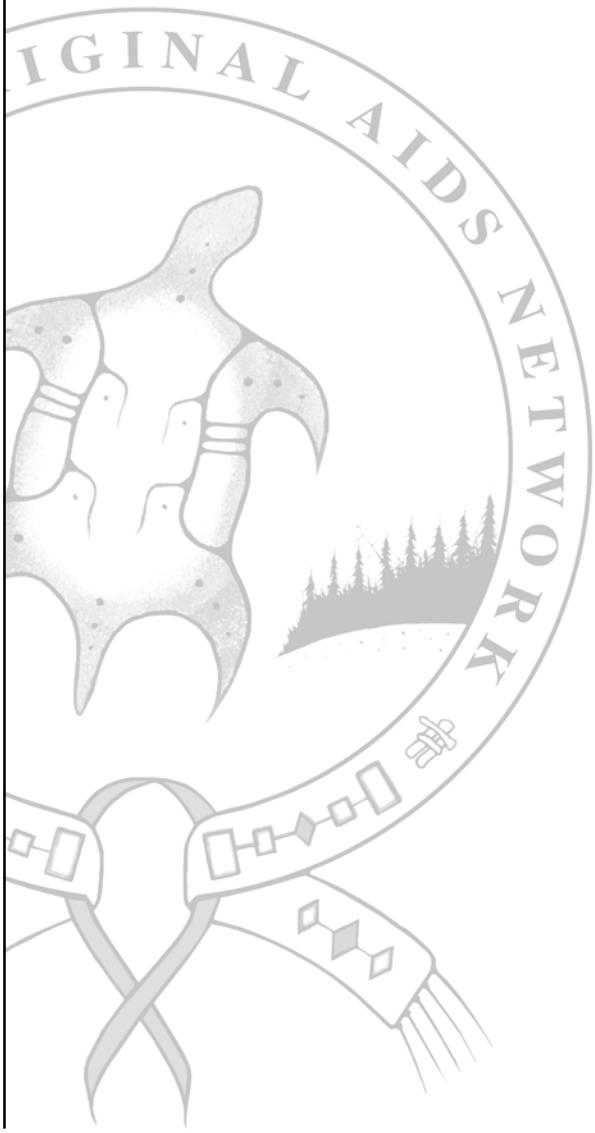
HIV/AIDS AND ABORIGINAL WOMEN, CHILDREN AND FAMILIES

A POSITION STATEMENT



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The Canadian Aboriginal AIDS Network (CAAN)

Overview

Established in 1997, CAAN:

- is a National and not-for-profit organization.
- represents over 160 member organizations and individuals.
- provides a National forum for members to express needs and concerns.
- provides relevant, accurate and up-to-date information on issues facing Aboriginal people living with and affected by HIV/AIDS in Canada.
- is governed by a twelve member National Board of Directors and operated by a four member Executive.

Mission Statement

The mission of the Canadian Aboriginal AIDS Network is to provide leadership, support and advocacy for Aboriginal people living with and affected by HIV/AIDS regardless of where they reside.

Acknowledgements

Thank you to members of the National Steering Committee who generously gave of their time and expertise in responding to questions, comments and drafts of this paper. It was an honour to work with you. Thanks also goes out to Kevin Barlow and Randy Jackson for your direction and advice.

Disclaimer

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"Brenda is a Cree woman from Northern Alberta.…When she speaks to me of her journey [with HIV], I am humbled by the strength and determination with which she forges ahead despite the never-ending roadblocks she encounters. I am also humbled by the grace with which she conducts herself in a society that often judges her according to her past. She embodies the spirit and strength of every Aboriginal woman I know."

