV infections identified as Aboriginal are women and girls (PHAC 2007; Mehrabadi et al. 2008).

The alarmingly high levels of HIV infection reported among Aboriginal women are believed to be the result of entrenched marginalization and discrimination within Canadian society, the ongoing legacy of colonialism and oppression. Complex, interwoven factors of gender, class, and ethno-culture, both systemic and particular, have increased exposure to HIV among Aboriginal women. One of the most pervasive and damaging outcomes of these factors is the widespread occurrence of sexual violence and exploitation of Aboriginal women and girls. Research has shown that sexual violence and HIV/AIDS are deeply interrelated and often reinforcing. Yet very little is known about the relationship between sexual violence and HIV/AIDS in the context of Aboriginal women's gender and cultural identity.

CAAN members called on the organization to turn its research attention to the issue of sexual violence against Aboriginal women living with HIV/AIDS (AWHAs). The Network held focus groups with AWHAs in three Canadian cities, where women confirmed that sexual violence had profound effects on their health and well being and that the issue was deeply related to their ability to manage their HIV illness. In response, CAAN developed a qualitative, community-based research study, using the research principles of Ownership, Access, Control and Possession (OCAP). The study was designed to give a voice to AWHAs in the academic literature, as well as to better understand the interplay between such factors as gender, culture, HIV and sexual violence. The results are presented below.

#### **METHODOLOGY**

This was a qualitative study that employed a grounded theory approach. The study explored issues of sexual violence and HIV/AIDS among Aboriginal women. By examining the 'lived experiences' of AWHAs through in-depth, semi-structured interviews, the study sought to shed light on how AWHAs relate sexual violence to their HIV infection, their current social realities, and their past life experiences and how, if at all, these experiences influence their health management.

The objectives of this study were:

- To explore the ways in which AWHAs understand and cope with experiences of sexual violence in their personal lives and in the context of Aboriginal culture.
- To gain a better understanding of the interplay between sexual violence and culture.
- To identify the distinctive features of the female Aboriginal experience of sexual violence and HIV infection.

To achieve these objectives, field researchers interviewed 20 AWHAs about their experiences with sexual violence and HIV/AIDS and about their thoughts on the relationship between the two. Participants were asked to discuss the unique challenges they faced as AWHAs when seeking services and the role, if any, that culture played in their health management. Lastly, participants were asked to provide recommendations on how the services they receive could be improved to better meet their unique needs in the context of gender, culture and HIV.

This study followed the research model known as OCAP, wherein the principles of ownership, access, control and possession provide a framework that brings self-determination into the research process, enabling Aboriginal peoples to assert their authority over research that concerns their communities. In accordance with OCAP principles, the research team included community-based collaborators and members of the AWHAs community, as well as Aboriginal scholars. Community representatives and members of the AWHAs community were involved in every stage of the research process.

#### **EXPOSURE TO VIOLENCE**

The Aboriginal women who participated in this study experienced many forms of trauma, which often began in childhood. Similarly, the sexual violence experienced by participants occurred in a general climate of violence against Aboriginal women and girls. Many of the participants were exposed to violence through childhood experiences of physical, sexual and emotional abuse, neglect, parental drug and alcohol use, the legacy of residential schools and the foster care system. Exposure to violence was also rooted in social determinants, including racist sexism, disadvantaged socio-economic conditions, punitive social services, and lack of access to opportunities and support. Gender inequities emerging from power disparities, emotional connection to abusers and fear of men played a role in these AWHAs' heightened exposure to violence. Lastly, participants revealed that sexual violence contributes to damaged self esteem, internalized blame, negative body image, suicidal thoughts and attempts, lack of self care, anger/resentment/sense of betrayal, and addictions/involvement in the sex trade.

#### VIOLENCE-RELATED EXPOSURE TO HIV

Many of the same factors — gender inequities, social determinants, self concept and childhood experiences — that exposed Aboriginal women to violence also exposed them to HIV. Participants identified a variety of pathways and connections linking their HIV/AIDS status with their multiple experiences of trauma. The links were both direct and indirect. Some women acquired HIV directly when they were raped or knowingly infected by their abusive intimate partners. AWHAs also described many indirect relationships between their traumatic experiences and their HIV infection. Participants said traumatic experiences impacted their mental health, resulting in addictions, involvement in the sex trade and an inability to set sexual boundaries or to negotiate safer sex with men. Such responses to trauma create exposure to HIV, and in many cases, led to HIV infection for the women who participated in this study.

#### HIV-RELATED EXPOSURE TO VIOLENCE

For many of the AWHAs who participated in this study violence and HIV went hand-in-hand. Not only did violence expose women to HIV infection, but being HIV positive also exposed women to many different forms of violence. Some of the participants in this study described being threatened with legal action, stalked, intimidated, robbed and physically abused because of their HIV status. Some were targeted for sexual violence while attempting to access harm reduction resources. Some participants also described being blamed for bringing HIV into their intimate relationships, or were branded as sexually promiscuous by their partners. The HIV-related violence experienced by these women was reported to have significant effects on their ability to effectively manage their HIV illness and overall health.

#### RACISM, SEXISM AND HIV/AIDS: AWHAS' EXPERIENCES OF HEALTH SERVICES

Many of the participants in this study believed their gender and cultural identity, as well as their HIV status, affected how they were treated by service providers. Several participants experienced gender-based, cultural stereotyping in health care and social services settings. People who provided welfare or housing support perceived Aboriginal women as prostitutes, junkies and/or as sexually promiscuous. AWHAs also reported experiences of stigma and discrimination in health care settings. For AWHAs who participated in the study stigmatization of their HIV was often intertwined with discriminatory attitudes surrounding their gender and cultural identity as Aboriginal women.

Based on these findings, society's treatment of AWHAs creates a form of 'triple jeopardy' that contributes to their continued social marginalization and isolation. This triple jeopardy can also create significant challenges to AWHAs' ability to mange their HIV illness, as well as to access support for sexual trauma. Furthermore, these inter-related categories of prejudice based on race, sex and HIV status substantially undermine the quality of health services that AWHAs do receive.

#### AWHAS' UNDERSTANDING OF HEALTH AND HEALING

AWHAs who participated in this study reported engaging in diverse, holistic practices and strategies to manage their health. Participants identified a range of activities (Aboriginal health centres, healing ceremonies, powwows, gatherings, church and prayer, smudging, faith in the Creator, Elders and spiritual leaders, activism, western style counselling for HIV/AIDS, counselling for violence against women, writing, reading, going to the gym, special diet, etc.) as helpful for managing their HIV illness and dealing with the impacts of sexual trauma. The majority of AWHAs who participated in this study interpreted 'health services' as involving more than strictly physical or medical health needs. Many of the participants described holistic visions of health and healing, which included aspects of spiritual, physical, mental and emotional health that they felt to be unresolved in their lives. Participants also reported involvement in a variety of community awareness raising initiatives that could provide a source of empowerment and healing. Despite the resiliency demonstrated by these AWHAs in their healing efforts, the structural inequities responsible for their exposure to violence and HIV continue to make managing health and wellness a daily struggle.

#### DISCUSSION

When this study was originally planned, very little had been written about the relationship between sexual violence and HIV/AIDS specifically among Aboriginal women. This study describes the pathways through which experiences of childhood abuse can lead to future violence in the lives of Aboriginal women with HIV/AIDS and how multifaceted and interwoven these two areas are. The discussion summarizes the links between childhood experiences, social determinants, gender inequalities, self concept and literature to contribute to a deeper understanding of the research findings. We honour the trust that the study participants showed in revealing a very private aspect of their lives so that others may learn from these experiences. To develop successful programs and policies, we must attempt to understand this complex web of determinants.

#### CONCLUSION

Aboriginal women living with HIV are among the most vulnerable individuals in Canadian society. Yet, the violence perpetrated against them seemingly goes unchallenged and therefore, unabated. The sexual violence experienced by the AWHAs who participated in this study occurred in a general climate of violence against Aboriginal women, which often begins with exposure to violence in childhood. Furthermore, violence against Aboriginal women and girls is deeply related to the ongoing legacy of colonization, including the experience of residential schools. We found that the relationship between HIV and sexual violence compounds exposure to both. Culture, gender identity and HIV status combine to create a triple-jeopardy leading to the social marginalization and isolation of AWHAs within Canadian society.

Our research was designed to be action-oriented — to inform policy and programming, leadership and community members about how to improve the situation for AWHAs. This report highlights some of the many actions that could better meet the unique gender and cultural needs of AWHAs who have experienced violence. Above all, we hope that the findings presented in this report have illustrated the urgency of the issue and will inspire and assist in efforts to end violence against Aboriginal women and girls.



## **ACRONYMS**

#### ASO

AIDS Service Organization

#### AASO

Aboriginal AIDS Service Organization

#### AIDS

Acquired Immune Deficiency Syndrome

#### APHA

Aboriginal Person Living with HIV or AIDS

#### AWHA

Aboriginal Woman Living with HIV or AIDS

#### CAAN

The Canadian Aboriginal AIDS Network

#### CIHR

Canadian Institutes for Health Research

#### **GBV**

Gender-based violence

#### HIV

Human Immunodeficiency Virus

#### IDU

Intravenous Drug Use

#### PHA

Person Living with HIV or AIDS

#### PHAC

Public Health Agency of Canada

#### VAW

Violence against women



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## PREFACE

#### SEXUAL VIOLENCE, HIV AND ABORIGINAL WOMEN

It is important to note that qualitative research such as this is generally aimed at exploring an issue about which relatively little is known or about a population that has been under researched in a particular area. It was not our intention, nor is it possible, to generalize the results of this study to all Aboriginal women living with HIV/AIDS. The following discussion therefore applies only to the 20 Aboriginal women who came forward to participate in this study.

## THE CONTEXT OF SEXUAL VIOLENCE AGAINST ABORIGINAL WOMEN AND GIRLS

To fully understand the extent and impact of sexual violence suffered by Aboriginal women and girls it is critical to situate this issue in the context of a pervasive environment of historical, social and interpersonal violence in general. Sexual violence often occurs in a general climate of violence against Aboriginal women, including childhood physical and emotional abuse, as well as neglect, which is not always thought of as a form of violence.

Understanding how the general climate of violence against Aboriginal women and girls increases an individual's exposure to future violence is a critical first step in addressing the experience and impact of sexual violence against Aboriginal women with HIV/AIDS.

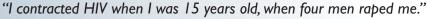
Extensive evidence has shown that life traumas, particularly those experienced during childhood, affect the physical, emotional, mental and spiritual health of individuals. It is also clear that traumas are not experienced as isolated incidents; later traumas compound earlier ones, creating a cumulative effect. In the case of Aboriginal women, those who experience various forms of trauma throughout life become increasingly vulnerable to the detrimental impact of each trauma.

The issue of violence, including sexual violence, against Aboriginal women is by no means a new one. In fact, media and research reports dating back to the 1980s have documented many forms of violence perpetrated against this most vulnerable group. The conspicuous lack of a strategic response by federal, provincial, territorial or Aboriginal leadership to this reality creates further trauma to women and girls, not only because the violence continues unabated, but also because societal disregard sends a clear message about the status of Aboriginal women in Canadian and Aboriginal society.

#### **EXPERIENCES OF SEXUAL ASSAULT**

As community-based Aboriginal HIV researchers concerned with protecting Aboriginal women from being exploited or depicted in an undignified way, we struggled with whether to include quotes related to sexual and other forms of violence. After much deliberation, we decided that it is necessary to provide the reader with a 'snap shot' of the violence being experienced by a sample of Aboriginal women with HIV. This exposé is not intended to be voyeuristic, but rather to sensitize readers to the devastating trauma that shapes the lives of a great number of Aboriginal women and ultimately increases their exposure to HIV/AIDS.

"I got abused by my neighbour. He started fondling me and touching me, but he never penetrated me. And then my brother-in-law does it to me. It just seemed like it was after what... after the priest started...it just seemed everybody kinda knew I was open target. And then my brother-in-law did it to me. And then when I got married, my old man used to beat me up if I didn't let him. I didn't feel good, so he used to force himself on me. So it ended up being such a [emotional]..."



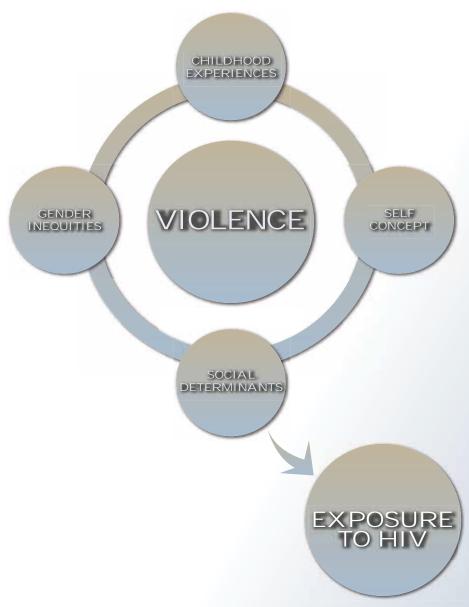
"[I was] being raped from age I3 to 24, the same person was raping me and raping me, the same married man." "I'm not interested in sex. And then he tries to like, if I say no I don't want to. Like, once in a while he'll - he'll be in the mood and he'll try and force himself on me and I just totally freak. Like it brings back the flashbacks..."

The above quotes demonstrate the cumulative and lasting effects that repeated experiences of sexual trauma may have on Aboriginal women's ability to set sexual boundaries, develop healthy relationships and ultimately navigate exposure to HIV.

#### UNDERSTANDING EXPOSURE TO VIOLENCE AND HIV/AIDS

Throughout this report, we suggest that the contexts of these Aboriginal women's lives have increased their exposure to various forms of violence, which in turn have led to exposure to HIV.

The first section of the report has been organized around major themes that emerged from individual interviews conducted with Aboriginal women who are living with HIV and who have experienced sexual violence. According to the experiences of the women who participated in this study, there are several personal, relational, gendered and social circumstances that influence Aboriginal women's exposure to numerous forms of violence, including sexual violence. These conditions include childhood experiences, social determinants and gender inequities, which create direct and indirect exposure to HIV. The model below was developed from these themes to provide structure to our discussion of the findings.



## EXPOSURE TO VIOLENCE & HIV/AIDS MODEL

#### INTRODUCTION

In recent years, the face of the HIV/AIDS epidemic in Canada has changed significantly. What was once a disease concentrated among men who have sex with men is now increasingly an epidemic among women. Aboriginal women are experiencing a disproportionate burden of new infections in this country (Shannon et al. 2008: 912). According to the Public Health Agency of Canada (PHAC) (2007), Aboriginal women represented 48.1% of all positive HIV test reports among Aboriginal people between 1998 and 2006. Although Aboriginal people represent just 3.8% of the Canadian population, in 2005, estimates indicated Aboriginal people were about 7.5% of all prevalent HIV infections (PHAC 2007; Mehrabadi et al. 2008).

The alarmingly high levels of HIV infection reported among Aboriginal women are believed to be the result of entrenched marginalization and discrimination within Canadian society, the ongoing legacy of colonialism and oppression. Complex, interwoven factors of gender, class, and ethno-culture, both systemic and particular, have increased exposure to HIV among Aboriginal women. One of the most pervasive and damaging outcomes of these factors is the widespread occurrence of sexual violence and exploitation of Aboriginal women and girls. Research has shown that sexual violence and HIV/AIDS are deeply interrelated and often reinforcing. Yet very little is known about the relationship between sexual violence and HIV/AIDS in the context of Aboriginal women's gender and cultural identity.

Aboriginal women living with HIV/AIDS (AWHAs) called on CAAN to address this challenge. Focus groups, held with AWHAs in Vancouver, Regina and Montreal, confirmed that the experience of sexual violence was indeed an urgent health concern deeply affecting their mental, emotional, physical and spiritual health. A thorough review of the literature yielded very limited research on the connections between HIV/AIDS and sexual violence in the context of gender, culture and the impact of colonization on Aboriginal peoples. In response, CAAN designed a community-based, participatory action research project built on the research model known as OCAP (based on the principles of Ownership, Control, Access and Possession) to examine the impacts of and relationship between sexual violence and HIV/AIDS from an Indigenous perspective. A partnership of community organizations, women's groups and academic and community investigators worked together to ensure that the study design and analysis were informed by an understanding of gender and culture issues.

