

“It’s Hard To Be A Woman!”

First Nations Women Living with HIV/AIDS

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“I want to go home. I want to be accepted. I want a life back there. I have things I want to teach my kids. I just need to go home. I have that hope that somehow the CHR is like a key. I really hope that they open the door for me.”

This paper focuses on the experiences and perspectives of First Nations women living with HIV/AIDS and explores how HIV/AIDS affects their lives differently from men’s lives. It is based on original research carried out as part of a larger project on Aboriginal Women and HIV/AIDS for the National Indian and Inuit Community Health Representatives Organization in which we also explored the experiences and perspectives of female caregivers of people living with HIV/AIDS and women in “hard-to-reach” communities.

Our interviews with a small number of First Nations women living with HIV and AIDS reveal the clear links between HIV, cultural disruption, residential schooling and the legacy of multigenerational abuse in their lives. In addition to the multiple forms of stigma that seropositive men experience, First Nations women living with HIV/AIDS experience gender discrimination as women. Moreover, women’s social roles as primary caregivers and nurturers in the family constitute a fundamental difference when compared to men and their experiences of HIV/AIDS because First Nations women are more likely to be single parents responsible for the health and well-being of their children, in addition to their own, with fewer resources and supports.

We begin with a brief discussion of the appropriate conceptual approach to this project that we suggest entails taking gender and women’s subordination into account while situating them within the unique historical trajectory of First Nations in Canada. We then turn to an overview of the current literature on HIV/AIDS to show how gender bias and a problematic conception of “woman” as a social category renders First Nations women invisible in research, policy and services, followed by a discussion of some of the challenges we encountered in conducting our research. Finally, we explore the multiple ways HIV/AIDS affects First Nations women from their experiences and through their eyes.

Gender Analysis and the Subordination of First Nations Women: The Legacy of European Contact

A focus on First Nations women and HIV/AIDS necessarily raises the issue of gender and women's subordination in addition to the unique socio-economic and historical factors which shape First Nations women's lives. Gender refers to the social construction of men's and women's social roles which are historically shaped, culturally contextualized and class specific (Ship 1994:138). Understanding how HIV/AIDS affects women entails analysis of the socially constructed differences between men and women and their impact in shaping distinct female and male experiences. As Crowley and Feldman (1997:123) point out, this analysis involves looking at how women's social roles and social situations differ from men's, how women are treated publicly and privately, how HIV affects women's lives in different ways from men and how HIV affects the relationships between men and women.

Alternately, gender is usually taken to be synonymous with women in part because women continue to be subordinate in all spheres of economic, social, political and family life globally, in Canada and within First Nations communities. Women's subordination or gender inequality among First Nations people is largely a consequence of European contact and colonialism which altered the way First Nations men and women relate (Bourgeault 1989). The imposition of European notions of women's social position which occurred with the ensuing process of cultural disruption and residential schooling resulted in the dispossession of First Nations women's rights and the devaluation of women's social roles (Shawanda 1995). In addition to the legacies of multiple disadvantages and multigenerational abuse, which affect First Nations communities, families and individuals, cultural disruption and residential schooling served to deepen women's subordination to men.

Women's subordination to men places them as a social group at greater risk for HIV/AIDS (ICAD 1995). However, while women as a social group are disadvantaged relative to men, some groups of women experience multiple forms of discrimination and disadvantage in addition to gender based on poverty and racism such as is the case of many First Nations women and women of African descent in Canada (Stasiulis 1991). Women who experience multiple forms of inequality are at greatest risk of HIV. It is of no surprise that in Canada, HIV/AIDS does not affect women equally. It is disproportionately concentrated among historically marginalized groups, albeit with very different trajectories – First Nations and peoples of African descent. In 1990, the male-female ratio among white Europeans in Canada was 22 to 1, among people of African descent 2 to 1 and among Aboriginal peoples 3 to 1 (Berer 1993:46). The recent and

HIV/AIDS among First Nations women (Nguyen et al. 1997) demands that we place them on research and policy agendas.

The Invisibility of First Nations Women in HIV/AIDS Research

If women generally are marginal in HIV/AIDS research, policy and services, First Nations women remain particularly invisible (Ship and Norton 1999; 1998). From the beginning, gender bias and a problematic conception of "woman" as a social category of analysis have shaped research agendas in addition to homophobia. Women's invisibility in research, policy and services is in part the consequence of persistent and widespread public perception, both within Aboriginal and non-Aboriginal communities alike, that "HIV/AIDS is a gay male disease", reinforcing the widely held attitude that women are not at risk for HIV, despite growing evidence to the contrary.