– Catherine Baylis 2001:124

Introduction

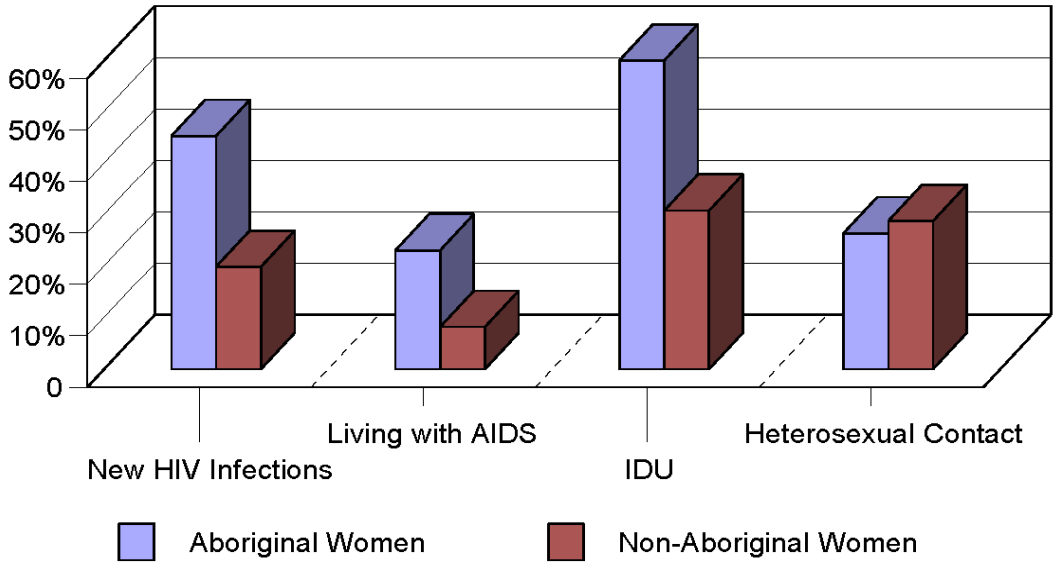
The purpose of this position statement is to draw attention to key issues facing Aboriginal women, children and families who are infected or affected by HIV/AIDS, and to act as a call to action.[1] Aboriginal women are greatly over-represented in HIV/AIDS statistics, yet there is a startling lack of gender-specific, Aboriginal-specific, HIV/AIDS resources, programs and services to support them.[2] Aboriginal women are the caregivers of their communities, and while they have repeatedly shown themselves to be strong, resilient and undaunted by hardship, they can not be expected to bear the burden of HIV/AIDS in Aboriginal communities alone. Governments, communities, health centres, and AIDS service organizations must recognize their responsibility to Aboriginal women and begin to provide the Aboriginal, women-specific research, programs, services and supports they need.

Epidemiology

The rate of new HIV infections among Aboriginal women in Canada has been steadily increasing over the past two decades. Aboriginal women now account for approximately 50% of all HIV-positive test reports among Aboriginal people, compared with only 16% of their non-Aboriginal counterparts (DesMeules et al. 2003:68). Aboriginal women comprise nearly 25% of reported AIDS cases among Aboriginal people, while non-Aboriginal women account for only 8.2% among non-Aboriginal cases (Health Canada 2003).

Alarmingly, a large and increasing portion of HIV infections are occurring in young Aboriginal women between 15-29 years old. Between 1985 and 1995, roughly 13% of HIV-positive test reports among Aboriginal women were in young

HIV/AIDS among Aboriginal and non-Aboriginal Women, 2002



"Source: Health Canada, HIV/AIDS Surveillance Report for December 31, 2001."

[1] This is not intended to be a comprehensive research document. The sources consulted consist of community-based research papers, government reports, journal articles, and other documents from the Canadian Aboriginal AIDS Network's (CAAN) resource library. A set of recommendations that address the gaps in programming, resources, research and funding are offered for future consideration and action.