This qualitative study explores the impact of sexual violence in the lives of AWHAs. By examining the lived experiences of 20 AWHAs, this study aimed to shed light on how AWHAs relate the impact of sexual violence to their HIV infection, their current social realities and their past life experiences and how these experiences influence their overall health management. The study also sought to give a voice to Aboriginal women who are often silenced in HIV/AIDS research and academic discourse and to develop policy and program recommendations that reflect the specific gender and cultural needs of AWHAs.

The following sections provide background and a rationale for the study by reviewing the available literature addressing the connections between colonialism and historical trauma, gender, sexual violence and HIV/ AIDS as they relate to Aboriginal women. There are sections describing our research methods, ethical review process and sample population. Research findings, analysis and recommendations complete the report.



## LITERATURE REVIEW: SEXUAL VIOLENCE, HIV/AIDS & ABORIGINAL WOMEN

Understanding Aboriginal women's current increased exposure to both sexual violence and HIV/AIDS necessitates an analysis of the impacts of colonization on gender relations and the status of women among Aboriginal Peoples in Canadian society. The over-representation of Aboriginal people in Canada's HIV/AIDS epidemic is believed to be both directly and indirectly linked to the effects of colonization, particularly the Indian Residential School System, on Aboriginal cultures and communities (Barlow 2003). It is further argued that the devaluing of Aboriginal women's status within their Nations, communities and families has bred social inequities and ultimately violence against women and girls (Ship & Norton 1999). The following section reviews some of the available literature on the relationships between colonization, gender, HIV/AIDS and sexual trauma.

#### COLONIZATION AND GENDER INEQUALITY

It is widely agreed that the gender role of Aboriginal women shifted dramatically as a result of the imposition of Eurocentric governance systems and social values (Mehrabadi et al. 2008; NWAC 2007; Mann 2005; Neron & Roffey 2000; LaRocque 1994; Chester et al. 1994; Maracle 1993). Many Indigenous and allied scholars contend that most, if not all, Indigenous cultures were once matriarchal or semi-matriarchal in their social structure (NWAC 2007; Brunen 2000; LaRocque 1994; Turpel 1993). Within these societies, women held unique roles and responsibilities vis-à-vis their Nations and their Creator. They were considered the givers of life and the keepers of the fire, meaning that they were responsible for passing on cultural knowledge and traditions. Women were seen as sacred human beings and were protected by the men of their communities. Although much diversity existed between populations, there was a prevailing trend of honour, respect and value afforded to Aboriginal women (NWAC 2007). It has further been argued that, prior to colonization, Aboriginal women held influential positions of authority and were substantially involved in the political, social and economic governance of their Peoples (ibid. 2007).

European culture had a very different view of women's role within society; women were considered men's subordinates and personal property. According to the Native Women's Association of Canada (2002), European patriarchal values and notions of gender and sexuality were forced upon Aboriginal peoples through processes aimed at assimilation, conversion and cultural genocide. The colonization process replaced Aboriginal values, which fostered the sacredness of sexuality, with European notions of women as sexually passive and submissive to men's sexual desires. In the short term, this ideology left Aboriginal women vulnerable to sexual exploitation by both European and Aboriginal men. The long-term outcome of this form of misogyny is that many Aboriginal men and women have internalized Eurocentric notions of the gender role of women, effectively displacing Aboriginal women and dispossessing them of their traditional positions of honour and authority (Fiske & George 2006).

#### RESIDENTIAL SCHOOLS

The Indian Residential School System was perhaps the most damaging element of colonial rule for Aboriginal peoples. The residential school system officially operated in Canada between 1892 and 1969, with the central goal of assimilating all Aboriginal peoples (AHF 2001). Generations of children were separated from their families, communities, cultures and languages and placed in boarding schools, where many suffered mental, emotional, physical and sexual abuse (Jacobs & Williams 2008). It has been argued that sexual abuse in Aboriginal communities was relatively rare or did not exist prior to colonization (Fournier & Crey 1997; Hylton 2002).

Jacobs and Williams (2008) describe the unique and damaging effects of the residential school system on Aboriginal women and their children. According to these authors, "Aboriginal women whose children and grandchildren attended residential schools were deprived of their traditional roles as mothers, grandmothers, caregivers, nurturers, teachers and family decision-makers" (ibid. 2008: 127). Moreover, the young girls who attended these schools were robbed of the opportunity to be loved by and to learn from their mothers and grandmothers and of the opportunity to acquire positive parenting skills. The result was a significant loss of culture and a corresponding devaluation of Aboriginal women within their communities.

Although the residential school system has been officially abandoned, its legacy lives on in what has been described in the literature as intergenerational or historical trauma (Barlow 2003; Pearce et al. 2008; Mann 2005). "Students who attended residential schools often brought back to their communities what they had learned about control and abuse and inflicted this upon their own children" (Chester et al. 1994). As the survivors raise their children and grandchildren, this trauma is passed on through generations. Mann (2005) describes this as a cycle of violence, where survivors become perpetrators. This intergenerational trauma has led to a host of social problems within Aboriginal communities, including the neglect of children, substance use, violence and sexual abuse (Pearce et al. 2008).

#### COLONIZATION AND HIV/AIDS

Aboriginal and non-Aboriginal scholars agree that the HIV epidemic among Aboriginal peoples in North America is fundamentally linked to the cumulative impact of colonization and the residential school system (Barlow 2003; Duran et al 2000; Vernon 2001; Pearce et al. 2008). The colonial agenda to devalue Aboriginal Peoples as uncivilized and in need of salvation was used to justify seizing land, imposing European governance and removing children from their families and communities to 'educate' them.

Colonial policies such as the reserve system have resulted in over-crowded and inadequate housing, as well as corresponding social and economic isolation of Aboriginal peoples. These policies have also led to increased exposure to HIV among Aboriginal people by reducing access to health and education resources (Barlow 2003; PHAC 2007). Although the mechanisms have not been fully explored, the impacts of colonization on women's gender roles, including the suppression of women's sexuality and the increased exposure to gender-based violence, are likely having profound effects on Aboriginal women's exposure to HIV (NWAC 2007).

Unresolved physical, sexual and vicarious trauma associated with the residential school experience and legacy has led many Survivors and their children to adopt negative coping behaviours, such as substance use and/or high risk sexual activities, which increase exposure to HIV (Mehrabadi et al. 2008; Pearce et al. 2008). Furthermore, damage to Indigenous cultural identities, including loss of language, tradition and family connection, have resulted in negative mental health outcomes, which may also increase exposure to HIV for Survivors and their families (Barlow 2003).

#### VIOLENCE AGAINST ABORIGINAL WOMEN AND GIRLS

In practice, violence against women and girls occurs on a continuum and includes emotional, physical and sexual violence; this tends to blur the lines that differentiate sexual violence from other forms of violence. This review therefore includes literature concerning all forms of violence, with specific focus on sexual violence against Aboriginal women and girls. According to the World Health Organization (2009: I), violence against women (VAW) is defined as

Any act of gender-based violence (GBV) that results in, or is likely to result in, physical, sexual or mental harm or suffering to women, including threats of such acts, coercion or arbitrary deprivation of liberty, whether occurring in public or in private life.

The term Aboriginal is sometimes contested, with some women preferring to be identified as First

Nations, Métis or Inuit, while others prefer the terms Aboriginal or Indigenous. There is a tendency among researchers and others to conflate diverse Indigenous groups living in Canada into the generalized category of 'Aboriginal' (Castellano 2004). However, there are significant differences in the lived experiences of women between and within these populations that must be acknowledged. Current research and surveillance efforts concerning VAW have tended not to report data using the categories of First Nations, Métis and Inuit; it is therefore difficult to assess cultural distinctions in Aboriginal women's experiences of sexual violence.

Nevertheless, all groups of Aboriginal women in Canada experience pervasive and disproportionate levels of emotional, physical and sexual violence relative to their non-Aboriginal counterparts. Aboriginal women are reported to be three times more likely than non-Aboriginal women to experience some form of violence at the hands of their partners and are eight times more likely to be killed by their partners after separation (Statistics Canada 2006). Results from the Nunavik Inuit Health Survey (2004) indicate that one in two women experienced sexual abuse or attempted sexual abuse in childhood and one in four women experience sexual violence in their adult lives. Statistics on sexual violence against women in the territories report rates from 3 to 14 times higher than the national average, with Aboriginal women being twice as likely as non-Aboriginal women to be sexually assaulted by their intimate partner (Statistics Canada 2006).

The exposure of Aboriginal children to sexual abuse and exploitation is also a major concern. While both male and female children are affected, national statistics suggest that girls are twice as likely as boys to be exposed to sexual abuse in childhood (Badgley 1988; Trocmé & Wolfe 2001). It has been reported that "up to 75% of survivors of sexual assaults in Aboriginal communities are young women under 18 years of age, 50% of those are under 14, and almost 25% are younger than 7 (METREC 2001)." According to Pauktuutit (1991), the incidence of child sexual abuse in some Inuit communities may be as high as 80%.

Not only are Aboriginal women more likely to experience violence, but they also report more serious and life-threatening forms of violence. In the 1999 and 2004 Canadian General Social Survey (GSS) Aboriginal women reported being choked or beaten, threatened with a gun or knife or having been sexually assaulted (Statistics Canada 2006). Aboriginal women also report more serious health consequences resulting from violence, such as "having suffered physical injury, received medical attention, taken time off daily activities as a consequence of the assaults, experienced 10 or more separate episodes of violence from the same perpetrator, and were more likely to feel their lives were in danger" than non-Aboriginal women living in Canada (Statistics Canada 2006: 65). McEvoy and Daniluk (1995) argue that the response to the numerous incidents of violence experienced by many Aboriginal women should be understood in terms of post-traumatic stress disorder (PTSD)<sup>1</sup>.

Aboriginal women are more than twice as likely as non-Aboriginal women to be sexually assaulted by a stranger (Cohen & MacLean 2004). Non-spousal violence is also more common among Aboriginal women and they are more likely to report assault by an acquaintance or other non-intimate person. Rates of stalking are also reported to be twice as high for Aboriginal women as among non-Aboriginal women (Statistics Canada 2006).

The actual level of violence committed against Aboriginal women in Canada has likely been underestimated, given the biases and restrictions in current data collection methods. For example, the 2004 GSS was conducted by telephone in French and English and consequently excluded Aboriginal women living in remote areas without access to telephones, as well as women who are comfortable communicating only in their Indigenous language (Statistics Canada 2006). It has also been suggested that cultural norms among some Aboriginal peoples may prevent women from disclosing personal information to an interviewer (ibid. 2006).

Violence against Aboriginal women and girls represents one of the most fundamental transgressions of women's rights in Canada. In fact, many researchers have attributed the higher levels of non-spousal violence against Aboriginal women to systemic racism and sexism (Amnesty International 2004; NWAC 2007; Mann 2005; Harper 2006). The perception of Aboriginal women as easy targets and as 'disposable' people — a view reinforced by socio-economic marginalization and sexist, discriminatory policing — has been linked to the increased risk of violence in and around urban centres (Mann 2005). The crisis was recognized by Amnesty International in its landmark publication Stolen Sisters: Discrimination and violence against Indigenous women in Canada (2004). The report sparked both a national and international outcry against Canada's treatment of Indigenous women. That 500 Aboriginal women might be missing or murdered without a proper police investigation or official inquiry into their disappearance suggests there is systemic discrimination against Aboriginal women (ibid. 2004).

Several factors contribute to the heightened exposure of Aboriginal women to violence. Violence in Aboriginal communities has been linked to economic and social deprivation, a younger population, a greater likelihood of living in common law relationships, substance use and emotional abuse (Brownridge 2003). The overrepresentation of Aboriginal women in the street-level sex trade is also considered to be a risk factor, given the pervasive levels of violence experienced by this population (Mehrabadi et al. 2007). As previously discussed, other research has linked violence to the effects of colonialism, such as the breakdown of healthy parenting resulting from the residential school system, systemic racism and discrimination against Aboriginal peoples, the devaluing of the Aboriginal woman's gender role, and the loss of traditional cultures and values (Barlow 2003; Amnesty International 2004; Jacobs & Williams 2008; Pearce et al. 2008; Harper 2006; RCAP 1996).

#### ABORIGINAL WOMEN AND EXPOSURE TO HIV

HIV/AIDS continues to be a pressing health concern for Aboriginal Peoples across the country. Aboriginal women in particular are experiencing an increasing and disproportionate burden of new HIV infections (PHAC 2007; Shannon et al. 2008). According to the PHAC (2007), women accounted for 48.1% of people who tested positive for HIV in the Aboriginal population between 1998 and 2006, compared with 20.7% in the non-Aboriginal population. Though Aboriginal people represent just 3.8% of the Canadian population, in 2005, estimates indicated Aboriginal people were about 7.5% of all prevalent HIV infections (PHAC 2007; Mehrabadi et al. 2008). Aboriginal women and girls are increasingly becoming infected at ever-younger ages and are more likely to be diagnosed with AIDS than women in the general population (Gatali & Archibald 2003). The main modes of transmission include intravenous drug use (64.4%) and heterosexual contact (34.1%) (PHAC 2007).

The links between gender-based violence (GBV) and HIV/AIDS are well established and sometimes referred to as 'twin epidemics' (Kathewera-Banda et al. 2005; Mamam et al. 2000). Both GBV and HIV/AIDS operate in a cycle of reinforcing exposures. Sexual violence against women may lead to immediate infection with HIV. As well, exposure to violence, particularly child sexual abuse, places women at increased risk of poor mental health outcomes, which may result in high risk activities such as sex work, multiple sexual partners and substance use (Farley et al. 2005; Heise et al. 1999; UNAIDS 2003). GBV can also make it difficult for women to negotiate safer sex or adhere to medicine regimens; it can also inhibit their overall ability to lead a healthy and dignified life. What's more, HIV positive women may face increased violence from their partners, families and/or communities as a result of stigma and fear surrounding their HIV status (ibid. 2003).

Aboriginal women are affected by HIV in ways that are unique to both their gender and cultural identities. Determinants rooted in the impacts of colonization have created entrenched poverty, social marginalization and unresolved trauma, which can increase their exposure to HIV/AIDS. For these reasons, Aboriginal women's position at the intersection of GBV and HIV/AIDS must be understood in the context of a colonized peoples (Ship & Norton 2001).

Analysis of demographic data from The Cedar Project is helping to expose the complex linkages between historical trauma and HIV risk among Aboriginal youth. The Cedar Project is an ongoing prospective cohort study<sup>2</sup> of young Aboriginal people (ages 14–30) who use drugs and reside in the cities of Prince George and Vancouver, British Columbia. Pearce et al. (2008) examined a sample of 543 Aboriginal youth (52% male, 48% female), participating in The Cedar Project, to determine whether historical trauma is associated with a history of sexual abuse and whether sexual abuse was predictive of negative health outcomes and HIV positive status. Their research found that involvement in the foster-care system and having at least one parent who attended residential school was significantly associated with having experienced sexual abuse. Sexual abuse was found to be associated with HIV positive status, as well as with HIV risk factors such as mental health problems, drug use, sex work and multiple sexual partners. The authors attribute the cumulative effects of historical trauma and current trauma to the heightened exposure of Aboriginal young people to negative health outcomes, including HIV infection (ibid. 2008). It is noteworthy that the majority of those who reported sexual abuse in childhood (71%) were girls and young women.

A qualitative study conducted by Mill (1997) interpreted interview data from eight HIV positive Aboriginal women living in northern Alberta illustrates how HIV risk behaviours also represent survival techniques for Aboriginal women. Mill's analysis illustrates how such formative life experiences as problematic family relations, substance use, and emotional, physical and sexual abuse contribute to low self esteem, which can lead to running away from home, substance use, multiple sexual partners, prostitution and re-victimization. Mill (1997) argues that such responses are survival techniques, which developed out of the need to escape a negative home environment, and in turn, positioned study participants at higher risk of exposure to HIV.

