HIV/AIDS and Aboriginal Women in Canada

BY SUSAN JUDITH SHIP AND LAURA NORTON

Dramatic and rapid increases in HIV and AIDS rates among Aboriginal peoples in Canada, particularly among Aboriginal women, have been recorded despite under-reporting and the small number of documented AIDS cases (Health Canada 2000a; 2000b). The patterns of HIV and AIDS among Aboriginal women are markedly different from that observed for Canadian women in general (Health Canada 2000a; Nguyen et al.) Epidemiological data for 1998-1999 shows that Aboriginal women constituted 49.6 per cent of newly diagnosed HIV cases among Aboriginal people while non-Aboriginal women comprise 20 per cent of newly diagnosed non-Aboriginal HIV cases (Health Canada 2000a). Injection drug use is the major mode of HIV transmission among Aboriginal women, followed by heterosexual sexual contact. HIV infection occurs at a younger age for Aboriginal women than for non-Aboriginal women. Young women constitute the largest proportion of Aboriginal AIDS cases. Consequently, the risk of HIV transmission from mothers to infants is increasing (Health Canada 2000a). Despite these facts, Aboriginal women continue to remain invisible in HIV/AIDS research and policy as well as face numerous barriers in accessing services (Ship and Norton 2000).

Cultural Disruption and the Subordination of Aboriginal Women: The Legacy of European Contact

A focus on Aboriginal women and HIV/AIDS necessarily raises the issue of gender and women’s subordination in addition to the unique historical and socio-economic factors that shape Aboriginal women’s lives. Gender refers to the social construction of men’s and women’s social roles that are historically shaped, culturally contextualized, and class-specific (Ship). Understanding how HIV/AIDS affects women entails analysis of the socially constructed differences between men and women and how this shapes distinct female and male experiences. Women’s subordination or gender inequality among Aboriginal peoples is largely a consequence of European contact and colonialism. The imposition of European notions of women’s social position resulted in the dispossessing of Aboriginal women’s rights and the devaluation of women’s social roles (Shawanda). In addition to the legacies of multiple disadvantages and multi-generational abuse that affected Aboriginal communities, families, and individuals, cultural disruption served to deepen women’s subordination to men (Ship and Norton 2000).

Employing a culturally-sensitive gender perspective in order to capture the unique aspects of Aboriginal women’s experiences, our research explored two themes: how cultural disruption, residential schooling, family and cultural breakdown, and the legacy of multi-generational abuse affects HIV risk among Aboriginal women and how HIV affects their lives differently from men.

Aboriginal Women in Hard-to-Reach Communities at Risk for HIV

Vulnerability to HIV risk has often more to do with, “social and environmental factors such as stigma, poverty, discrimination, sexism and racism than with individual behaviour” (Trussler and Marchand 63). Understanding how HIV risk and HIV/AIDS affect Aboriginal peoples necessarily raises the issues of the legacy of disadvantage that resulted from European contact and colonialism which continues to impact negatively on the physical, mental-emotional, social, and spiritual health of Aboriginal peoples, families, and communities. Residential schooling, multi-generational abuse, and forced assimilation in tandem with widespread poverty, racism, sexism, loss of culture, values, and traditional ways of life have given rise to a range of pressing social problems that include alcoholism, substance abuse, high suicide rates, violence against women, and family violence (Ship and Norton 1998; ANAC). High rates

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of sexually transmitted diseases, alcoholism, and substance abuse in tandem with low rates of condom use and high rates of teenage pregnancies continue to increase vulnerability to HIV, particularly among Aboriginal young people, who are also over-represented in high risk groups—runaways, sex trade workers, and intravenous drug users (Ship and Norton 1998). HIV risk is further compounded by the over-representation of Aboriginal people in prison and inner-city services (Health Canada 2000a).