[2] Despite the lack of funding for Aboriginal, women-specific services, some Aboriginal organizations have seen the need for women-specific services and responded to the extent their limited resources would allow (McKay and Pratt 2002).

women in this age group. However, this percentage has increased steadily to approximately 37% in 1998 and 45% in 2001(Gatali & Archibald 2003). Considering that almost 50% of the Aboriginal female population is under 25 years old, these are particularly frightening statistics (Dion-Stout et al 2001: 11).

Injection drug use is the main mode of HIV transmission for Aboriginal women, followed by heterosexual contact, sometimes with partners who use injection drugs. In 2002, 64.9% of reported AIDS cases among Aboriginal women reported their exposure category as injection drug use, and 30.9% reported the mode of transmission as heterosexual contact (Gatali & Archibald 2003:5). Research studies with injection drug users in Vancouver indicate that Aboriginal women are over-represented in the IDU population and consequently are overrepresented in HIV+ test reports with IDU as known mode of transmission (Craib et al 2003:4; Spittal et al 2002).[3]

Recommendation #1 - Develop a national response to HIV/AIDS that is designed, developed and implemented by Aboriginal women.[4]

< *Aboriginal women and Aboriginal women with HIV/AIDS must be integral in the design and delivery of these initiatives.*

< *Provide targeted prevention and education initiatives for Aboriginal women, particularly in relation to IDU.*

< *Provide targeted prevention and education initiatives for Aboriginal women between 15 - 29 years old.*

Factors Influencing Aboriginal Women's Vulnerability to HIV Infection

The HIV/AIDS epidemic was originally thought to afflict only men who have sex with men. However, recent studies have shown, and incidence rates have confirmed, that for a combination of biological, epidemiological, and socioeconomic reasons, women are twice as vulnerable to HIV infection as their male counterparts (Gatali & Archibald 2003). Research and incidence rates also confirm that Aboriginal women are epidemiologically and socio-economically more vulnerable to HIV infection than non-Aboriginal women.

Of the many factors that increase Aboriginal women's vulnerability to HIV infection, a common undercurrent is colonization. Intensive and sustained efforts on the part of the government to colonize Canada's Aboriginal peoples have had adverse affects on the socioeconomic status of Aboriginal women. Aboriginal women are twice as likely to be poor than their non-Aboriginal counterparts, and they are more likely to live in an environment where substance abuse and spousal violence are widespread (Dion-Stout et al 2001:15-16; Barlow 2003; Mill 1997 & 2000). These socioeconomic conditions are strongly associated with a positive HIV test result for Aboriginal women and they contribute to the creation of harsh living environments in which techniques used to simply survive often include high-risk behaviours such as rural to urban migration, homelessness, sex trade and / or sex work, injection drug use, and alcohol abuse (Mill 1997; Ship et al 2000; Neron 2000).

[3] Further support for this comes from the All Nations Hope AIDS Network in Regina. The ANHAN needle exchange program exchanged 1.4 million needles in 2003; the highest rate per capita for any city in Canada. Seventy-nine percent (79%) of exchanges were with Aboriginal people and 59% were with women (M. Akan, personal communication).

[4] The recommendations outlined in this paper are based on the identified gaps in research, programs, services and funding. Some of the recommendations are reiterations of those made by the National Conference on Women and HIV/AIDS held in 2000. These are marked with *. Others are the result of consultations with the National Steering Committee members who are themselves Aboriginal women living with HIV/AIDS, or have worked with Aboriginal women, children and families.

Not surprisingly, these same socioeconomic conditions have had an impact on the overall health of Aboriginal women. On average, Aboriginal women can expect to live 7-10 years less than non-Aboriginal women, they are more likely to report illnesses such as diabetes, heart disease and arthritis, and they are considerably more likely to experience sexually transmitted infections (Dion-Stout et al 2001:12-14; OFIFC 2002). While sexually transmitted infections have been shown to have a direct impact on HIV vulnerability, there is also evidence to indicate that poor health in general increases vulnerability to HIV by compromising the immune system (ANAC 1996:12).