Mill's findings were echoed in a more recent qualitative study conducted by Mckeown et al. (2003), which found that child abuse, neglect and violence are often associated with the ongoing legacy of residential schools. In a further cruel irony, such abuse, neglect and violence would often cause young Aboriginal women to be removed from their homes, whether through government intervention or because the young women would run away from home. Although, leaving an abusive home addressed one problem, it created another, giving rise to a sense of loss and absence and subjecting the young women to new dangers and risks. These authors argue that "economic imperatives combined with emotional and physical vulnerability, led to behaviours and situations which put [women] at risk for HIV infection" (ibid. 2003: 403).

Young Aboriginal women are reported to be over represented in street-level sex work (Kingsley & Mark 2000; Nixon et al. 2000). Women involved in sex work are exposed to very high levels of violence and drug related harm (Farley et al. 2005; McEvoy & Daniluk 1995; Nixon et al. 2002; Shannon et al. 2008). Shannon et al. (2008) examined the role of social and structural violence in HIV risk and women's prevention practices through peer outreach driven focus groups with 46 women engaging in commercial sex work or Intravenous drug use (IDU). Of the 46 women who participated in the study, 57% self identified as Aboriginal. This study sheds light on how gender power relations and systemic, structural violence directly and indirectly affect women's agency (ability to help themselves) and access to harm reduction resources. These authors identify barriers to agency at the micro-level, including "boyfriends as pimps and the 'everyday violence' of bad dates," at the individual level, including "a lack of safe places to take dates and adverse impacts of local policing," and at the societal level, such as "'dopesickness' and the need to sell sex for drugs" (ibid 2008: 911).

Ship & Norton (2001) argue that, because of their gender and cultural identity, Aboriginal women are experiencing HIV/AIDS differently from Aboriginal men and non-Aboriginal women. These authors argue that many First Nations women living with HIV are parents, often single mothers living below the poverty line. Limited financial resources force women to choose between purchasing expensive medication and providing for their families, with the latter often receiving priority (ibid. 2001). Because Aboriginal women's social roles

<sup>&</sup>lt;sup>2</sup>A prospective cohort study is a research initiative that follows a select group of people over an extended period of time

are as caregivers responsible for their children, husbands, extended families and communities, little time is left for self care.

Stigmatization of Aboriginal people living with and affected by HIV/AIDS exists in both Aboriginal communities and mainstream Canada (Mill et al. 2008). While some communities are accepting of their HIV positive members, many communities stigmatize and discriminate against them, motivated by fear and a general lack of knowledge about HIV (Ship & Norton 2001). In addition to the stigma that surrounds HIV/AIDS, Aboriginal women also experience gender discrimination. The risk of being branded as 'promiscuous', 'a bad mother' or 'deserving of HIV infection,' as well as the belief that disclosure will bring stigma upon their children, causes many HIV positive women to keep their status private or to leave their communities altogether (Ship & Norton 2001: 28). A perceived or actual lack of confidentiality within Aboriginal Health centres also prevents Aboriginal women from seeking testing for HIV (Matiation 1999; Vernon 2001; CAAN 2005). Systemic racism, notably discriminatory attitudes within the health care setting, adds a third level of stigma faced by AWHAs (Mill et al. 2008).

#### SERVICE BARRIERS

The numerous layers of stigma faced by AWHAs create barriers to health services, leaving many AWHAs and their children without formal supports (Health Canada 1996; Ship & Norton 2001). Many Aboriginal women have reported racial discrimination and a perception of racism in their dealings with the health care system (Adelson 2005; Browne & Fiske 2001; Bucharski et al. 2006; Tang & Browne 2008; Vernon 2001). Cultural and gender stereotypes such as "wag, squaw, dirty Indian, [and/or] black bitch" are examples of Aboriginal women's accounts of their negative experiences with service providers (Bucharski et al. 2006: 729). It is also a common perception that service providers in health care settings to presume that Aboriginal women are sex workers and drug users (ibid et al. 2006).

Ship and Norton (2001: 28) argue that stigmatization and barriers to service experienced by Aboriginal women are pushing them into a position of "extreme isolation." Community rejection, systemic racism and sexism, socio-economic marginalization, and a history of trauma and gender subordination related to colonialism have placed AWHAs in a position of extreme marginality and vulnerability.

A lack of accessible, culturally sensitive care presents a significant barrier to obtaining health services for many Aboriginal people living with HIV/AIDS; however, the nature of barriers to traditional health services differs along gender lines (CAAN: 2005a; Bucharski et al. 2006; Ship & Norton 2001). Results from the CAAN report, Canadian Aboriginal People Living with HIV/AIDS: Care, Treatment and Support Issues (2005b) suggest that AWHAs are less likely than Aboriginal men to know of the existence and location of Aboriginal health services and are less likely to have the logistical support to access such services (CAAN 2005a). It has been suggested that, due to a lack of culturally sensitive service options Aboriginal women may be less likely to pursue early testing (Bucharski et al. 2006; CAAN 2005; Ship & Norton 2001). Within the last few decades, Aboriginal communities have begun to control their own health services; however, Aboriginal women have expressed the need for gender analysis (Mann 2005).

Despite emerging research that investigates the associations between drug use, sex work, violence, HIV/ AIDS and historical trauma, very little is known about how AWHAs experience and interpret violence in the context of their personal lives and their cultures. Moreover, research to date has tended to look at samples taken from western Canadian urban centres, namely Vancouver's notorious downtown eastside. Thus, there is a need to understand how factors of gender, culture and sexual violence affect AWHAs in other areas of Canada.

Although much evidence exists about the relationship between sexual violence and HIV/AIDS, there has yet to be a national, qualitative study that explores the effects of sexual violence on Aboriginal women in the context of Aboriginal cultures and gender identities. By examining the lived experiences of AWHAs, this

study provides a comprehensive and detailed analysis of the interplay between gender, culture and HIV/AIDS as they relate to Aboriginal women who have survived and/or are experiencing sexual violence. Consistent with emerging research that situates Aboriginal health within the broader discourse of colonized peoples, this research employs an analytical framework of colonization and gender theory.

## METHODOLOGY

This qualitative study explored issues of sexual violence and HIV/AIDS among Aboriginal women. By examining the lived experiences of AWHAs, this study aimed to shed light on how AWHAs relate the impact of sexual violence to their HIV infection, their current social realities, and their past life experiences and how, if at all, these experiences influence their health management.

The objectives of this study were:

- To explore the ways in which AWHAs understand and cope with experiences of sexual violence in their personal lives and in the context of Aboriginal culture.
- To gain a better understanding of the interplay between sexual violence and culture.
- To identify the distinctive features of the female Aboriginal experience of sexual violence and HIV infection.

To achieve these objectives, four research questions were developed:

- I. How do combined factors of gender, culture and HIV/AIDS status affect Aboriginal women seeking services?
- 2. How do Aboriginal women understand and interpret sexual violence?
- 3. What cultural tools, if any, are being utilized by AWHAs to manage their health? (Examples: sweat lodges, country foods, sweet grass and sage for smudging, etc.)
- 4. What policy and program implications arise when considering issues of sexual violence, gender and culture?

The definition of sexual violence used in the design of this study was taken from the Ontario Coalition of Rape Crisis Centres (2005):

Sexual assault, including any kind of non-consensual touching to penetration; date rape; sexual harassment including words, actions, and other behaviours of a sexual nature that can cause a person to feel intimidated; childhood sexual abuse; incest; sexual abuse of someone with a disability; other offences may include uttering a threat, forcible confinement, child pornography and others.

#### STUDY DESIGN: COMMUNITY-BASED, PARTICIPATORY RESEARCH & OCAP

This research study was grounded in a community-based, participatory methodology in keeping with the Aboriginal principles of ownership, control, access, and possession (OCAP). The OCAP principles represent "self-determination applied to research" as follows: an Aboriginal community or group owns the information collectively, Aboriginal groups or individuals control the research process from conception, to analysis, to dissemination; information and data about Aboriginal people is accessible to Aboriginal people; and Aboriginal groups or individuals have the right to possess the data. (Retrieved from www.caan.ca 2009; Patterson et al. 2006).

"Participatory action research is an alternative philosophy in social science research [which is] often associated with social transformation" (Kemmis & McTaggart 2000: 568). CAAN uses this preferred method of research for its consistency with the principles of OCAP. The research 'problem' is articulated by the Canadian Aboriginal

HIV/AIDS community and reflects the aspirations of that community to influence changes in policy and practice that may benefit health outcomes.

The impetus for this study came from CAAN members who identified gaps in the information surrounding issues of sexual violence, gender and culture as they relate to AWHAs. At the CAAN 2003 Annual General Meeting held at Nakoda Lodge, Alberta, CAAN members called upon the organization to rise to the challenge of filling this gap. A preliminary focus group was conducted with AWHAs, who confirmed that sexual violence and related issues of poverty, racial discrimination, residential schooling and the absence of culturally and gender appropriate services were a serious and ongoing concern for Aboriginal women living with and affected by the HIV virus. Consistent with OCAP principles, this process represented a community-based, participatory approach to research in that the 'problem' was identified by the affected community. Through the focus group, the affected community was able to substantially influence the shape and direction of the research initiative.

In keeping with OCAP principles, the research team for this study included Aboriginal scholars and community-based investigators, each contributing expertise from the fields of HIV/AIDS, Aboriginal culture and gender. The research approach was developed and refined by members of the research team (Principal and Co-Investigators) who brought unique experiences, perspectives and expertise from the field of Aboriginal HIV/AIDS. Community members, including AWHAs and service providers, collaborated with community and academic investigators to promote a genuine partnership between the research team and the AWHA community. Community-based service agencies were solicited as Principal Collaborators and included the following CAAN member organizations: Healing Our Spirit in Vancouver, British Columbia, All Nations Hope in Regina, Saskatchewan, and The Native Friendship Centre of Montreal, Quebec.

The use of community-based, peer field researchers represents an additional level of community involvement consistent with ethical principles for conducting research involving Aboriginal peoples. Article 10 of the CIHR Guidelines for Health Research Involving Aboriginal People (2007: 27) states: "researchers should, where possible, employ community members" and should "include training in research methods and ethics." In this study, we employed as interviewers Aboriginal and non-Aboriginal women of a various ages living in Vancouver, Regina and Montreal.

International researchers on violence against women suggest that characteristics such as the sex, age and interpersonal characteristics of the interviewer measurably affect the willingness of female participants to disclose violent experiences (Jansen et al. 2004). Research has also shown that women interviewing women can result in a more positive overall experience for participants in the study and may reduce the occurrence of socially desirable responses (Jansen et al. 2008; Tang 2002). Employing Aboriginal women and young women knowledgeable about and sensitive to Aboriginal cultures and social issues, created an atmosphere of trust, respect and understanding during the interviews, facilitating intimate discussion of sensitive topics, including sexual violence.

#### STUDY DESIGN: GROUNDED THEORY

A grounded theory approach was used for this study and has been described as an inductive, subjective and process-oriented strategy for conducting social research (Corbin & Strauss 1998; Creswell 1998). This process begins with the acquisition of data representing the lived experience of participants. Theory emerges from the data in a 'ground-up' fashion, rather than being imposed ahead of time (Berg, 1998; Strauss, 1987). The object is not to obtain responses to a rigid set of predetermined questions, but to grasp as completely and fully as possible, the perspective of participants. Once data are collected, they are coded into categories and themes, which are then compared, contrasted and developed into meaningful theory. Coding is "the process by which data are fractured, contextualized and integrated" for analysis (Strauss & Colbin 1990). Given that little is known about the relationship between HIV and sexual violence in the context of Aboriginal cultures and gender identities, this qualitative approach was determined to be best suited for exploring the topic.

Qualitative methods (semi-structured, one-on-one interviews) allowed for interpersonal interaction and the opportunity to gain thick, rich descriptions — crucial to understanding the interplay between sexual violence and HIV infection. This approach was designed to draw on the preliminary focus group data to ensure a "commitment to the ways participants interpret and make sense of their experiences" (Harrison 2002: 864). Semi-structured interviews typically involve raising certain predetermined topics and questions, but participants are also encouraged to digress, to raise new issues and to go beyond the questions raised. Hence, data collection instruments were not finalized prior to the commencement of interviews and focus groups. Rather, these instruments were carefully formulated within the parameters of the research study's objectives and scope of inquiry, and then adapted to each data collection situation and cultural context. In this study private interview environments provided safe spaces for AWHAs to share their stories, some for the first time.

The interview guide addressed sexual violence and HIV/AIDS, as well as health management. The interview template was intended as 'a guide' and 'a living document,' which evolved as participants raised issues. Open-ended questions allowed participants to digress from the guide and to raise new issues. Different interviewers used different approaches, resulting in changes to the wording and order of questions. Although interviewers were encouraged to probe participant responses, it was left to the discretion of the interviewer which questions to include and which to omit. This allowed the interviewer to avoid questions that might upset a participant.

#### RECRUITMENT

Participants were recruited using a passive strategy of discreetly located information posters with tear-off flyers and pocket-sized hand-outs. Posters were placed in AIDS Service Organizations (ASOs), abused and homeless women's shelters, needle exchange sites, community clinics and hospitals in Montreal, Ottawa, Vancouver and Regina. As well, outreach workers, service providers and CAAN APHA advocates assisted by informing AWHAs about the study. In an effort to recruit participants from both urban and rural areas, recruitment took place in urban centres where both rural and urban AWHAs are known to congregate.

Eligibility criteria for participation in the study included:

- Aboriginal women (self identified Métis, Inuit and First Nations, with or with out status)
- HIV positive status (self reported)
- Experience of sexual violence
- Over 18 years of age
- Residing in Montreal, Vancouver, Regina, Ottawa or surrounding areas<sup>3</sup>

A cash honorarium of \$25.00 was given to every participant. Participants were made aware that they could refuse any question for any reason and that they were free to end their interview at any time without affecting their entitlement to the honorarium.

#### DATA COLLECTION AND ANALYSIS

All interviews were recorded using digital audio-equipment and software. Interviews were transcribed using Ottawa Verbatim Services and checked for accuracy against the tapes by the research coordinator. Ottawa Verbatim Services signed an agreement of confidentiality before receiving the raw audio data. Transcripts were cleaned of all identifying information including names, places, service centres and any other information.

Those who had access to the raw data included the Principle Investigators, interviewers, research

coordinator, research assistant and the transcribers. The raw audio data and transcripts are stored in locked cabinets at the CAAN office. Signed consent forms and any other forms that identify participants are also being stored in a separate locked cabinet. Participants were given the right to request that the audio-material be destroyed at any time during the research process. Unless otherwise instructed by the participants, all data will be kept locked for five years then destroyed. The information and data collected for this study will not be available to any other research initiative or program, apart from those made public in this report.

Data were coded using ATLAS.ti Scientific Software. The results of initial open coding were interpreted individually by research team members. A series of telephone and face-to-face research team meetings allowed team members to integrate their interpretations of initial codes into broader patterns and themes. An Aboriginal led research team allowed for the findings to reflect realities that were most relevant to the AWHA experience.

#### ETHICS PROTOCOL

Ethical considerations for this study were guided by the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (CIHR et al. 1998), with particular reference to Section 6: Research involving Aboriginal Peoples, and the CIHR Guidelines for Health Research Involving Aboriginal Peoples (2007). Ethical review and guidance for this study was provided by the Dalhousie University Health Sciences Research Ethics Board.

Research involving violence against women presents unique challenges and risks to both the participants and those involved in the research (Jansen 2007). In this study these risks were further complicated by issues surrounding the maintenance of confidentiality when conducting research on persons with HIV/AIDS (PHAs). The participants faced potential emotional and mental health risks associated with disclosing personal experiences of sexual violence or reliving traumatic events (Jansen et al. 2004). Moreover, the interviewers were made vulnerable to vicarious trauma through continued exposure to graphic details about participants' experiences (Health Canada 2001).

There was also concern regarding the use of community-based field researchers, particularly those who might be associated with service centres used by potential participants. There was a risk that women might feel obligated to participate so that they could be assured of ongoing access to services. Issues of confidentiality surrounding HIV status and disclosure of violence were of principal importance. The use of community-based field researchers meant that information about participants had the potential to circulate in their communities.