The majority of the Inuit women involved in sex-work in Montreal that we interviewed, left their communities as a result of the sexual and physical abuse they suffered within the family or at the hands of a partner. (Although it is not well-publicized, the Inuit are also survivors of Residential schooling.) The women chose Montreal because they had a family member there or because they knew that there were Inuit people in the city. While these women pointed out that the Inuit community in Montreal is growing, the people are spread out and there isn’t a sense of community. They came down to a major metropolitan centre where they do not speak the language and could not find work despite the fact that most of them were working as teachers, nursing assistants, and in communications back home. Victims of racism and gender discrimination, in addition to an inability to speak French, these Inuit women found themselves in very precarious situations, ending up on the streets in sex-work to survive; in a spiraling cycle of abuse, violence, alcoholism, and drugs.

All of the Inuit women we interviewed were aware of the risks of HIV from unprotected sex and sharing needles. Moreover, they seemed to be aware of the existence of the Needle Exchange Program in Montreal as well as where to obtain free condoms. All expressed fear about contracting HIV. All of the women stated initially in no uncertain terms that they do not have unprotected sex (sex without condoms) with clients, even when clients offer to pay more. However, staff working with the Inuit women involved in sex-work suggested that the actual use of condoms was far less frequent than the women themselves reported. We were told that many Inuit women still don’t use condoms because they are afraid that the men are going to get violent. Only three women had undergone HIV testing and staff informed us that many women do not keep appointments to be tested for HIV. Racial discrimination from health professionals, the long waiting period for test results, and the lack of pre- and post-counselling were cited as reasons, but many women are also afraid of the results, indicating that they most likely engage in more risky behaviour than they had revealed in the interviews.

While Inuit women in the sex trade reported using condoms more frequently with clients, they all said that they don’t usually use condoms when they are involved in long term or regular partners. Most of these women expressed the view that their long term partners were “clean” and “safe.” This pattern has been identified as fairly typical among non-Aboriginal sex trade workers as well (Ship and Norton 1998).

Only one of the women reported using IV drugs. She mainlines cocaine and asserted that she never shares needles. Eight of the women we interviewed use alcohol and soft drugs such as marijuana—which they did not see as posing a risk for HIV—on a regular basis. However, it is a widely shared view that alcohol and soft drug use play a major role in risky behaviour as it clouds judgment, for example, not using condoms when engaging in casual sex which increases the risk of contracting HIV.

To a much greater extent than was revealed in these interviews, sexual abuse and physical violence appear to be a pervasive factor in these women’s private lives and on the street. One woman, in tears, told us that she had been the victim of what appeared to be a “gang bang.” While attending a party, drugs were slipped into her drink and she woke up completely nude the next morning. One older Inuit woman confided to us that her daughter, who is an alcoholic, had beaten her up. More telling than what women actually revealed about themselves is the fact that four of the Inuit women broke down into tears during the interviews, conveying a more vivid sense of the pain and abuse they have endured.

The situation of Inuit women on the street in Montreal can only be described as one of extreme marginality, isolation, and invisibility—women, with few supports and resources, cut off from their communities. Most of the women we interviewed did not return home frequently—because they did not wish to or because they could not as a result of expulsion. Most women only returned home to visit with children or attend a funeral. They fall through the cracks of the system because there are no organizations mandated to address their needs. There is no separate organization or cultural centre for Inuit people in Montreal and many of these women expressed some discomfort at patronizing the Native Friendship Centre. Although none of the Inuit women were HIV-positive at the time of the interviews, they are at high risk for HIV, as the stories of their First Nations sisters on the streets in Vancouver, now living with HIV/AIDS, reveal.