Recommendation #2 - Integrate HIV/AIDS prevention and education into job training programs, life skills education, nutrition workshops, and healthy lifestyles training.

< *Since poverty is directly related to HIV vulnerability, increasing meaningful job opportunities and job training for Aboriginal women will, over time, decrease their vulnerability to HIV infection.*

< *Train Aboriginal women who are familiar with street life and can relate to the experiences of Aboriginal women who are vulnerable to HIV infection to deliver this training.*

Gender Roles, Self-Esteem and Violence Against Women

There are many factors associated with gender, and a power imbalance between genders, that increase Aboriginal women's vulnerability to HIV infection. For instance, studies show that repeated physical and sexual abuse is strongly associated with a positive HIV test report (Barlow 2003; Mill 1997 & 2000) and that Aboriginal women are significantly more likely than non-Aboriginal women to have experienced all kinds of violence, including physical and sexual abuse (DesMeules et al 2003: 68; Dion-Stout et al 2001:13)). When women are forced, or coerced into having sex against their will, the likelihood of contracting HIV is increased; their abusers are unlikely to wear condoms and women are unable to insist that they do so, and the likelihood of tears or abrasions to the women's genitals is increased which in turn increases the likelihood of HIV transmission.

Repeated sexual or physical abuse affects women's vulnerability in others ways as well. Women who experience abuse are highly likely to be poor, have limited access to education and employment, have low levels of self-esteem and often turn to alcohol and drugs as a way of coping and reducing the pain or post-traumatic effects of sexual abuse and other traumas (Neron 2000; Ship et al 2000; Baylis and Loyie 2001). The experience of abuse often results in powerlessness in intimate relationships and an inability to negotiate safer sex, even during consensual sex. The following passage highlights the impact of abuse and gender imbalance on Aboriginal women's self-esteem:

> *"Heather represents a minority group of HIV+, Aboriginal, addicted women. Her low self-esteem is a recurring barrier. Heather feels that many women who have led a life similar to her own suffer from low self-esteem, for many of these women have been told most of their lives that they are worthless...She feels that if programs were directly designed for [Aboriginal] women with HIV/AIDS and if she had ongoing support with her self-esteem issues she would be able to offer more of herself to the AIDS movement and become more involved in a leadership role" (CAS 2004:18).*

Recommendation #3 – HIV prevention efforts for Aboriginal women must begin to address the imbalance of power that is often a feature of intimate relationships.

< *Prevention and education must target Aboriginal heterosexual men as well as women. It is unrealistic to think that Aboriginal women can negotiate safer sex without the consent of their heterosexual male partners.*

< *Prevention efforts must address domestic and sexual violence against women.*

< *Healthy sexuality and harm-reduction programs must target both heterosexual men and women.*

< *Aboriginal women living with HIV/AIDS must be encouraged to speak out about their experiences, and provide positive role models for other Aboriginal women.*

Injection Drug Use Among Aboriginal Women

Of all new HIV infections among Aboriginal women, 64.9% of infections with known exposure category are by injection drug use (IDU). This makes IDU the main mode of HIV transmission for Aboriginal women in Canada. Sharing needles, having unprotected sex when high, or trading unsafe sex for money, drugs, or shelter are all thought to be survival techniques that help Aboriginal women cope with their daily living situations (Mill 1997). However, they are also thought to increase women's vulnerability to HIV.

Despite the fact that IDU is known to be the main mode of HIV transmission among Aboriginal women, there is an appalling lack of services or continuum of care for Aboriginal women who use injection drugs. While women-specific programs and services are available in limited numbers, Aboriginal women IDUs may not be accessing them for fear of losing their children to systems that penalize women struggling with addictions (M. Akan, personal communication). In addition, the absence of long-term residential programs and lack of safe housing and neighbourhoods all contribute to a newly-rehabilitated injection drug user being exposed to lifestyles and environments which put her immediately back at risk (CAAN 2003).