Several strategies were used to avoid and/or mediate the emotional risks to study participants. At the time of enrolment, an initial screening was conducted by the research coordinator to ensure that participants were aware of the questions that would be asked and to ensure that they would be comfortable speaking about their experiences. All participants were required to read and sign an informed consent agreement, the content of which was discussed in detail before the interview. A detailed contact list of local, free referral services for HIV/AIDS and sexual trauma counselling was provided to all participants. Referral lists included traditional Aboriginal healing services, ASOs and western style counselling. In most cases, interviews were conducted in service centres where immediate onsite trauma counselling was available.

To mediate the potential risks associated with community-based field research, all field researchers were required to attend a formal training workshop facilitated by CAAN. The Field Research Training Workshop: In Depth Interviewing and Aboriginal Women (Ottawa, August 25–27 2008) included workshops on privacy and confidentiality, HIV sensitivity, research involving violence against women and skills for conducting empathetic, qualitative interviews with AWHAs. In addition, field researchers were given training on how to handle a participant who becomes emotionally overwhelmed and were provided with resources relating to vicarious trauma. Both the field researchers and the research coordinator were contractually bound by CAAN terms of confidentiality during and after their involvement with the study.

## CHARACTERISTICS OF THE SAMPLE

Twenty (20) interviews with AWHAs were conducted between September 2008 and February 2009. Interviews ranged in length from 20 minutes to slightly more than two hours. All interviews were conducted in private rooms at service centres, hotels and other locations of the participant's choice. The sample included Inuit, Métis and First Nations women living with HIV from British Columbia, Saskatchewan, Manitoba, Ontario and Quebec. Of the 20 participants interviewed, half indicated that they once lived on reserves or in rural areas. Participants ranged in age from 25 to 55, with most between 30 and 39 years (25%) or between 40 and 49 years (35%).

All the participants said they were mothers; many were single mothers and some, grandmothers. The majority of the sample (18) identified themselves as heterosexual; one was two-spirit and another transgendered. Participants reported a range of professions and hobbies and a range of socio-economic situations; the group included professionals from diverse backgrounds, as well as women who said they were currently homeless and/or unemployed.

Thirteen participants reported that they spoke their Aboriginal language and almost all participants described strong connections to their culture and community. Although participants were not asked specifically about residential schools, three of them said they had attended a residential school in their childhood, and 18 reported having had one or more immediate family members who had attended.

## FINDINGS

#### **EXPOSURE TO VIOLENCE**

#### CHILDHOOD EXPERIENCES

Many of the women who participated in this study spoke about their childhood and how early experiences had shaped their lives. Almost all told of various forms of abuse and trauma experienced from a relatively young age. Many participants spoke of their experiences with parental neglect and substance use, as well as sexual, physical and emotional abuse within their family. These situations often had profound effects on their mental health, including low self esteem, poor sexual boundaries, feelings of powerlessness, depression and violent relationships.

#### **EMOTIONAL TRAUMA**

The emotional trauma experienced by participants often emerged from witnessing the behaviour of their parents or abuse suffered by one or both of their caregivers.

"...I used to have to go pick up my mom at trick's houses, you know, 'cause she wanted that drink. I don't know - I never seen her kiss or touch a man or nothing, but you know, she got her drinks and she got high, you know...."

"I went running into that house next door at my uncle's and I ran in there to see nothing but blood, man, smeared all over the walls, and that bed, that bed that my mom laid on..."

"Interviewer: ... So, from the time you were 12, you started with these abusive relationships. Was there anything before that in your childhood or anything?

Participant: No. Just I just watched my dad with my mom. That, all through my life...I used to hide under the beds..."

#### **SEXUALABUSE**

Many of the women suffered sexual abuse as a child; they were often vulnerable to many perpetrators but did not believe there was any help for them.

"And I saw my dad - how he was treating his brother, my brothers and sisters... molesting and uh, that drove me hay-wired, panic, I was scared... He, he ran after me, I ran everywhere, I had nowhere to run to in, in the middle of nowhere."

"What our Elders tell us [is] that sometimes in those situations, we are not supposed to say so much because the man will be, will make them more lost, the ones who, who disturb girls, we're asked never to talk about stuff like that. It doesn't make change..."

"...I was being sexually abused at the time, but nobody knew that. Not by my dad, but by a boarder that was living in the basement that used to babysit me and, because my dad used to beat me up, I wouldn't say anything because he would use that against me..."

#### **PHYSICAL ABUSE**

Physical abuse was a common experience among the participants of this study. Many of the caregivers in their lives had physically abused them consistently throughout their childhood.

"I grew up in a violent house. I was taken away by Children's Aid the first time when I was six because my dad used to beat me up."



"A lot of the scars on my face is from him. My foster dad. And that's where the abuse first started."

"Um, my stepmom, my brother, my sister like abuse me, abusing me. See I got a big cut there. Really abused."

#### **NEGLECT**

Although neglect is not typically defined as abuse, in the case of the women in this study, extreme neglect was experienced as trauma, not only physically, but emotionally as well, often leaving them with no one to turn to in times of trouble.

- "...I was basically on my own since I was like about 15 and then of course, I met a guy that abused me and was violent, but I-I don't know. I guess I was just so used to it that it didn't bother me. I had nowhere to go, so he just continued beating me up and basically held me prisoner there. And I had no family..."
- "...I've lived a pretty rough life. I grew up in a...in the foster care system and by age of II, I was...it was going to courts for me to be a long term ward because my mom refused to quit her drinking and behave properly, and besides witnessing violence, you know, and being a survivor of sexual-sexual abuse as a child as well, I have experienced a lot of neglect..."
- "... We were neglected and quite often we were in, in the house and there was no food and my sisters tell me um, I never wore shoes..."

#### CARE GIVING ROLES

Responsibilities to care for their parents and siblings were also experienced as a form of neglect, and therefore trauma, by some of the participants. Rather than having their physical and emotional needs met, these women had spent much of their childhood caring for a parent who was using drugs and/or alcohol.

"...My brother was always there. He was always there. He was-he was like my child, you know, and my mom she continued her ways [drug use], you know..."

I was sick of responsibility man, you know? My mom, I was sick of being her caregiver and her caretaker..."

#### PARENTAL DRUG AND/OR ALCOHOL USE

- "...My mum-my mamma would leave many times, you know... She woke up in a hospital bed and they told my mother that she was pregnant that she better quit her drugs and her drinking because she had a baby in her belly and I thank God that I'm not FAS ...the doctors said I was supposed to be a very ill, like slow child..."
- "....I was placed because my mom-my oldest sister left home with her boyfriend to start her own family and my dad was an alcoholic and, but I was living fine. I mean we didn't eat great. We ate...I ate toast and sardines. That was my luxury meals and uh I used to take in the empties to go to movies. Like uh, back then it was very, very cheap..."

#### RESIDENTIAL SCHOOL LEGACY

Through their discussions, it became clear that several of the women had experienced trauma that was linked to the residential school experiences of their parents. This was especially apparent in the trauma suffered by women whose parent(s) could not offer them the emotional support they required as children.

- "...My mom and I just never... she hated...like she did-she had something against me. I don't know what it was exactly, but her and I just never really got along. Um, she went to residential school, so she probably went through stuff herself, but...and I ended up paying for it..."
- ".. I was impacted by residential school, I never knew how much I was impacted because my family was impacted,



I was impacted. Um, and I had huge abandonment issues as a result of those impacts [emotional], on my siblings and it kind of rippled through the whole family."

#### FOSTER CARE

In many cases, foster care did not afford much safety for the women in this study. In fact, many women were moved several times, from home to home, because of abuse they experienced at the hands of foster parents.

- "...I became a permanent ward of the court and moved from foster home to foster home, one of which was, um, on a reserve, and it was with the chief of the reserve, and he was sexually abusing the girls that went in and out of there. But, because I was, like, always in trouble, my social worker didn't believe that because, of course, it was the chief of the band and that was unthinkable that...and so I was the liar and...So I got kicked out of there and I moved around from foster home to foster home, but then I just ran away permanently after that and ran away..."
- "...My dad raised me up until 8.Yeah, that's where I was, and then I got taken away and placed into foster homes, group homes, and that's where I was sexually abused and beaten and raped..."

#### SOCIAL DETERMINANTS

During discussions with participants of this study, it became clear that social determinants such as poverty, racism and stigma (particularly in the health care system), as well as punitive social services and lack of support, played an important role in shaping their exposure to HIV.

#### **POVFRTY**

Conditions of very low income, poor housing, lack of proper nutrition, homelessness and low levels of education appear to be a pattern throughout the lives of many participants.

- "...I see women with kids. I see women, Aboriginal women, like they're so sick or they need, like a pair of socks or something like that, right?.."
- "... We were pretty poor, very poor, and she said mom took off and left... I didn't even have a name... left baby at the hospital, so my dad just took the day off of work and him and my sister... My sister had to get out of school and she has only had a grade 4 education. She had to drop out of school to be my mother. To raise me..."
- "...Cause you know like when you go to the [Aboriginal Service Provider], there are so many Aboriginal women going there and they have no food. They got nothing..."
- "...Um, part of it had to do with me losing my house when my son was two years old. I lost everything, and um, my partner getting his first 10 years. I was alone. I had nothing. No home..."
- "...It's hard, it's very hard. I don't even have enough money because I live on disability and I get \$1,300 a month. Eight hundred of it goes to rent and then to try to pay your phone and internet and then your hydro and your, get groceries..."

#### RACISM/STIGMA

Several of the women talked candidly about their experiences of racism and stigma based on their Aboriginal identity. They also expressed frustration, sadness and anger over the discriminatory treatment they received from society in general, as well as from sectors directly linked to their health, such as housing, service, education, criminal justice and health care.

"...I wasn't accepted by white people because I was brown and I wasn't accepted by brown people because I was too white, so that was really unfair..."

- "...I find that the white people are not doing good service for us Aboriginal people, that's how I look at it. Yeah, like I said, we're not, we're not respect, we're not do everybody all equally, you know, we're all different nation, we're all god's child, you know, and the different all nationality to all different. So we're all god's child, why not treat us all equally?"
- "...I feel sometime there is a lot of racism, so why not pick up more Inuit people and communicate with us and learn from us too because we love, we love meeting people and that's us Inuit people we're, you know, easy going, we love, we just love meeting people..."
- "...But, yeah, I do. Society moulded us Aboriginal people into how we are today and then they want to sit there and condemn us and convict us in jails for what? You know, they taught us and instilled it in us that we were bad, you know. When we were little kids, you know..."

#### PUNITIVE SOCIAL SERVICES

The general consensus among the women in this study was that social services played a putative role in their lives. In general, women did not feel served by social welfare; rather, they had to guard against being caught or 'found out' by 'the system.'

"...I couldn't just shake the pain from my face, it was so sore, and my face was so...like it was puffy. I thought of the fact of going to the hospital and getting the pain medication, right, and he's like, 'no babe. I can't do that. If we do that, look it social services gonna be called, the cops gonna be called."

"Then all of a sudden somebody called [social services] 'cause I didn't give them a whack [drugs], they called social services on me. I just finished doing a shot before child services knocked on the door. That's the day they took my babies."

"I was broke. I had no food in my cupboards at that time. Word was going around - I was getting pretty bad...and the system never found out about it yet."

"And welfare system wasn't giving me shit and I refused to sell myself, so I started boosting, but when I couldn't boost enough, I started hustling. I picked up skills and the mentality to start hustling. I'm not proud of it man. It's not something I do today. I felt the effects all my life for that drugs and alcohol, man, and I realize the wrongness it has in it, you know..."

#### LACK OF OPPORTUNITIES AND SUPPORT

Not only have most of the women in this study experienced detrimental social conditions, but they also face challenges to addressing them. In particular, they are often rejected by their home communities, marginalized in education, housing and work environments, and ostracized by society in general.

- "...I'm working two jobs now and trying to, you know, make sure my kids are okay... Being a grandmother and mother, working two jobs and looking after a sick mother...it's hard..."
- "...I went to work at the canneries when I was I4..."
- "... I really don't really contact with those kind of people because I feel like I'm, I'm Aboriginal and I feel like I get no support by, by them or something..."
- "...So, these people are supposed to be all relatives and stuff like that and I just get so mistreated there so I just stay away from my mom's territory and my dad's territory because they all look down at me and I don't like that.".

"...I just wanna live what life I have left as someone that does what everyone does in this world and that's learn and work. That's what I want, that's all and I want at least that. [emotional]..."

#### GENDER INEQUITIES

The women who participated in this study talked a great deal about the role gender inequities played in their lives. Most of the women suggested that, as Aboriginal women, they were treated poorly by men and relative to men. In general, their discussions centred around men as perpetrators of physical and/or sexual abuse, as well as the absence of a supporting role played by the men in their lives.

- "...I think the stigma, you know, you're, you're already treated like, as an Aboriginal woman like you're the lowest as you can go and um, I've had men tell me that, you know..."
- "...I kind of seem to withhold myself from it a lot just to, just to avoid the abuse that I get from some of the people that are mentally disturbed in the area and men don't care when they um, hurt women even because they're miserable with AIDS too, and it's just not safe..."
- "...Because when you go somewhere, if you are weak in your condition to save yourself...You're helpless, very much. And especially when you're an Aboriginal, they can't take no for an answer, even though when you're trying to say no and they could just snap...It is now, for any man now it doesn't matter..."
- "...I find that with Aboriginal women, it doesn't matter, you know, if...they still have to be the strong one to do everything no matter what..."
- '...I consider myself a single parent because even though my son has a dad, he's never took responsibility for him. Um, I basically um, raised him alone and provided for him alone and, but I'm kind of glad that happened because I know, and like I'm trying to leave now and I know that I'll be able to look after him, I don't need him..."

#### POWER IMBALANCE

In many instances, women talked about how they had lost control of their lives to a man. In some cases the power differences were rooted in disparities in resources (money or drugs), while others talked about men attempting to gain control over them physically or through drugs.

- "...He could control me and had something over me...So, I was just in his hand man and he gave me a whack of coke.And I don't even remember liking the damn shit.All I knew was that I was just like him and he would love me..."
- "...He's brainwashed me so much um, making me believe that I was at fault, I was the slut, you know. Um, I was the one who slept around..."
- "...But still, sometimes, even if you want to be in control, to be in charge of your own life, sometimes you... you don't have that control. You know what I mean? We are controlled!"
- "...I was trapped, not to mention being lost. I was trapped, okay? And I fell into the shit and that [guy] was the candy man. I accepted it. I was scared. Sometimes I still feel fear. I do, and ... he had me right in his hand, and he fed me dope like it was candy. I didn't have to stand on the street corner. Not to mention that he so repeatedly told me that he loved me..."

#### FEAR OF MEN

Control and abuse at the hands of men has left many of the women in this study afraid and distrustful of men. For the most part, they fear being physically or sexually abused.

- "... Yeah like that's what kept me in the relationship, a lot of fear. And um, like he's threatened me many times..."
- "And I, I kind of um, fear with men now, even today [emotional] sorry. Um, even today I feel fear sometimes, I feel like I have no trust in men because of what I went through for 12 years and I kept a lot to myself and even today I, I'd love to date with men but I, I just can't because I, I flash or flash back from my teenage life. Its like, is he going to be aggressive, is he going to be rough, is he going to, is he going to be gentle with me?"
- "...It is the worst. It is. It does. It makes you feel like an animal would do the same. 'Cause they [Aboriginal women] would be beaten, beaten, beaten down, beaten down. They just... they're scared, you know like when an animal goes like that when...you know when an animal's been hit. I can tell right away because I lived... I live like an animal. I know what it's like..."
- "...Like I was finding it very hard to reject men and, in a ways but um, I was rejecting them but feeling fear for rejecting them because some men don't like being rejected. They're very aggressive and they said when they want sex they, they go out and pursue it aggressively. But I found I was like um, always that fear of transmitting, always that fear..."

#### EMOTIONAL CONNECTION TO A BUSER

Several women talked honestly about their intimate relationships with men who often abused them emotionally, physically, and sexually. Despite the abuse and their better judgment, many women confessed to remaining in love with these men.