**First Nations Women Living with HIV/AIDS: Cultural Disruption and Residential Schools: HIV and the Legacy of Abuse**

Our interviews with First Nations women living with HIV/AIDS revealed the painfully clear links between cultural disruption, residential schooling, family and cultural breakdown, multi-generational abuse, and HIV. Almost all of them told us that they came from families where one or both parents had attended residential schools and alcoholism was a problem. Eight HIV-positive women admitted that they had been victims of sexual abuse as children. As
one positive woman who was involved in an abusive relationship explained,

*My mother and father drank. They were products of residential schools. I was the youngest. I was placed in a foster home… It’s tough being an Aboriginal woman. I was part of an abusive relationship. What I saw in him is what I got from my family. I was sexually abused.*

Many First Nations women who have been sexually and/or physically abused leave their communities and end up on the street; as was the case of most of the women we interviewed. More often than not, abused women become victims of a spiraling cycle of abuse which includes alcoholism, drug addiction, prostitution, and violence; a cycle which places them at greater risk for HIV; for some this spiraling cycle of abuse culminates in HIV, as this positive woman confirmed,

*I never told them. I was afraid I would get beat or they would send me away. One day I finally stood up. My uncle was sent away after my mom died… My family is Christian. They are too proud… to find out that their youngest girl has turned to the street and IV drugs. That’s how I deals with abuse.*

Nine of the eleven HIV-positive women we interviewed had used alcohol and drugs extensively; in some cases, since their early teens. Half of the women admitted that they were still using IV drugs, mostly cocaine and to a lesser extent heroin, despite the fact that they know it is harmful to their health; some still engaging in risky behaviour such as sharing needles. Almost all of the women smoke pot and drink. Drinking and using drugs are coping mechanisms to deal with abuse and HIV; to dull the intense pain these women carry deep inside. One woman said,

*I used drugs to forget. It made me feel good… sex and men… a big party but the poverty and my children. It’s a coping mechanism… The pain is overwhelming.*

Some positive women do find the courage to begin the healing process and stop the cycle of abuse so that their lives and their children’s lives will be different. As this woman explained,

*There is a need to reclaim family identity and community… residential schools polluted. It’s a disease of the spirit. Our people need to move beyond this. They need to love one another. My family is making a conscious effort to change that cycle. It is a healing process reclaiming family identity. My daughter won’t have to deal with this as I did, as my mother did and as my grandmother did.*

**HIV affects First Nations Women Differently from**

**Men: Seropositive Single Mothers with Children Living Below the Poverty Line**

Unlike gay men, many First Nations women living with HIV and AIDS are parents, and most are single mothers, living below the poverty line. All but one of the women we interviewed were receiving social assistance and most were living “in the East Hastings area of Vancouver, the poorest postal code in Canada.” Many financial supports are geared to the needs of single men or single people. Most women do not have adequate housing for themselves and their families.

Women’s social roles as primary caregivers and nurturers in the family means that for HIV-positive women, they are responsible for caring for themselves, their children, their families and their partners, more often than not, with fewer supports and resources. As this woman explained,

*I think for a lot of women it’s scary when you find out (you’re positive), you’re responsible for the whole world. You’re responsible for your children… your man… your home, for everything.*

For First Nations women living with HIV and AIDS, their health and well being is last on their list of priorities, as this mother told us,

*What I find for a lot of women I talk to is that they are so busy taking are of everybody else’s needs is that their own needs are at the bottom of life. Their own health, their well-being, physical mental, emotional and spiritual, doesn’t count.*

Life is a daily struggle as most positive women can barely provide for basic needs—food, clothing, shelter and transportation—for themselves and for their children. Many women can not afford expensive treatments and difficult choices are often made between purchasing medications for themselves and basics for their families. As this single HIV-positive mother told us,

*Your first priority is your child. All the money that you get if you live on welfare or have a job goes to your child, to your child’s well being. Sometimes you get a little bit for yourself… money, time out or chance to sit and share with other women.*

For many First Nations women living with HIV/AIDS, their children’s health, well-being, security and future assume a greater importance than their own health, well-being and needs. A primary and universal concern of seropositive mothers is who will take care of their children if they get sick and after they die. As one mother explained, “The first thing that popped into my head when I found out [I was HIV-positive] was who is going to take care of my
children.” Most women expressed guilt and anxiety about how their children were coping with the knowledge that their mother was HIV-positive and the impact on them when they discuss their illness. Caught between wanting to protect their children and feeling that their children should know the truth, deciding when, how and to which children to disclose their HIV status is difficult, stressful and complex for HIV-positive parents, but particularly for single mothers with little social and emotional support. But children are also a source of joy, hope, support, and a primary motivation for the women we interviewed to find the strength and the courage to live with HIV. One woman declared, “I have to live with it and I have to stay strong for my children.” For women who fell that their own lives have been shattered, their hopes and their dreams are for their children.