Recommendation #4 – Provide short and long-term supports for Aboriginal women struggling with addictions.

< *Provide more opiate replacement programs (ex. Methadone) that are user friendly and respond to the specific needs of Aboriginal women.**

< *Increase funding and support for long-term residential programs for Aboriginal women who use drugs and / or alcohol. Childcare must be included in residential programs.*

< *Advocate for safe, affordable and comfortable second-stage housing options for women who are recovering from addictions. Childcare must also be considered.*

HIV/AIDS & Aboriginal Women in Prison

Of all the potential environments that increase Aboriginal women's vulnerability to HIV infection, Aboriginal women in prisons perhaps fare the worst. Not only have they experienced situations which led them to be imprisoned, but they lack consistent HIV information, services and supports, suitable traditional helpers and are often isolated from sustained family contact. Aboriginal women prisoners with HIV face the same issues as their non-incarcerated sisters, however, they are at higher risk for self-harming behaviours due to their isolation and harsh environment (CAAN 2003). Injection drug use among prisoners is particularly high risk because drugs and the equipment used to inject them are illegal inside prisons, and as such,

prisoners are forced to share unclean needles and sometimes homemade injection devices that damage the skin when used (Barlow 2003). If Aboriginal women prisoners are mothers, they do not have the daily incentives to cope for the sake of the children, and incidents of intense depression and suicidal ideation or attempts, are experienced frequently.

Recommendation # 5 – Aboriginal women in prison should have greater access to harm-reduction materials and enhanced prison supports, such as transition houses for incarcerated Aboriginal women living with HIV/AIDS and their children.

HIV Testing and Treatment Options for Aboriginal Women

While Aboriginal women are becoming the largest part of those newly diagnosed with HIV, there is a distinct lack of Aboriginal women-specific information on HIV testing and treatment options. Many Aboriginal women find out their HIV status when they become pregnant or develop complications during pregnancy. This increases the risk of vertical transmission (from mother to child) because it reduces the window of opportunity for antiretroviral treatments to be effective. Research has shown that Aboriginal women are just as likely to receive antiretroviral treatment as non-Aboriginal women, however, more than 1/3 (38.6%) of Aboriginal women receive this treatment late in their pregnancy (in the third trimester or during labour/childbirth) compared to 9% of non-Aboriginal women (Gatali & Archibald 2003).

When Aboriginal women seek HIV tests outside of pregnancy, research shows that they test significantly later than non-Aboriginal women for HIV. 75% of HIV tests for Aboriginal women who tested positive were administered late in the development of the infection, compared to 45.2% of non-Aboriginal women. This means that the infected individual and her partners in IDU and sexual activity can not benefit from HIV treatments or counselling that could reduce high risk behaviours and stop the spread of HIV (Gatali & Archibald 2003).

Recommendation # 6 – Revise medical formularies (the list of treatments provided free of charge to some segments of the Aboriginal population) to reflect Aboriginal culture (e.g., the addition of Aboriginal healing methods).*

Recommendation # 7 – Develop cultural sensitivity training for health professionals to equip doctors, nurses, etc. with appropriate skills to communicate about HIV with Aboriginal women – explain what it means to have HIV, treatment regimes, etc.*

Recommendation #8 - Develop a set of Best Practice guidelines for pregnant Aboriginal women that includes information on informed consent, testing options and procedures, treatment options, pregnancy options, etc.

Disclosure

For many Aboriginal women, one of the most difficult aspects of being HIV+ is disclosing their status to family members, friends, and children (CAS 2004:21). HIV/AIDS is feared in many Aboriginal communities, and as a result, stigma and discrimination against those who are HIV + is frequent. The Aboriginal Nurses Association of Canada points out that "the worst punishment that can happen in an Aboriginal community is banishment and this is happening to people with HIV/AIDS" (in McKay 2002). Aboriginal women must be supported in their decisions around disclosure, and supports must be available to them when and if their disclosure goes badly.