- "....Oh yeah, he made me feel really bad. I just wanted to hurt myself, all because of him, and my mom kinda just said to me, "You know what?... If he doesn't love you, he can go somewhere else." But I didn't want him to go anywhere else..."
- "...I was like 20 some years old after being in a violent relationship with my first love. Like, I reunited with him while my baby's dad was in jail, right. So, I mean it was passionate down to the sexual part, but the jealousy tore us right apart.
- "...Cause he cheated on me. I found panties in his pants, he'd come home smelling like somebody else and all that lovely shit that happens when you love somebody so bad. You know and all the dirt you go through to tryin', you know, and you think that's your worth, you know."
- "And it came right down to my dignity and my respect, man. I loved that guy more than I even loved my damn self..."

#### SELF CONCEPT

Abuse, neglect and abandonment were common themes in the lives of the study participants. These experiences left many of them with a diminished self concept.

- "... I felt like I was just floating, floating along and my kids were in social services at the time and I didn't know what to do. My-like my world was falling apart..."
- "... I know how to handle it. It just seems I know when to go numb, not to feel, 'cause I've done it all my life, I know how to cut the emotional strings per se..."
- "....Oh yeah, he made me feel really bad. I just wanted for to hurt myself, all because of him....
- ... Yeah. I just didn't care anymore. Just frickin made me feel like, you know, like an animal. If you beat an animal..."

"...The sexual violence affects um, they leave a huge scar and if it's several incidents of sexual violence... Like if the initial sexual violence that occurs escalates and also it affects your sexuality, it affects you sexually. It either closes you down or it manifests itself in perverse ways, sexually. You know? Um, and it affects your self worth and so all these things when you put them together make you vulnerable to HIV, all these things..."

#### DAMAGED SELF ESTEEM

Damaged self esteem emerged as an important theme in the women's stories. Whether it resulted from abusive relationships, drug/alcohol use, or living with the stigma of HIV, almost every woman in this study talked about situations and times in her life when her sense of worth was diminished.

- "...I hated myself..."
- "...You know, I wanted to be loved, I wanted to be hugged, you know?..."
- "...Okay, well, by the age of 16, I mean 15 years old, man, I became pregnant I with [child's name]. You know, and like hell, I wasn't gonna give up this baby, you know. This was my time to make things right and this was my time to have something love me back, you know..."
- "...And I was lost...to me, myself I was worthless. I was useless. I blamed myself. I hated myself. I was lonely and all those negative shit in my life from bad choices..."
- "...Like it's been um, four years, going on five years. And ah like being in that relationship it's been, it's brought my self esteem down ..."
- "...Oh you're sick, don't come around, oh don't come near us," and, and I feel unwanted, I feel rejected, I feel, you know, left out, I feel. So I um, kind of like accept them for who they are, you know, I'll let them be. At the beginning I used to take it hard, I used to cry about it but today it's like, let them be, they'll learn by themselves like what I was learning, yeah..."
- "...Participant: She always says that to people, "Don't touch her, she got HIV."

Interviewer: Um hmm. How does that make you feel?

Participant: Feel dirty..."

#### NEGATIVE BODY IMAGE

Several of the women talked about how having HIV and/or the experiences of violence and racism throughout their lives has resulted in negative feelings about their body. These feelings were sometimes also expressed by their partners, further diminishing their self esteem and/or increasing feelings of self blame.

- "...And he kept saying it was ah, "It's because you're sick. You have this illness in your body why you're not getting pregnant." So but he didn't understand you know, didn't know nothing about HIV/AIDS and I tried to explain to him but you know he had it in his head that it was because I was sick why I wasn't getting pregnant." "The depression...I do get depressed. Like sometimes, like anything with my body, goes wrong with my bod ...it's like a reminder..."
- "...Like I felt so dirty. So, so dirty. You mean I'm gonna carry this [HIV] the rest of my life? You know that sort of thing..."
- "...I didn't treat my body the way my body, you know, have that respect for my body..."

"...lt [racism] affected my self esteem in a severe way, man, you know. You know my lips were too big, man, you know. My nose was-wasn't right, you know, and my skin was too pink, you know. I had freckles you know..."

#### INTERNALIZED BLAME

Feelings of self blame and accompanying self loathing and worthless were a frequent experience for the women in this study. Rather than find fault with the perpetrators of abuse or a system that allowed them to fall through the cracks, women often blamed themselves for the abuse they had suffered, for coping with abuse through drugs and/or alcohol, for seeking love through sex and for becoming infected with HIV.

- "...No, but I-I blame myself for that, you know, like being in a relationship with him and...like he was-he was a really nice person at first too..."
- "...I started to get high every day, man with my friends. 'Cause you know what? That disappointment and self hate ate at me and I medicated it. That's where my drug addiction and alcoholism started to stem from..."
- "...After hearing it like so often I grew to believe it. Even when I found out my partner was the one who um, infected me, I still believed that I was the bad one, you know..."
- "...I couldn't say no to men, you know. Um, I knew HIV was out there but I couldn't, I couldn't speak for myself to say no, you know, and I gave myself to a lot to men...not even liking sex, you know and hearing that I was the risky one, I believed it..."
- "...It is my fault what happened to me..."

#### EMOTIONAL WELL BEING

It is clear that the general environment of violence against Aboriginal women, including various forms of sexual violence, affects women's emotional well being.

- "I've been sick a lot and I constantly worry about the worst, biggest scar...I'm not afraid to go to spirit world because I know my creator's there waiting for me and I just the most pain of all is my family. I can't get over that. I just can't get over how people get treated when they contract the disease."
- "...They want to put me in a hospital in a mental health hospital, because I'm so suicidal and I just say why do I ...there's no reason for me to be on this earth right now [emotional]..."
- "... I think testing positive really affected me mentally because I have a disorder where I can't sleep, so that's basically what... What happened to me when I tested positive, I snapped, something went crazy in me..."
- "...I used to disassociate. It was like kind of out of body, out of body stuff and, and everyone thought I was crazy. By then my father had remarried and uh, I would just disassociate sometimes without even no control and um, so I ended up in a mental hospital at 13 years old..."
- "My God, the stuff I saw, you know like, by the time I was I 4... The stuff I'd experienced I was like um, I don't know, I could never figure it out like, until later. Um, I could never figure out the relationships I had with men were very unhealthy because I was unhealthy... I didn't really know any boundaries, I, I had uh, unprotected sex, I did everything, I used drugs..."

#### SUICIDAL THOUGHTS AND ATTEMPTS

Some of the women talked candidly about suicidal thoughts or attempts, dating back to their adolescence. Loss of innocence, children, families, opportunities and their own health prompted a few women to consider suicide as the only option.

- "...Yeah, I think I probably would have done it. I always think I'm gonna do up a rig with tons of heroine and just shoot it...that's the quickest way to go...."
- "...Interviewer: Do you still feel that you wanna commit suicide now or have you gotten past it?
  Participant: Not so much anymore, but occasionally I do, 'cause I-I...It scares me when I see people and just...I
  don't wanna, I don't know, it just seen too much suffering, but I have to deal with it, but...right..."
- "...I really, really, honest to God, considered suicide...I lost my oldest son to [illness]. It literally killed my soul. Like that's when I felt, I'm gonna quit living. I've had enough. No more living. I just can't..."
- "...I got into the solvent thing and tried to kill myself..."
- "...I actually tried to commit suicide about a week ago and I ended up in the hospital. I almost ended up in the psych ward. I took a bunch of pills, but it wasn't quite enough..."

#### LACK OF SELF CARE

Many of the women either did not have the time to care for themselves, have not yet fully accepted their illness, or the violence they experienced created emotional barriers to seeking care, especially sexual and reproductive care.

- "...I don't have time to look after myself I think as a, as a woman because I'm busy looking after other people... it's finally when I'm almost crashing to the bottom that I realize I have to do something for myself..."
- "... Well a lot of women, like even for myself when I talk about it, they talk about the triggers. Especially for Pap smears and having to have it done every six months like it's very, well sometimes it's um... it has to be some kind of steps that they need to take to, to um, help the person get that done without feeling violated..."
- "...I'm supposed to go back to the doctor, but like I said, I just haven't dealt with it. I've just been, like, avoiding it because I don't wanna even deal with it. It's like I feel maybe if I don't deal with it then it'll go away, but I mean I know that it won't..."

#### ANGER/RESENTMENT/BETRAYAL

Feelings of anger, resentment and betrayal were common among the women who participated in this study. These feelings often developed as a result of childhood trauma and other life traumas, sexual violence, and discrimination, racism and stigma.

- "...That's why I have this lifestyle.That's why I'm so angry all the time.There's a lot of anger in me. It's never come up. I'm glad, I would be in jail by now, you know. [Shared laughter] And it's just like...I didn't know that was that much rage inside of me to...it's there...but it's slowly like I spend a lot of time with [friend]..."
- "...I think yeah because it's-it's made me not being able to trust people, like especially men..."
- "...You know, I'm an easy-going person and, but it changed my life a lot in to discrimination, to hatreds, to loneliness too..."
- "...My family thinks that I'm a bad person because I contracted AIDS and I [emotional] and I love them so much, but I ...but they just don't want me to be a part of their life..."

"...One time it was for three months and I wouldn't answer my phone, my door, nothing. I just felt so depressed and so alone and even if there were a lot of people in the communities that I was going to the community centres I was going to, I was still so secluding so I thought to myself I'm not getting anything out of this right now so I just secluded myself at home and just stayed there and all I could think about was the miserable people out there that, you know, they think they're the only ones that are hurting and going through turmoil with HIV..."

#### ADDICTIONS AND/OR SEX WORK

The violence and trauma experienced by many of the women in this study led some of them to seek relief and escape in drugs and/or alcohol. Many of the women either were not aware of or were not able to obtain access to alternate forms of support to cope with traumatic life experiences. For some women, involvement in sex work originated in their drug/alcohol use or their inability to meet basic survival needs on the income available through social or disability services.

# VIOLENCE-RELATED EXPOSURE TO HIV

An important objective of this research was to identify the links between sexual violence against Aboriginal women and girls and the increasing incidence of HIV among Aboriginal women living in Canada. To help us achieve this objective, we asked all participants to discuss their thoughts about the relationship between their experiences of violence and their HIV infection. Participants identified numerous connections between their HIV/AIDS status and their many experiences of trauma. Some links were direct, others indirect.

#### DIRECT LINKS

Many of the AWHAs interviewed reported that sexual violence was directly related to their HIV infection. Some women acquired HIV when they were raped and some were knowingly infected with HIV by their abusive intimate partners. In all cases, the direct infection of HIV through sexual violence occurred as one incident in a context of ongoing and repeated trauma affecting Aboriginal women and girls.

- "...It actually started from, um, when I was a young teenager. Um, my mom and 'em used to party a lot and our house was always full of people, all weird...just all strangers and even on school days this would constantly happen 24/7 and sometimes I would get raped by different men in my room. Sometimes up to three or four times in a week at different times by strangers and, and when I showed my mom the blood from all the tears she said that it was my period and I knew it wasn't because it...they were booboos down there. And I contracted HIV when I was 15 years old, when four black men raped me at [public park]..."
- "...Well that relationship I was in when I got infected, um, like when I thought about it after...after becoming infected with HIV...like when I think about it now, to me it's still, you know, like that part too was like, like was...I see it as sexual violence too..."
- "...Um, my last sexual assault was um, with this black guy from Africa. That's when I became HIV positive. My husband of 17 years left and I was grieving at the time, I was very vulnerable at the time that I met him. On my first date I, you know, same thing. Um, the first date was sexual encounter except that um, I insisted that he use a condom if he was going to have sex with me because I didn't feel that I, you know, wanted to be, wanted to feel safe that way. But during the sexual act he ripped the condom off and I was, I tested positive for HIV about 12 weeks later..."

#### INDIRECT LINKS

AWHAs also described indirect links between their traumatic experiences and their HIV infection. Many of the same factors implicated in Aboriginal women's exposure to violence were also responsible for their heightened exposure to HIV. Participants attributed their addictions, involvement in the sex trade and difficulties setting sexual boundaries or negotiating safer sex with men to mental health problems brought on by trauma. Such responses to trauma increase exposure to HIV; and in several cases, led to HIV infection for the women who participated in this study.

"Well it, there was a pattern there of uh, the type of men that I attracted in my life. And all those sexual predators. And um, yeah there's, there's a definite pattern...."

AWHAs described being displaced from their homes due to violence, which in turn placed them at increased risk of HIV infection. Some women were forced to leave home or foster-care because of sexual abuse. Other women described fleeing violent relationships and being unable to find safety and shelter. One participant described hiding from her abusive partner, and becoming infected with HIV through a dirty needle provided by the people with whom she had sought shelter:

"Oh yeah, to sleep. Exactly where I went to hide. Trying to run away from violence. It was the only place I could hide where I would... They said, "Oh well, I'll protect you, don't worry, make sure you're okay. The guy won't get hold of you I'll make sure..." And they did, they made sure, he wouldn't let him get a hold of me. He ain't gonna wait outside forever..."

# HIV-RELATED EXPOSURE TO VIOLENCE

For many of the AWHAs who participated in this study, violence and HIV went hand-in-hand. Not only did violence create exposure to HIV infection, but being HIV positive also made women vulnerable to many forms of violence. For example, some AWHAs described verbal and emotional abuse because of their HIV status. Many described being shunned by their families and communities.

- "... Uh, [sighs] I get a lot of name calling and, uh, verbal abuse, unwelcomeness... try to go in somewhere so happy and they go, ew, get out of here. You're not welcomed here and stuff and I just leave and cry and walk. [emotional]..."
- "...Really lots, yeah, because it took my family. My family thinks that I'm a bad person because I contracted AIDS and I [emotional] and I love them so much, but I ...but they just don't want me to be a part of their life ever since and I haven't been in it. My parents are deceased now. I got lot of forces through to the brother here that he would need...he wouldn't even acknowledge me because of my contraction. Out of fear..."

Some of the participants in this study described being threatened, intimidated, robbed and physically abused by people who targeted them because they knew they were HIV positive and therefore likely to be physically vulnerable.

"...Oh it's been dreadful. People...I've gotten robbed, I've gotten, you know, locked out from Army Navy 'cause I went shopping there and it's been very dreadful because people, when they find out that you're HIV positive, they target you to rob you and stuff like that 'cause they know that you're vulnerably weak. So that-that's another thing that would be good for the First Nations Aboriginal women's centre would be to have security and escort service there especially around cheque days..."

Another participant, who requested that she not be quoted, described being attacked after she had used a service centre in her area (needle exchange centre). This participant felt that she and her peers, who are also AWHAs, were often targeted by sexual abusers when making use of harm reduction resources and homeless shelters, as well as after leaving bars. She felt that they were being targeted for three reasons: I) because they were Aboriginal women, 2) because they were HIV positive and/or 3) because they were using drugs or alcohol. She believed that the latter two reasons made them easy targets due to physical exposure. AWHAs in this study often described being blamed for bringing HIV into their intimate relationships and being branded as sexually promiscuous by their partners.

"...Yeah, and then, and um, he doesn't want to acknowledge that he was the one who infected me and I know because I'm, since I've been with him I have, you know, I have never been with anybody, you know. Sure I ran around and he knew that because I shared some of my past with him, how I was before I got with him ... Now I'm still the slut, I'm still... And I don't have time to look after myself I think as a, as a woman because I'm busy looking after other people. And I do ..., you know, and it's finally when I'm almost crashing to the bottom that I realize I have to do something for myself. And you know I have a very high-maintenance [young child, who's] got issues, you know..."

Many of the women believed their HIV status might be one reason their partners became very controlling and possessive in their behaviours. One participant described being stalked after terminating a relationship with her intimate partner:

"...He became my stalker after ah we had separated. I, I couldn't move from where I was. He knew where I was living. But I just, you know periodically I would have to change my number because somehow he would...get my number. And but he would always be driving around my house and you know, not coming to the door but just driving around and the one time he did show up..."