Gender Discrimination as HIV-positive Women

Many First Nations women live in secrecy because of the multiple forms of stigma associated with HIV/AIDS but they also suffer from gender discrimination because as women they carry the additional stigma of being branded “promiscuous,” “a bad mother,” and “deserving of HIV/AIDS.” Some of the women we interviewed felt that secrecy is perhaps a bigger issue for positive women because of a need to protect not only themselves but also their children. As one woman explained, “Women are afraid of the shame and the guilt placed on them. People will not be so accepting of them and their families.” Many women fear disclosure of their seropositive status will bring discrimination and rejection not only for themselves but particularly for their children. One positive woman put it so poignantly,

“It’s hard being a woman with HIV in a society that rejects women who are HIV-positive and that rejects the children…. It’s still hard being a woman with HIV because of discrimination. It seems more acceptable for a man who is HIV-positive to be accepted than it is for a woman. I fear for my children.”

Multiple Barriers to Services

Many First Nations women living with HIV/AIDS under-utilize First Nations and non-Aboriginal services for fear that their communities will find out they are seropositive. They also encounter multiple barriers based on gender, racism, and class in accessing a broad range of services. As is well-known, gender barriers persist in women’s access to treatment and clinical drug trials, partly because “of their reproductive capacities,” as one woman pointed out. There is a lack of services and supports for positive women and their children because “most AIDS services are geared to gay men, not to women and their families.” One positive woman explained,

“I think that women as caretakers in society don’t have a lot of places they can go and don’t have a lot of support systems. There is only one organization in Vancouver that is specifically an AIDS organization for women. All the rest are 90 per cent for men. They don’t discriminate against women, but there really is no place for them.

Some of the positive women we interviewed acknowledged encountering subtle forms of racism in their interaction with non-Aboriginal, mostly white, health professionals. The lack of culturally-appropriate services and counselling for First Nations women living with HIV/AIDS was noted. Almost all agreed that many health professionals needed to improve their understanding of First Nations cultures and traditions. Half the women we interviewed expressed the need for “more Aboriginal counsellors, particularly those who know street life.”

Extreme Isolation

As a consequence of multiple stigmas and barriers to services, First Nations women living with HIV/AIDS and their children, have little, if any, emotional and social support. Many of these women live in extreme isolation. The positive women we interviewed live in urban and metropolitan centres, far from their home communities because they city provides anonymity and because they feel that there is greater acceptance of HIV-positive women. Many positive women desire and need to return home. One woman observed, “I know a lot of people that have no sense of family or community and they die really quick.” But many women fear isolation, rejection, and discrimination if they return home, not only for themselves but also for their children and their families. Community responses vary. Some communities are very accepting of their members living with HIV/AIDS while others are far less so, as lack of knowledge and fear predominate. One woman was forced to leave her community:

“When people found out, they reacted very badly. It wasn’t safe for me…. It’s a small community. I was the first person in the community to test positive.

First Nations women with HIV/AIDS living far from home, family, culture, and community, hope that their children will one day be able to go home.

I have been told by my doctor that I am dying and have to go on anti-virals. It’s a hard choice to make but I’m doing it because I want to live. I have two daughters.
Aboriginal Women Caring for People Living with HIV/AIDS: Women’s Social Roles as Caregivers in the Family and in the Community

For every First Nations and Inuit person who is living with HIV or AIDS, there are many other people who are affected. Female caregivers constitute the largest proportion of Aboriginal women most immediately affected by HIV/AIDS. The majority of caregivers of Aboriginal people living with HIV/AIDS are women—mothers, sisters, aunts, grandmothers, partners, friends, and professional caregivers such as AIDS educators, CHRs, CHNs and home support workers—a consequence of women’s social roles as “nurturers” and “caretakers” in the family. As one AIDS educator pointed out,

Women’s roles are caregivers. I think that’s why we also see mostly women in our workshops because they are in the positions of home care workers, CHRs and CHNs. They are in those caregiving roles in the community.