Recommendation #9 – Develop a guide for Aboriginal women on their rights and responsibilities regarding disclosure of their HIV status. Who are they obligated to disclose to?

Recommendation #10 – Develop a guide for Aboriginal communities and families on how to be supportive when someone discloses their HIV+ status.

Issues Related to Children and Families

Children are not immune to the impact of HIV/AIDS. Whether they are HIV-positive or have parents who are infected, these children face discrimination, fear, isolation, rejection and bullying from their peers. If they are HIV-positive, the additional stress of complex medical regimes, lack of Aboriginal child-support services and parents dealing with their own AIDS issues all contribute to a very complicated life. Sometimes these children have been orphaned or placed in foster care which further compounds the stress. These children must often live with the sense of impending loss if they know a parent is infected, or deal with their grief long after a parent has died.

Recommendation # 11 – Provide supports for Aboriginal children living with or affected by HIV/AIDS.

- Train Aboriginal counsellors to work specifically with children and families affected by HIV/AIDS.
- Develop and sustain camps and retreats for Aboriginal children living with / affected by HIV/AIDS. These camps should allow children to have fun and 'just be kids' without fear of discrimination, stigma or exclusion.
- Develop a program to train and support Aboriginal children who are living with or affected by HIV/AIDS to speak to other children and community members about their experiences.
- Children must be made to feel like they are an integral part of the family. They must be made to feel like they can help.
- Develop a guide for children on rights and responsibilities regarding disclosure.
- Ensure that foster care or adoptive parents have culturally appropriate information to care for Aboriginal children infected or affected by HIV/AIDS.

Many HIV infected women are primarily responsible for their own self-care, and the care of their children, partners and other family members who may also have HIV or AIDS. The day to day stress of living with HIV, being forced to survive on an inadequate income in poor living conditions with little or no community supports often force women to place their health and needs at the bottom of their priority list. This is consistent with the tendency among women in general, and Aboriginal women in particular, to put the needs of others ahead of themselves (Tallis 2001; M. Akan personal communication). However, in the context of HIV infection such disregard for one's own health needs could have fatal consequences.

Recommendation #12 – Provide childcare, respite, and domestic assistance for Aboriginal HIV+ women, and Aboriginal women who are caregivers of infected family members.

Gaps in Information

Despite the fact that Aboriginal women are over-represented in the HIV/AIDS statistics, there is still very little gender-specific, Aboriginal specific research being done. Little is known about the experiences of Aboriginal women living with HIV/AIDS, the circumstances that lead to their infection, what happens to them after diagnosis, the circumstances that lead to treatment (or not), and the experiences with and of their families and children.

Recommendation #13 – Researchers and funding agencies must take a greater interest in Aboriginal women, children and families.

- Research efforts, in collaboration with community-based organizations, need to be focussed on Aboriginal women living with HIV/AIDS. Qualitative as well as quantitative data is required.

- A Positive Aboriginal Women's Network must be established to contribute expertise and leadership.

- A National Conference on Aboriginal Women and HIV/AIDS must be organized. This will highlight the issues that Aboriginal women must deal with, act as an impetus for further research, and give HIV+ women an opportunity to network with each other and with researchers.

Conclusions

Despite the increasing numbers of Aboriginal women who are living with HIV/AIDS, there is a disturbing lack of targeted supports, services, programs and prevention. Many Aboriginal women do not have the information or the skills they need to protect themselves from HIV, and many HIV+ women live in isolation and fear of having their status revealed. On the whole however, the voices of Aboriginal women have not been silenced, nor have their spirits been dampened. On the contrary, Aboriginal women, and Aboriginal HIV + women are speaking out in record numbers, offering their experiences to others as learning tools, telling their stories, breaking down stereotypes, acting as role-models, and changing the way we think about Aboriginal women living with HIV/AIDS. For this, they must be applauded. For this, they must be respected. In this, they must be supported.

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