One participant was threatened with legal action:

"...And you know he was pretty upset you know like during that whole time you know when he kept you know blaming me and it was well we used to argue a lot over that and eventually you know it just got you know worse and worse you know like the arguments and shortly after that a friend of mine, she had ah, her and another lady had had a gentleman charged that was ah, infected them and that was in the paper. And my partner at the time, I didn't, I didn't tell him who, who this lady was, I didn't want him to know but when he seen that article in the newspaper one day he comes up to me and shows me this paper and then he's telling me you know he says, "If you ever leave me," he says, "This is what I'll do to you. I will take you to court. And I will tell, tell them that you infected me..."

Violence against HIV positive women may also act as a significant barrier to self care and overall health management. One participant described how being in a violent relationship delayed the shock and processes associated with HIV diagnosis:

"....Well I've been um, I was, I've been living with it since, since I met my partner, my son's dad um, he knowingly infected me. Um, I didn't find that out until like years later when he got sick and um..."

This participant goes on to describe how living in a violent relationship negatively affects her health and ability to deal with life's daily challenges:

"I think it affects me quite a bit. Just the energy to have to put up with it, you know, like um, you know look after my son and, you know, it, it, it, it's like I have two children instead of one, you know..."

For many AWHAs who participated in this study, being HIV positive led to verbal, physical and/or sexual violence perpetrated by current and former intimate partners, family and community members and/or strangers. It is clear that the HIV-related violence experienced by these women significantly undermines their ability to effectively manage their HIV illness, overall health and well being.



# RACISM, SEXISM & HIV/ AIDS: AWHAS' EXPERIENCES OF HEALTH SERVICES

This research aimed to develop a better understanding of how factors of gender, culture and HIV influence AWHAs' ability to address their HIV illness as well as their experiences of sexual violence. Participants were asked to describe the unique challenges they faced as AWHAs when attempting to obtain access to services and supports for both HIV and sexual violence. It should be noted that some AWHAs who participated in this study spoke of positive experiences in service provision, particularly those who had built lasting and healthy relationships with counsellors or spiritual leaders. However, many participants described negative experiences of HIV stigma, sexism and racism in their encounters with service providers. The following section presents some of the challenges and barriers to service provision AWHAs related to their gender, culture and HIV status.

Many of the participants in this study believed that their gender and cultural identity affected how they were treated by service providers. Discrimination against Aboriginal people in general and Aboriginal women in particular were common issues identified by AWHAs. Gender-based, cultural stereotypes including perceptions of the Aboriginal woman as a 'prostitute', 'junkie' and/or as 'sexually promiscuous' in health care settings, as well as other essential social services such as welfare and housing support, were reported by several participants. Even the perception of racist and/or sexist treatment was enough to cause emotional distress. The following quote provides an example of one participant's negative experience during her stay at the hospital and her interpretation of why she was treated the way she was:

"...I almost ended up in the psych ward. I took a bunch of pills, but it wasn't quite enough, almost. And, uh, I ended up in (local hospital) and that's just a horrible hospital too. You know they just...that-that look again, you know. You know. You know. And I could hear the nurses in the background, you know, "Well she tried to off herself and," blah, blah, and they're almost making a joke about it. And they lost my clothes. And then they asked me if I actually came in with clothes, and I mean they wouldn't ask a white person, you know, person, a lawyer or somebody like that something like that, you know. They wouldn't lose your clothes. Like, how do you lose somebody's clothes and ask me if I actually had clothes when I came in, you know...they found me like these awful clothes. It was just, you know, like I... and I just wanted just to go out and just get more pills but I didn't have any money because all my money was in my clothes, 'cause I just wanted to just finish it already, I just... you know. When I woke up in the hospital, I was just really disappointed that I woke up..."

Stigma and discrimination on the basis of their HIV status was a common theme among participant accounts of negative experiences with service providers. The following quote provides a description of a hurtful scenario when one nurse's ignorance about HIV caused this participant emotional distress:

"...I was in the hospital for this [skin infection], there was one nurse, she was a black nurse and she come to change the dressing and, uh, everything was fine, she had everything out there and then uh...She didn't have her gloves on or anything, you know, and then she went to pull my chart. As soon as she read on my chart HIV and Hep C. Holy moly her attitude changed and I said, "You know what? Get the f\*ck out of my room right now," and I started crying because she'd offended me, and uh they sent another nurse and they said, "Well what seems to be the problem?" I said, "Just her total ignorance towards me, and it upset me. I don't want her in my room..."

For the AWHAs in this study, stigmatization of their HIV status was often intertwined with discriminatory attitudes surrounding their gender and cultural identity as Aboriginal women. Because racism and sexism are

not always explicit, AWHAs sometimes identified 'feelings' of discrimination experienced when they used health services.

- "...Um, that's hard for, for me to say because um... I, I've never thought about it, you know. I, I just see myself as an, as a woman with HIV. I guess like how we, like for me I think the stigma, you know, you're, you're already treated like, as an Aboriginal woman like you're the lowest as you can go..."
- "...There is a few places where you will go and, uh, they seem to look at you the more dirtier because you're not only Aboriginal but now you got HIV on top of it..."
- "... when I get my blood work done, um, I don't know I just...because I don't know if it's because like um, somesome nurses and doctors they just, they don't, they kind of...I can feel that they're looking down on me sometimes, you know, like I get that feeling even though it's not, you know, they don't say it outright I can feel it you know. I think it does affect me [being AWHA] because like, um, if I didn't...if I wasn't HIV positive, I probably would be treated better. I would, I think, you know, but yeah.... Because they're always like oh how did...they always want to ask the question like how did you get it? You know like it's none of your business how I got it..."

Society's treatment of AWHAs creates a form of 'triple jeopardy' that contributes to continued social marginalization and isolation. This triple jeopardy can also create significant challenges to AWHAs' ability to mange their HIV illness, as well as to seek support for sexual trauma. The above accounts illustrate interrelated categories of prejudice based on race, sex and HIV status, which substantially undermine the quality of health services that AWHAs receive. When these prejudices are acted upon by health and social welfare providers, trust and confidence in service provision is undermined, which may lead AWHAs to avoid seeking those services.

# HOW AWHAS UNDERSTAND HEALTH & HEALING

An important objective of this research was to better understanding how AWHAs interpret health and healing and to learn what strategies they employ in their personal health management. We also wanted to examine what role, if any, culture and tradition plays in the healing process for AWHAs. To achieve this objective, we asked AWHAs which health services they found helpful and which services they found were not helpful when dealing with both HIV and sexual violence. We also asked them to compare how they felt about their experiences using Aboriginal health services and non-Aboriginal health services.

#### CHURCH, THAT'S MY HEALTH SERVICES. A SWEAT LODGE, THAT'S MY HEALTH SERVICES

AWHAs who participated in this study reported engaging in diverse, holistic practices and strategies to manage their health. When asked which health services they found helpful, participants identified a range of activities, including Aboriginal health centres, healing ceremonies, powwows, gatherings, Church and prayer, smudging, faith in the Creator, Elders and spiritual leaders, activism, western style counselling for HIV/AIDS, counselling for violence against women, writing, reading, going to the gym and attending to their diet. Some participants saw returning to culture and tradition as important elements of the healing process. Others emphasized religion and notions of 'forgiveness' as central to their recovery. To illustrate the diversity of health management approaches employed by AWHAs who participated in this study, we have selected the following quotations:

- "...Um, the only thing I do right now is like I smudge...and that helps me because I used to have bad dreams and stuff. Then when I do get bad dreams I do smudge, but lately I haven't been doing that, like...Um, I think it's been good because like, um, when you're in a sweat and you're good, you just-you're just letting out everything. You know you're trying to let-let go of stuff. So for me that has been good..."
- "...A lot of uh, when I first started healing I was um, I was travelling as an educator and travelling to come here to [AASO] conferences and skills building and participating in a smudge ceremonies and, and uh, different cultural practices that they brought in. It was beginning of my healing in a ways that um, I started, you know, practising different healing ceremonies and different methods from different cultures and participating in them. And they were very therapeutic in a way so it helped me..."
- "...Yeah. I think my biggest strength comes from uh, comes from uh, connecting with the Creator, God and that's where my strength comes from. And I can look back now on my life and uh, and I can see all these red flags that I didn't see. It was like uh, it's like looking back on a, looking back and seeing all the, the pitfalls and, that I didn't see and the, the flags and all the signposts and it's like looking back now, I can look back and, and uh, think to myself, why didn't I see that. It was like my eyes opened when I connected with my Creator and it was like he opened my eyes and I could suddenly see that um, he was the one that brought me through all those places, safely..."

The majority of AWHAs who participated in this study interpreted 'health services' as meeting more than just physical or medical health needs. Many of the participants described holistic visions of health and healing, which included aspects of spiritual, physical, mental and emotional health, which they felt to be unresolved in their lives. In fact, many participants felt that the ability to effectively manage their health was dependant upon resolving issues of sexual trauma. The quote below was a response given by an AWHA when she was asked which health services she found helpful. The quote depicts a vision of healing that attributes a higher value to aspects of her spiritual, mental and emotional health than to medical solutions for her physiological illness:

"...Everything from healing circles to, um, the meetings for alcoholics and narcotics, to the healing circles done for people living with HIV and AIDS at (ASO) to these conferences. This is what I consider my health services, 'cause they're with my vitality my longetivity (sic), and my healing you know. I don't need that healing in a f\*!kin' bottle. I need a healing in my heart and my soul, you know. Church, that's my health services.... A sweat lodge, that's my health services! ..."

The most positive response reported by participants in this study was the commitment and engagement of AWHAs in the fight against HIV/AIDS and violence against women. When asked what activities they enjoyed or hobbies they pursued, many participants identified activism and community support work as a strong source of enjoyment and fulfilment in their lives. A few volunteered and worked at women's shelters and resource centres. Some participants work the frontlines as outreach workers, distributing condoms, needles and food. Others spoke of the happiness they found in their positions working with HIV/AIDS organizations and committees at local, regional and national levels. A few participants discussed travelling across the country in an effort to educate Aboriginal communities, youth and leadership about HIV and AIDS. AWHAs from Vancouver spoke of their efforts to organize and mobilize AWHAs in their community.

"...I work in a drop-in centre, you know and a lot of our clients are homeless people, solvent abusers, and I like working there.....Mm, my favourite thing is working at the drop-in...like in the last couple of years. That is my number one favourite. And...well...I shouldn't say that it shouldn't be my number one favourite. Being with my grandchildren would be number one..."

The positive activities AWHAs reported being involved in can be seen as part of the healing process. Collaborating and associating with other PHAs and AIDS service organizations is providing AWHAs with the opportunity to reduce the social isolation they experience. The chance to make a difference in the cause of HIV and violence against Aboriginal women has provided a source of empowerment for many of the AWHAs who participated in this study.

#### THE HEALING PROCESS, IT'S A LIFELONG JOURNEY

Despite the resiliency illustrated in participant accounts of their positive responses to trauma, the AWHAs who participated in this study continue to face challenges to health management in their everyday lives. In the following quotes, two AWHAs discuss their efforts to address their HIV and the effects of sexual trauma on their lives:

- "...I went to, uh, I went onto all the appropriate medication and then I tried to start healing circles and all the positive things that I could do for myself and I still kept, had breaking down and turning to street drugs or alcohol and to this very day I keep picking myself up and I still have such really nice goals that I would like to meet before I go to spirit world, is to feel productive and important with society..."
- "...I kind of left the past behind and moved on but I was still in pain inside me, you know. All the things I went through in my community, I kind of tried to get the healing and I was grieving and I was constantly, you know, crying and hurting and it was hard to talk about it, but it but it was a relief. I took a lot out when I went to counselling and therapy and psychologists.... I went through counselling, spiritual counselling and I'm actually going to go back to counselling when I return home, after [career activity]. I think I need to go back and get more counselling because I really believe that the healing process, it's a lifelong journey of, you know, the healing process. It's not like an instant kind of healing..."

The difficulties AWHAs experience in their recovery and daily health management are fundamentally linked to the structural factors responsible for their social isolation. Systemic barriers, which cause Aboriginal women and girls to be at increased exposure to violence and HIV, are complicating the healing process by further exposing AWHAs to violence and to HIV stigma and discrimination. Society's apathy and disregard essentially re-traumatize AWHAs, compromising their health and healing efforts.

# PARTICIPANT RECOMMENDATIONS

This research project was designed to be action oriented. The findings were intended to inform and influence service providers and policy makers about how to create positive change in the lives of AWHAs who have experienced or continue to experience violence. To draw on the unique insights of AWHAs, we asked participants to provide recommendations about how CAAN and other service providers might improve the situations they face. We also asked participants what messages they would like to share with their community and political leaders concerning issues of HIV/AIDS and sexual violence. The following section will highlight the recommendations provided by AWHAs.

#### SAFE SPACES

Many of the recommendations given by the participants in this study reflect a strong desire and a critical need for 'safe spaces' where AWHAs can gather and address the various elements of their illness and traumatic life experiences in an environment free of fear and judgement.

Providing safe spaces entails consideration and accommodation of AWHAs' gender-specific health needs. Both the physical and psychological impacts of sexual trauma represent barriers for AWHAs attempting to get services. This participant suggests some ways in which HIV service providers might better meet AWHAs' needs in formal settings:

"...And the gatherings have got to be held, should have a lot of rape care, like if, for instances if, if a AWHA has a disability and wants to come and she's in a wheelchair, that she should be able to come and, if she's going to fly somebody's at the airport to pick her up and bring her here. And we would also have personal support workers to help, or a family member would come with that person but to also have a personal, couple of personal support workers available to help women with disabilities at our gatherings. This is what I, I'd really like to see because I think it's, it's so needed."

For some AWHAs who participated in this study, a truly safe space was described as one with no men present. Many participants felt that they had issues with men as a result of their experiences with sexual violence. Some AWHAs reported avoiding services where men were present. Avoidance of co-ed services also prevents AWHAs from associating with other AWHAs who use those services. Where men are the providers of service, particularly gynaecological services, AWHAs may avoid essential sexual and reproductive health services altogether.

Safe spaces could provide opportunities for AWHAs to confront their trauma, take back control of their lives, and heal from their past. Participants described reaching a place in their healing journey where they have come to understand the impact of sexual violence in their lives and the relationship between experiences of violence and their HIV status. Some of these women found strength, empowerment and even spiritual enlightenment in this discovery.

"...Sometimes when people have the authority... they take advantage and for people that are so vulnerable, like children, and there are so, you know, so much that a person becomes angry about, but we need to stop and say to our selves this happened to me. Now I have to go forward..."

One participant recommended that more information sessions and healing ceremonies be made available to AWHAs, especially those who had not yet made the association between their experiences of sexual violence and their HIV infection:

"...I think there should be more um, healing kind of a, sessions that take place um, at our gatherings, like a combination of those kinds of uh, gaining knowledge about uh, sexual trauma for instance and how it affects you, those kinds of things because maybe some women haven't made that connection..."

In addition to permitting comfortable and confidential discussions about the connections between sexual violence and HIV, a safe space would provide a secure and confidential forum to discuss AWHAs' physiological and sexual health issues. AWHAs who have experienced sexual violence feel uncomfortable discussing issues concerning their bodies, sexual health or sexuality in the presence of men. One participant suggested that there needs to be more information made accessible to AWHAs on the unique effects of HIV on the female body:

"...And, um, well I'd like to see more research done on women, on Aboriginal women. Like on, on scientific kind of stuff like um, on how the virus, if there's any differences in how the virus lives in our bodies. And uh, I'd like to see more information about the female body, like the anatomy, the workings of the body...I don't think women really understand sometimes that, why we're so vulnerable to HIV, you know that biologically vulnerable to HIV..."

#### ISOLATION

A prominent research finding identifies racism, sexism and HIV stigma as the root of AWHAs' experiences of social isolation. Feelings of loneliness and seclusion and the corresponding desire to meet, gather and collaborate with other AWHAs, were common among participants.