Moreover, as our interviews indicate, initial disclosure of seropositive status or AIDS by the person affected is usually made to a close female family member—an aunt, a mother, a spouse or a partner—while initial disclosure by a female caregiver is usually made to another female-friend or family member.

In some cases, the female caregiver—a wife, a mother, or a grandmother—is the anchor for the entire family. Women, as unpaid and paid caregivers, tend to form the nucleus of support for people living with HIV/AIDS. We were repeatedly told by caregivers and AIDS educators alike, that women were far more likely to be primary caregivers to people living with HIV/AIDS and commit themselves to the very end while men were less likely to make this kind of commitment. We were moved by the strength and depth of the commitment of the caregivers we interviewed.

The needs and the concerns of female caregivers tend to go largely unnoticed and unattended to, in part because caregiving is seen as the natural role of women, but in part because women are supposed to be the nurturers and the caregivers, they are not allowed to get sick. Female caregivers are concerned with the health of the person living with HIV/AIDS, with the health of the family while their own health is the least important priority. Many caregivers need to learn how to better take care of their own physical, mental-emotional, social, and spiritual needs and not feel guilty about this. As one caregiver told us, “I think there should be more things done for caregivers so that they can be rejuvenated and go back energized ... retreats where they learn meditation and give back massages.”

Isolation of Caregivers

Isolation is the biggest problem caregivers face that negatively affects their own health and well being, the person with HIV/AIDS and where pertinent, the family living with HIV/AIDS. Isolation of caregivers is a consequence of the continuing stigma attached to HIV/AIDS in Aboriginal communities and the resulting dilemmas of disclosure. Lack of services, counselling and supports for the caregiver, the loved one living with HIV/AIDS and in some cases the family, particularly those living in Aboriginal communities and smaller urban centres, serves to reinforce their isolation.

Given that the stigma of HIV/AIDS may also be associated with additional stigmas around injection drug use, homosexuality and/or lesbianism, there is enormous anxiety and stress to whom and when to disclose the seropositive status of a loved one to family, friends, school, workplace, and the larger community. Reluctance to disclose the seropositive status of a loved one is also related to fear of rejection, fear of emotional and physical harm to children, fear of discrimination and/or simply needing time to come to grips with the reality of living with HIV/AIDS. For many caregivers, the burden of silence reinforces their own isolation and negatively affects their health and well being. As one woman explained,

I had to get it off my shoulders. I went down to the AIDS organization and talked to someone. Then I told Mike: Mike, I had to tell someone. You don’t want me to tell the family.

Few Supports and Services

Counselling and support for caregivers are almost nonexistent. Many caregivers find it difficult to accept the diagnosis of HIV of a loved one. As one woman told us,

The day he told me he had AIDS, I just lost it. I didn’t believe it. I said “You’re lying. You’re just trying to hurt me.” It was very difficult accepting it. I just couldn’t believe it. I’m one of those Aboriginal people who thought we would never get AIDS in our communities.

Caregivers need time and support in working through their complex and often, contradictory feelings and undergo a grieving process just as the people living with HIV/AIDS they are caring for. As this woman explained,

I went through much of the same

“...It was very difficult accepting it. I just couldn’t believe it. I’m one of those Aboriginal people who thought we would never get AIDS in our communities.”
AIDS educators told us, denial was a common experience. One woman explained, "I attended a seminar for patients with AIDS and the speaker said, 'You don't have the medical diagnosis, so you don't have the disease.'"