The period immediately following initial diagnosis of HIV infection can be particularly traumatizing and often involves feelings of extreme loneliness, despair, confusion and fear. Someone newly diagnosed may experience what can be described as a form of 'cognitive paralysis' in which regular life activities and thought processes are put on hold while the person tries to analyze what it means to be HIV positive. This critical time presents a unique opportunity to provide AWHAs with culturally appropriate and gender customized posttest counselling services and resources. Resources that allow AWHAs to identify and associate with other AWHAs are critically important to combating feelings of isolation. One participant recommended providing a book of stories about AWHAs:

"... You know that, um, that would be nice to have a book like that just for Aboriginal women. Like even transgender in there. Like young women, grandmothers... 'Cause you know, like for myself, when I was first diagnosed like I didn't want to go out and meet people or, you know, even to meet the first positive woman that I did meet or talk to over the phone.....But, you know, to have a book of other Aboriginal women that are positive, I think it would help a lot of women. Aboriginal women..."

Several of the AWHAs who participated in this study were living in same area of large city. A common narrative among these participants was the desire for more opportunities to associate with other AWHAs within their geographic community. Many participants discussed the need for a resource centre designed specifically and exclusively to address AWHAs' unique gender, cultural and HIV needs. One woman described Aboriginal women as possessing a unique world view, which encompasses a different language, sense of humour and gender identity. This participant felt that she could best identify with other Aboriginal women who shared her culture and gender, and if given the opportunity, felt she would greatly benefit from sharing her story with other AWHAs who shared similar life experiences. The following quotes discuss the importance of a centre, a safe space, for AWHAs in their neighborhood:

"...I would like, uh...what would be good is because some of us that, like, me for example is a slow learner and I would really love to get my grade I2 and, um, I just need support that's all...for-for women, you know. I know there...I know men are important that have HIV as well, but the women are...they're...we need, a community centre for women with HIV and women that are Aboriginal only because that's where we would feel safe and that I really, truly believe that's where I would have a great big pickup because I-I so pray for this all the time and just

go please open a native centre for women with HIV so I could meet my goals and learn from there and have a counsellor there and everything all in one building for-for Aboriginal women, is what...that's what I would need the most......Yeah, uh, getting the centre for us women so we can have someone to talk to about not only the HIV but to talk about how many times that we've been beat up and sexually abused by drunkards..."

- "...Well, just more support groups [for AWHAs]. Groups in general. There's no, like...there's AA there's this for that, there's that for this, but there's no real support groups for that [AWHA], where you can sit as a whole group and...or even you know a few people..."
- "...Yes I would, 'cause that's always been my dream, opening up a...I wanted to open up a women's centre for Aboriginal HIV... they should have a centre where women could go in there even if they're wanna lie down for a few hours or whatever and they don't have that there, right. I want...I wanna open up something, like I could, you know, I could rent a big house and make that into like a rooming house, right, and... 'cause there's a lot of Aboriginal women sleeping on the street... 'Cause you know like when you go to the [ASO], there are so many Aboriginal women going there and they have no food. They got nothing. They, if they, they should have a place like this where they can come in, use the phone, have some coffee..."

#### INUIT AWHAS: "I FEEL LIKE I'M THE ONLY ONE..."

Inuit AWHAs expressed their desire to see greater inclusion of Inuit women at APHA gatherings. As minorities within the AWHA population, feelings of isolation may be intensified:

"...Oh, okay. Um, yeah I would like them to communicate with more Inuit people, like to uh, contact this person and uh, get that person involved and you know, bring them, bring them to here or wherever we have our conference and stuff like that. I'd like to have the, more Inuit involved with it too because sometimes I feel like I'm the only one, me or [another Inuit AWHA], and I feel like we're the only two, where are the rest?..."

This participant went on to recommend how APHA service providers might attract more Inuit AWHAs to their events. She suggested that providing Inuit traditional foods and cultural activity workshops might draw more Inuit AWHAs to APHA gatherings. She also felt that returning to culture and tradition could be a source of spiritual healing for Inuit AWHAs.

"... You know, like I'd like to have more Inuit people get involved with the culture or their traditional, especially their uh, country food, you know, that would be wonderful because we love country food too, you know. It's very hard for us in the south to try to get some country food and it's not easy, yeah. So for me I find it's hard for us Inuit people to try to get these good tools that we, we need in the city, you know what I'm saying. It's like, oh I, I don't mind having a teacher to teach us how to make little moccasins or little mittens or gloves, you name it, just to occupy our mind, get it off our illness, you know. I think this is why a lot of people are so depressed, you know, it's because they have nothing to do in their life at times, yeah. So for me I don't mind having culture or, you know, something to keep us going. Because I seen a lot of them stay at their home, "Poor me, poor me, I'm ill, I'm sick, da da da..."

#### **BASIC NEEDS**

Many of the participants made recommendations on how service providers might better accommodate their basic needs. Entrenched poverty faced by many AWHAs who participated in this study made managing their health and well being a daily struggle. AWHAs whose primary source of income was welfare or disability benefits often found themselves unable to make ends meet. Basic needs such as food, clothing and shelter were often unattainable for some participants. For AWHAs caring for young children, the situation was more desperate. Where supply services are available, they are often inadequate to meet the needs of AWHAs. For example, free food distribution services such as food banks and community lunches were reported to be low in protein — an important dietary requirement for someone living with HIV/AIDS.

Governments and AWHAs also disagree about what services are essential to a person's health and dignity.

One participant shared her frustration about not being able to afford services she considered important to her well being.

"...Hm. I'd give us more money...well, yeah for food, for bills, I mean, they call luxury cable luxury, like our cable and our phone is luxury. Like you know. I'd like to get a computer..."

Resources which might be considered luxury by some may in fact be necessities for AWHAs. Communications services facilitate association with other AWHAs and are therefore an important tool for combating feelings of isolation. A computer with Internet access can be an important source of health information, support services and access to employment resources. Telephones are vital for obtaining emergency health services or making medical appointments, not to mention talking to family and friends. Even television can be an important source of comfort for AWHAs, offering also a chance to escape.

Some of the AWHAs who participated in this study saw a link between their inability to meet their basic needs and the structural inequities they experience in social life. AWHAs' marginalized social position may prevent them from obtaining equal access to resources and knowledge. One participant reasoned that the unfair treatment Aboriginal women experience when accessing services prevents them from accessing the resources and support they need:

"...In my books it's not [fair], because I see women, you know, I see women with kids. I see women, Aboriginal women, like they're so sick or they need, like a pair of socks or something like that, right? And you know and, me you know, 'cause I work out there with the working girls. I do outreach for (service provider) and I give them the condoms, the sandwiches and juice and a lot of these Aboriginal women they work on the street because they can't live on what they get on a single welfare....they need a place where they can go and they can get, like, you know how they can get free clothes, shoes, pills, whatever. 'Cause you know sometimes it's really hard to... Some of these doctors here, out here, they don't really give Aboriginal... they don't tell the Aboriginal what their rights are for medication.... And Welfare never tells them what they you know. You're allowed five-five crisis grant, right, I mean grant, not a grant, a crisis even if it's like clothes, food, but you're allowed five. And none of them know. They can, you the Welfare doesn't write it on a piece of paper and tell you what that your rights are, but I-I do. I did an applicant course and I know. And every time a woman needs someone to go with them to the Welfare office, I go, right? And, you know, and they... You know, I did a workshop at (Aboriginal service organization) about that. A lot of the women say they want... they like to know what they want, because, 'cause a lot of people like, people that are sick with cancer, whatever, they need, they need to know. But out here, if you don't stand up and speak up, then you don't find out..."

#### GREATER UNDERSTANDING OF CULTURE BY SERVICE PROVIDERS

When reflecting on how the services they received could be improved, many participants suggested a greater understanding and respect for traditional Aboriginal healing and medicine approaches. Here are two examples of participants' responses when asked if they felt that services providers should have knowledge of Aboriginal culture:

- "... I think they should like, like for me like going to sweats and sometimes um, you know, like I would like to um, complement like um, traditional and the western medications and, you know, like but even getting connected with someone who does that, you know. And like having my doctor maybe work with someone like that, you know, to see like, you know, how they fit together or, you know, if, if there, if it's good for me to take it or, you know, things like that..."
- "...smudging...uh yeah, like what's things mean, like values. The four directions. The appreciation of the four nationalities. Our-our animals..."



#### MORE SENSITIVITY BY SERVICE PROVIDERS TO SEXUAL VIOLENCE

Several participants expressed the importance of sensitivity to issues of sexual violence in the health care setting. Participants felt that nurses and doctors treating AWHAs should be aware of the impact of sexual violence in their lives and how sexual trauma affects many aspects of their health. The following quote illustrates how the effects of sexual violence can deter women from seeking out sexual health services. This participant believed that prior experiences of sexual trauma might be one of the reasons why Aboriginal women are avoiding HIV testing and why they tend to be diagnosed in more advanced stages of the illness:

"....Well a lot of women, like even for myself when I talk about it, they talk about the triggers. Especially for Pap smears and having to have it done every six months like it's very, well sometimes it's um... If the person that, that's taking the Pap smear is not very sensitive around these issues then it uh, creates a lot of triggers and traumas and, and uh, the system that is used, especially when it comes to having to insert something inside the body and the woman's been physically violated in ways with different kinds of objects, having to be traumatized it's, it has to be some kind of steps that they need to take to, to um, help the person get that done without feeling violated..."

Generally speaking, participants recommended that there be more accessible sexual violence services in the health care setting. Some participants said they would like to see more Aboriginal women working as nurses and doctors because they felt that Aboriginal women would likely have a better understanding and be less judgemental of their life circumstances. One participant said she wanted to see an Aboriginal medicine woman made available by a service provider in her area. Another participant proposed that HIV counselling services, including pre-test and post-test counselling services, should address the impacts of sexual trauma on patients.

#### DO MORE RESEARCH

It is often said that Aboriginal peoples are resistant to research as a result of past experiences with research initiatives, which caused more damage than good in their communities. However, several AWHAs who participated in this study stressed the immediate need for more research on violence against Aboriginal women as well as more research on how HIV is affecting Aboriginal women differently than other (A)PHAs.

"... Do more studies and make maybe let them know like what's-what's really happening...like what the heck, really look at it. If you look at the violence...Like really look at her, 'cause it's crazy. 'Cause there's so many... Yeah. Because like there's so many women out there who are not saying anything...who are just keeping it quiet 'cause they're getting threatened at home, you know what I mean? I know what it's like, believe me. I know when I had to keep my mouth shut. I remember all those...I remember I had to keep my mouth shut and whatever. If I opened my mouth I'm getting it when I get home and, uh, it's just all kinds of things, it's like...and I believe it. There's a lot of women that are probably running around that are Aboriginal and not saying anything..."

Some of the AWHAs who participated in this study saw the issue of HIV/AIDS as only one component of the complex web of factors influencing their life circumstances. Participants recommended that HIV research on Aboriginal women must look deeper into conditions of intergenerational trauma and gender-based violence in Aboriginal communities. The participant quoted below considers HIV to be a product of the life experiences of trauma and loss that affect the emotional and spiritual health of Aboriginal people:

"...they should have more surveys and they should have more sh\*t like this that-that...you know...not only to the specific questions but like gets down to the emotions because I just feel that our emotions and feelings are so f\*!kin' vital to getting the questions that you...like the answers to the questions that you do need, you know. 'Cause I mean it's not, it's not just about-about the HIV man, it's about all the f\*!kin' sh\*t that leads up to it. It's about the whole story..."

#### STOP THE VIOLENCE: " SHOW OUR WOMEN THE RESPECT THEY DESERVE!"

By far the most common recommendation given by AWHAs who participated in this study was to **stop the violence against Aboriginal women and girls.** This was the most frequent answer to the question: "what would you say to your community leaders?" For many AWHAs in this study the violence they experienced in their past or in their everyday lives was the most important issue they faced and the greatest challenge to their personal health management. Moreover, many participants felt that, if it weren't for the violence and multiple experiences of trauma they experienced, perhaps they would not be HIV positive today. Although participants did discuss their aspirations to see Aboriginal leadership address issues of stigma and HIV/AIDS in their communities, many felt that the issue of violence against women was of primary importance. The message was "address violence first, HIV second".

Many AWHAs recognized the violence they have experienced, and continue to experience, as part of the overall impact of colonization on Aboriginal peoples. They understand that the violence they have experienced is rooted in the intergenerational impacts of residential schools on their communities. However, the participant quoted below reminds us that regardless of the 'reasons', it is time to put an end to the cycle of violence:

"...I don't care what they been through, but, you know, everybody makes their own choices in life...and we gotta stop this cycle. Yeah. Too many innocent women are getting killed you know and beaten for no reason at all? Like, sure there may be a reason, but still, the reason is not good enough. There is no reason to beat us up. You want to beat something up? Go outside and go pick a fight downtown or something or break something you know or take your anger out on something else..."

Some AWHAs spoke of the structural inequities and negative social perceptions of their gender and cultural identity, which they believed to be partially responsible for their increased exposure to violence. The participant quoted below recognized that the discrimination and violence Aboriginal women face is systemic and based on the presumption that the Aboriginal woman is a disposable sexual object:

"...I would um, like to be shown some kind of respect by the law enforcements, or the people that um, in the justice system, especially with the police that um, are extremely violent towards women. I'd like to see some kind of an education around um, sexual violence and, and more violence by being confrontational with, especially with Aboriginal women, where they feel that they have to be defensive in ways that, that's the only way of survival for them. And um, I'd like to see some source of um, sensitivity happening around um, Aboriginal women that have experienced sexual violence, sensitivity training around it. Make it a priority, especially for Aboriginal women..."

"There was some women that walked across Canada, Walk for Justice, that made it to Vancouver.... I lost one of my cousins along the Highway of Tears, she was murdered. Sometimes I wish I was there to protect her but, you know, but I work so hard at just trying to protect myself. That really just, you know, run into these things that, that we have to face as Aboriginal women and it's not an easy road for us. And we need to have this thing changed about our image as um, sexual objects that, you know, that's there for anybody's disposal, whether they're Native or non-Native. We need some kind of healing there, happening with our men, to show us some kind of respect and show our women our, the respect that they deserve..."

A few participants spoke of a time in the history of Indigenous cultures when women were respected and honoured — a time when men protected women. They expressed the need to return to this way of life. The participant quoted below viewed the devaluation of women's gender position within Aboriginal communities as connected to women's exposure to HIV and sexual violence:

"...At one time men were - protected women in our cultures. It was on, it was an equal partnership. That's why we have no word for he or she in our languages, there's no gender separation, because we were equal. Men protected women. But that view is so skewed now that our Aboriginal leader, even our Aboriginal leaders might

think we're disposable as HIV positive women, that we don't matter, that we're number 25 on the list of priorities that leadership has to deal with. Or HIV is number 25 in that long list of priorities and uh, Aboriginal women with HIV are number 30 in that long list of what our leaders need to address. It has to be in, within the one to five, you know, priority... We've adopted the patriarchal thinking. Our men have adopted that for the most part, the view of uh, that skewed view of their own women, you know, that sexual violence happens and, and sometimes they're the perpetrators too. It's - so much work needs to be done, so much healing..."

Many of the AWHAs who participated in this study gave a strong and clear message to their leaders and their community members. They want to see an end to the imagery that defines Aboriginal women with HIV as expendable. They want to see the natural balance and partnership between women and men restored within their cultures and communities. They want to be treated with the respect they deserve. Above all, they want an **end to violence against Aboriginal women and girls**.

## DISCUSSION

The pathways through which experiences of childhood abuse lead to future violence in the lives of Aboriginal women with HIV are multifaceted and interwoven. However, to develop successful programs and policies, we must attempt to understand this complex web of determinants.

#### CHILDHOOD EXPERIENCES

Abuse and neglect in childhood create both direct and indirect exposure to future violence among Aboriginal women. In the most general sense, abuse of any kind damages children's self esteem, their belief in a just world and their trust in other human beings. Research in this area has linked experiences of childhood abuse, victimization and witnessing the abuse of others with poor mental health in general and the development of post-traumatic stress disorder in particular (Choi, Reddy, Liu, & Spaulding, 2009; Martinez, Hosek, & Carleton, 2009; Meade, Kershaw, Hansen & Sikkema, 2009). According to researchers, physical and emotional abuse can cause disruptions in the development of children's self esteem that can become evident later in life as either extreme passivity/apathy or intense aggression, both of which create exposure to violence (Brayden, Deitrich-MacLean, Dietrich, & Altemeier, 1995; Finzi-Dottan & Karu, 2006; Maxwell, 2003; Parker & Benson, 2004).