Caregivers and the person they care for may both need counselling and support in dealing with death and dying. Caregivers and their families may also need counselling and support in situations where the loved one is still engaged in risky behaviours such as alcoholism or drug abuse; behaviours that pose a greater health risk to their seropositive condition and that may be linked to underlying issues of cultural disruption, residential schooling and the legacy of multi-generational abuse. Some of the caregivers we talked with expressed frustration and anger, at feeling powerless to help. As one woman explained,

Not being able to help them, you see all the frustration. They're compounding their illness by doing negative things. They are drinking and making themselves sick. There is nothing you can do to stop them and you know they are getting worse by drinking more."

One caregiver observed:

It's like living in crisis mode... But it makes you stronger and more compassionate when you go through these hard times.... You get a lot of strength from crisis and that's the positive thing that comes from it.

Services for caregivers and Aboriginal people living with HIV/AIDS, particularly for individuals in an advanced state of AIDS, in small communities and smaller urban centres, for example, such as in the Halifax-Dartmouth region, are inadequate. Getting appropriate information and accessing services as quickly as possible can be difficult. We were told that in one case, a young man who had come home to his reserve to die, was growing progressively sicker and because it was Good Friday, there were no services open either in the community itself or in the surrounding region that his caregivers could access. They had to call an AIDS organization in Ottawa for help. Other caregivers felt that many health professionals needed enhanced HIV/AIDS education. As one AIDS educator explained,

Access to services is the biggest barrier. You go to a community that is isolated, and you don't have access. You don't have a doctor. You don't have the medications. You may not have the knowledge. You may not have the ability. At least in the city we can go to the clinic or the hospital but in the small communities, you don't even have that.

But even where available, many Aboriginal people living with HIV/AIDS are reluctant to use services offered by AIDS organizations, health agencies and other social service organizations because they may have experienced racial discrimination while some heterosexual men articulated discomfort utilizing services set up for single gay men. The lack of services intensifies the burden of caregiving for Aboriginal women and diminishes the quality of life for the loved one they are caring for.

Aboriginal communities vary in their support for people living with HIV/AIDS. As AIDS educators told us, denial of HIV/AIDS and fear in many communities means that they do not act until there is a crisis. Most Aboriginal people with AIDS want to go home to die but most Aboriginal communities do not have the necessary services and trained personnel to make that journey as comfortable as possible, particularly where several infections are in evidence at the same time. Moreover, there are few supports for female caregivers. One woman told us that she drives three and half-hours to attend a support group for female Aboriginal caregivers that is in another province. The cost of transportation for these trips is high, particularly as she is living on a fixed income. Increased financial assistance, better home-care, respite-care and support from family, friends and the community go a long way in easing the burden of caregiving.

For many caregivers, their spirituality—in whatever form it takes—is the glue that keeps them together. As one woman told us,

My brother is a traditionalist. He was a sweat lodge keeper. He earned his pipe. He told us the proper way. We prayed for him in a Native way; the whole celebration from sunrise to the end.

For other caregivers finding joy in life gives them the strength to go on such as a new addition to the family that keeps the circle strong.

Conclusion

The over-representation of Aboriginal women in HIV/AIDS statistics demands that we place them on research and policy agendas in addition to developing a greater range of culturally appropriate, gender-specific services, supports and counselling to reduce HIV/AIDS risk and to improve the quality of life for women in hard-to-reach communities, for women living with HIV/AIDS and their children and for caregivers.

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JOANNA M. WESTON

To Imagine Peace

is this how the sky falls
full of white crosses
from war cemeteries
all over the world

it falls on women in blue dresses
who open their mouths
and drink snow
not understanding the scars
they will wear in the morning
on hands and feet
when the wars are over
and the men are gone

is this how the sky falls
emptying trees of sparrows
who are tossed—each small brown
into fires that rage
in Dieppe, Berlin, Belfast and Guatemala
until the last burrowing owl mates with a
rabbit
and women lie vacant amidst fescue and
clover
watching as maples throw leaves in their eyes
and vetch grows through their hands

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