Sexual abuse has an even more profound impact, often destroying children's trust in not only the abuser, but in people generally (Walker, Holman & Busby, 2009). Children who are sexually abused do not learn how to establish sexual boundaries as they grow older, thereby, perpetuating their exposure to further sexual exploitation and victimization (van Roode, Dickson, Herbison & Paul, 2009). In an effort to cope with the abuse, children frequently dissociate from the experience and can develop dysfunctional sexual practices in which they assume a passive role (Bowyer, 2009; Frost-Pineda, 2008). The role of neglect in creating exposure to violence lies in its capacity to undermine children's self worth and create a deep need to be loved and valued; sometimes to the extent that they will tolerate future violence (Bowyer, 2009; Chambers & Potter, 2009; Merrick, Litrownik, Everson & Cox, 2008).

The connection between the legacy of residential schools and the abuse of Aboriginal children has proven to be substantial and destructive (Cuomo, Sarchiapone, Giannantonio, Mancini & Roy, 2008; Million, 2000). In many cases, addictions and the subsequent abuse and neglect of children can be traced to the trauma experienced by parents and grandparents who attended residential school (MacLachlan, 2007; Miller, 2003). Similarly, foster care appears to be a potential threat to the physical, emotional and sexual well being of Aboriginal children, as many have reported abuse within this context (Gramkowski, Kools, Paul, Boyer, Monasterio & Robbins, 2009; Jacobs, 2008; Onyezia, 2009).

Overarching the impact of abuse and neglect on the emotional, physical and spiritual health of Aboriginal children is the role of drugs and alcohol as a means of coping with the trauma of these experiences (Chambers, 2005; Hamburger, Leeb & Swahn, 2008; Hayatbakhsh, et al, 2009;

University of Montreal, 2008). The research literature has established a strong relationship between the mental health impacts of trauma and the misuse of drugs and alcohol (Haller & Miles, 2003; Haller & Miles, 2004). As an example, Walker, Scott and Koppersmith (1998) found a link between the severity of child sexual abuse and the extent of future alcoholism. Others have discovered that witnessing the addictive behaviours of one's parents can normalize the activity, encouraging children and youth to use drugs and alcohol, particularly to deal with life stress (Holt, Buckley & Whelan, 2008; Werner, Alain Joffe & Graham. 1999).

#### SOCIAL DETERMINANTS

Disadvantages such as lack of opportunities, poverty, racism and punitive social services are mutually reinforcing and heighten women's exposure to violence. Racism against Aboriginal women perpetuates racially motivated physical and sexual violence, as well as diminishing women's opportunities for education

and employment, as well as their sense of optimism about the future (Doyle-Bedwell, 2008; Dylan, Regehr & Alaggia, 2008; Hoagland, 2007; Tyagi, 1999; Wallace, 2007). Lack of opportunities can lead to poverty, dependency on others, including social services or men, and potential involvement in the sex trade (Gowans, 2001; Kwesiga, Bell, Pattie & Moe, 2007; Kurz, 1998; Petterson & Friel, 2001; Rice, 2001; Scott, London & Gross, 2007).

The stress and/or depression caused by these circumstances, and often exacerbated by past trauma, induces some women to use drugs and alcohol (King & Chassin, 2008; Reed, Anthony & Breslau, 2007; Weaver, Haston Turner & O'Dell, 2000). Unfortunately, social services, intended to assist vulnerable women, repeatedly generate additional stress by creating a punitive environment, rather than a nurturing one (Cooper Altman, 2007; Haight, Shim, Linn & Swinford, 2007). Women are essentially left alone to attempt to deal with past and current traumas, thus diminishing their capacity to safeguard against future violence.

#### GENDER INEQUITIES

The physical, economic and social impact of inequitable power relations between Aboriginal women and their male partners is well documented in the literature (Comaskey & Marquis, 2001; Liodakis, 2009; McGillivray, 2001; Stirbys, 2008). In the context of Aboriginal women with HIV, particularly those who are living in conditions of poverty and/or with addictions, partner selection can be somewhat limited (Rotheram-Borus, Desmond, Comulada, Arnold & Johnson, 2009). As a result, women may partner with men who tend to be more violent and exploitive of women and who attempt to control them through money and/or drugs. In some instances, men encourage their female partner to use drugs, thereby facilitating her eventual addiction and perhaps even her subsequent work in the sex trade (Dalla, 2001; Earls & David, 1990; Women of the World, 2004).

The interpersonal violence (physical, emotional and sexual) of these relationships leads women to fear men in general and their partners in particular (Avakame, 1998; Haskell & Randall, 1998; Sev'er & Cheryl, 2004). This fear facilitates further violence in two ways: I) women are often reluctant to leave an abusive relationship because they fear retribution by their partner (Hamby & Gray-Little, 1997; Richards, Rollerson & Phillips, 1991; Shoos, 2003), 2) in an attempt to circumvent violence, women may become excessively passive with men, yet, this passivity can actually create further exposure to abuse/exploitive men (Castano, 2006; Ruiz-Perez, Mata-Pariente & Plazaola- Rothenberg, 2003).

One of the most perplexing factors deterring women from leaving abusive relationships is love for the abuser, which does little to diminish further violence. Some researchers and clinicians believe that this attachment emerges from neglect in childhood (Feiring, Taska & Lewis, 1998; Mcgee, Wolfe & Olson, 2001). Child physical and sexual abuse may also increase women's tolerance for violence, making them less likely to leave an abusive partner. Many people do not understand this form of attachment, however, failing to appreciate the role childhood experiences play in forming women's self concept and relationships.

#### SELF CONCEPT

The role of self concept in heightening Aboriginal women's exposure to violence cannot be overstated. Cumulative trauma, particularly by caregivers and loved-ones, often devastates women's self esteem and frequently leads to self blame. When linked to sexual abuse, addictions and the effects of HIV medication, women also may suffer from negative body image (Clark & Griffin, 2008; Price, 2005; Treuer, Koperdak, Rozsa & Furedi, 2005). The anger, resentment and betrayal women experience can lead to poor mental health and/or addictions, which, along with self blame, negative body image and diminished self esteem, can lead to lack of self care (e.g., physical, mental, spiritual, sexual and emotional health) (Peltzer & Hobbs Leenerts, 2007). When women feel badly about who they are, they are more likely to become exposed to violent men and are less likely to appreciate their own value and their right to live without exploitation and violence (Bulanda & Majumdar, 2009; Chuang, Liebschutz, Horton & Samet, 2006; van Roode, Dickson, Herbison & Paul, 2009).

# POLICY RECOMMENDATIONS

### (WISE PRACTICES)

#### 1. CULTURALLY & GENDER SAFE HIV & HEALTH SERVICES

HIV service provision in Canada has historically been designed to accommodate the needs of gay men. As a result, Aboriginal people and women living with HIV have been pushed to the margins of HIV service provision. More recently, there has been an emergence of Aboriginal specific HIV service provision, which aims to accommodate the unique social and cultural needs of APHAs. Yet AWHAs continue to face gender barriers to HIV service provision, even within Aboriginal AIDS Service Organizations (AASO). Many of these barriers are directly related to AWHAs' experiences of sexual violence and corresponding fear and mistrust of men.

- Existing AASOs must re-evaluate how adequately their organizations and service providers have considered the unique gender needs of AWHAs and take active measures to accommodate these needs. AASOs need to ask what services are being provided to assist AWHAs and how the quality of services they receive can be improved. More female staff, childcare services, women-specific gatherings, meetings and workshops, rape and disability care, confidential sexual violence counselling services and information on the unique effects of HIV on women's bodies were among the ideas put forward by participants in this study on how AASOs might reduce the gender barriers to adequate HIV service.

# 2. INCREASED AWARENESS BY HIV & HEALTH CARE PROVIDERS OF THE ROLE OF VIOLENCE IN ABORIGINAL WOMEN'S LIVES

AWHAs who participated in this study spoke of the powerful influence of sexual trauma on their ability to manage their health and wellness. For AWHAs the experience of sexual violence can act as a significant barrier to seeking health services. They may avoid sexual and reproductive health services to avoid becoming emotionally triggered by routine medical procedures such as pap-smears or Sexually Transmitted Infection (STI) screening. This may also be a reason why Aboriginal women are less likely than Aboriginal men to pursue early HIV testing. When AWHAs are involved in violent relationships, their ability to attend to their health is compromised.

- Efforts must be taken to educate health and HIV service providers on the role of sexual violence in the lives of AWHAs, including how sexual trauma can deter a woman from seeking health services. Strategies should be developed to address the effects of sexual violence. Specifically in the context of sexual and reproductive health services, procedures should be developed to accommodate sexual trauma survivors. HIV and STI clinics should provide trauma counselling referrals and where possible have counsellors onsite or on call. Referral resources should reflect a balance between western style counselling and traditional Aboriginal healing practices.

#### 3. INCREASED SERVICES FOR AWHAS & THEIR CHILDREN

AWHAs face unique challenges balancing their personal health with the needs of their families, for whom they are most often the primary providers of care. Often AWHAs must ration very limited financial resources between themselves and their children. Under these circumstances, AWHAs may be compelled to place their children's basic needs above their own.

- Resources should be made available that assist AWHAs with these challenges. Increasing the availability and accessibility of family services and resources such as food, school supplies, clothing and affordable housing for single mothers will free up AWHAs' existing resources for their own health needs. Affordable and culturally appropriate child care services can also help by affording AWHAs more time to attend to their personal health and well being.



# 4. CULTURALLY APPROPRIATE & GENDER SPECIFIC COUNSELLING SERVICES

AWHAs who have experienced sexual violence often attempt to address their trauma by actively seeking out counselling services of various forms. Overcoming past trauma is often connected to a person's ability to manage their HIV illness. While some AWHAs who participated in this study discussed the helpfulness of western style counselling, several others used traditional Aboriginal healing tools and strategies as their primary source of trauma care. Many AWHAs reported combining traditional and western health approaches in an effort to cope with their experiences and manage the HIV illness. Religion was also described as an important source of healing.

- Counselling services and service providers associated with programs for women who have experienced violence (including, for example, those who work in abused women's shelters and safe housing programs) should be aware of the potential role and importance of culture and tradition in AWHAs' understanding of healing. Service providers should also be made aware of the transformation and devaluing of Aboriginal women's gender position in their communities. The loss of Aboriginal women's traditional gender position may influence perceptions of their self worth and may have caused them to internalize denigrating images of themselves. Mental health has significant influence on an AWHA's ability to comprehend and cope with sexual trauma.

# 5. PROVIDE OPPORTUNITIES FOR A BORIGINAL WOMEN TO HELP THEMSELVES & TO HELP ONE A NOTHER: SAFE SPACES

Gender discrimination, cultural inequity and the stigma associated with being HIV positive, have placed AWHAs in extreme social isolation. AWHAs are isolated even within the HIV community, where the needs of men and non-Aboriginal women are prioritized. Participants in this study described facing isolation even in urban centres, where many HIV resource centres were available.

- AASOs should ensure that they are able to provide a 'safe space' for AWHAs. Existing AASOs should assess how well they are meeting AWHAs' gender specific needs, identify the gender-based barriers preventing AWHAs from accessing their services, and devote the necessary human and financial resources to filling gender gaps in service provision. For example, AASOs could provide gender-specific programming, such as women-only events and workshops, female Elders and Medicine women, violence against women counselling services and child care accommodation and transportation support.
- In areas where large numbers of AWHAs reside, HIV service centres designed specifically to meet the unique gender, culture and health needs of AWHAs are imperative as many AWHAs are deterred from using both mainstream HIV services and Aboriginal health services where men are present. AWHA specific centres would also provide opportunities for AWHAs to associate and gather together, reducing their social isolation, and ultimately improving their ability to manage their HIV illness. Moreover, AWHA-specific centres would provide a forum where AWHAs could share their experiences of violence. By providing safe spaces for AWHAs, service providers will create opportunities for AWHAs to help themselves and help one another to overcome their experiences of trauma and live a fulfilling and dignified life with HIV/AIDS.

#### 6. INTEGRATION OF HIV/AIDS AND VAW SERVICES

Violence against women (VAW) and HIV are deeply interrelated, particularly for Aboriginal women. VAW makes women vulnerable to HIV and HIV makes women vulnerable to increased violence. This research also found that VAW has significant effects on AWHAs' ability to manage their personal health and well being. Violence may also cause social and financial costs to the family, which may undermine health and healing.

There is a critical need to increase integration of VAW and HIV policy and programming. Integration of VAW and HIV means making both services available in the same location and presented as reinforcing and

complementary services. For example;

- Legal advocates working to end VAW can make information available to their clients about rights and services relating to HIV/AIDS;
- HIV and harm-reduction outreach workers could provide information on access to legal resources to combat VAW, as well as information on how violence relates to HIV.
- Health services for women who have experienced violence should when necessary be able to provide HIV test kits, Anti-retroviral therapy (ARVs) and condoms.
- Counselling services devoted to VAW or HIV should have adequate knowledge and skills to provide therapy in both areas.
- Pre- and post-test HIV counselling services that serve AWHAs should also develop strategies to assess the risks faced by women currently involved in violent relationships and help clients to develop harm reduction strategies to reduce those risks.
- Service providers should assess the risks of disclosing an HIV positive status to a violent partner and how violence may affect AWHAs' ability to mange their health.

# CONCLUSION

When viewed together, it is clear how childhood experiences, social determinants, gender inequities and negative self concept make Aboriginal women particularly vulnerable to violence. Physical, emotional and sexual violence heightens exposure to HIV infection through injection drug use, sex trade work and an inability to negotiate safer sex.

Aboriginal women living with HIV are among the most vulnerable individuals in Canadian society. Yet the violence perpetrated against them seemingly goes unchallenged and unabated. The neglect of these women must be viewed as a national tragedy for which we must all take responsibility.

Working closely with Aboriginal people living with HIV and violence, researchers must document their experiences. Health promotion program planners must also work with women and community advocates to develop and implement interventions that address real needs. Finally, political leaders, both Aboriginal and mainstream, must possess the will to establish policies that support community interventions that might stem the tide of this epidemic of violence against Aboriginal women, particularly those who are living with HIV.

This study was designed to develop a greater understanding of the effects of sexual violence on the lives of Aboriginal women living with HIV/AIDS, to explore the interplay between sexual violence and culture, and to identify the distinctive features of the female Aboriginal experience of sexual violence and HIV infection. The sexual violence experienced by the AWHAs who participated in this study occurred in a general climate of violence against Aboriginal women, which often begins with exposure to violence in childhood. Furthermore, violence against Aboriginal women and girls is deeply rooted in a legacy of colonization, including the experience of residential schools. The findings of this study indicate that the experience of HIV and sexual violence compounds exposure to both. Violence produces negative emotional and mental outcomes that can lead some Aboriginal women to employ coping strategies that place them at greater risk of HIV infection. In turn, Aboriginal women who are HIV positive may be at greater risk of violence at the hands of intimate partners, family and community members, and society at large.

Sexual trauma and the stigma and discrimination associated with being HIV positive have very serious implications for the mental, emotional, physical and spiritual heath of AWHAs. The women who participated in this study held diverse and holistic understandings of health and healing and sought both traditional healing practices and western approaches to health management. However, racism and sexism undermined their mental health and blocked access to adequate health and social services. The effects of sexual trauma can even deter AWHAs from using health services, including reproductive and sexual health services, at all. Culture, gender identity and HIV status combine to create a triple-jeopardy, leading to the social marginalization and isolation of AWHAs within Canadian society.

Our research was designed to be action-oriented — to inform policy and programming, leadership and community members about how to improve the situation for AWHAs. This report highlights some of the many actions that could better meet the unique gender and cultural needs of AWHAs who have experienced violence. Above all, we hope that the findings presented in this report have illustrated the urgency of this issue and will inspire and assist in efforts to end violence against Aboriginal women and girls.

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