In addition to homophobia, a pervasive gender bias which assumes that women and men experiences, perspectives and social positioning are identical serves to render gender differences in HIV/AIDS research, policy and services invisible. As a result, insufficient attention is paid to how social and economic inequalities along with women's distinct biology differentially affect women's health, HIV risk and capacity/resources to cope with HIV/AIDS. Women remain a disadvantaged group with regard to clinical research, diagnosis, treatment and health care (Health and Welfare Canada 1990). Services are generally geared to the needs of "gay men." The late inclusion of the clinical manifestations of HIV unique to women has meant that many health professionals may miss the HIV/AIDS diagnosis in women. Late or missed diagnosis impedes the provision of appropriate counseling, information, support and care to HIV positive women as well as contributing to higher mortality and lower survival rated for women living with AIDS (Health and Welfare Canada 1990).

Moreover, the lack of attention paid to how HIV/AIDS affects women is also related to a problematic conception of "woman" as a social category of analysis, which has dominated HIV/AIDS research agendas. What little research there was during the first decade of the AIDS pandemic in Canada, as elsewhere, focused on women solely as "vectors of transmission" of HIV (through pregnancy or prostitution), with women's own health and well-being of secondary concern (McGovern 1997; Sherr et al. 1996; Patton 1994; Labelle and Decosas 1990). This view is embedded in current Health Canada epidemiological research: "the HIV epidemic among women is of particular concern because of the potential for transmission to their infants" (Health Canada 1999). Apart from reproducing dominant gender stereotyping of woman as "mothers" or as "whores", this narrow concern with women as "transmitters of the disease"

has meant that inadequate attention continues to be paid to how HIV/AIDS affects women.

Even with the growth of social research on women and HIV/AIDS since 1990, there are only a handful of studies focussing on women living with and caring for people with HIV/AIDS in Canada. First Nations women barely figure in these studies (with few exceptions such as Kali-Shiva 1998; Salter Goldie and DeMatteo 1997; Allen 1994). Moreover, in spite of the growing need for this research, there have been no comprehensive studies of the experiences, perspectives and needs of First Nations women living with and caring for people with HIV/AIDS. Although Aboriginal women's HIV/AIDS knowledge base, attitudes to the diseases, risky behaviours and information needs have dominated research agendas (see Ship and Norton 1998 for an extensive review of the literature), little is known about First Nations women in "hard-to-reach" communities, particularly where the risk of HIV is greater than in the general population, among street youth, in the sex trade and in the prison population.

The invisibility of First Nations women in HIV/AIDS research, policy and services is further related to the general tendency to conceptualize "woman" as a homogenous social category with identical experiences, views and needs (Hammonds 1997; Patton 1994; Allen 1994; Manthorne 1990), notwithstanding the increasing recognition of the culturally specific but diverse life situations and material circumstances of First Nations women. As a consequence, there is little, if any, systematic research as to how poverty, racism, sexual orientation and age, in addition to gender discrimination, affect women's health, HIV risk potential, capacity to cope with HIV or AIDS and access to services. Moreover, little, if any, research has looked at the links between multigenerational abuse and HIV/AIDS among First Nations women.

Research Methodology: A Woman-Centered Focus: HIV/AIDS through First Nations Women's Eyes and from Their Experiences

As a consequence of the lacunae in the existing research and literature, little is known about First Nations women living with HIV/AIDS. Employing a culturally sensitive gender perspective in order to capture the unique aspects of their experiences, our research explored how residential schooling and the legacy of multigenerational abuse affects HIV risk among First Nations women and how HIV affects their lives differently from men. We wanted to identify positive women's physical, mental-emotional, social and spiritual needs and the challenges they face in meeting their own needs and the needs of their families.

Because this research was exploratory in nature, qualitative research methods based on semi-structured individual and group

interviewing were utilized. Moreover, as we wished to put Aboriginal women's faces on HIV/AIDS statistics, qualitative research methods allow women's voices to be heard; voices normally silent within dominant discourses and representations of HIV/AIDS. Finally, as the primary purpose of this research was to develop training materials for Community Health Representatives (CHRs) to enhance their skills in HIV/AIDS education, prevention and care, qualitative research methods were utilized in order to provide a more personal and in-depth view of a range of HIV/AIDS related issues, particularly the under-examined social and emotional dimensions, as they affect and are experienced by women.

Our research with First Nations women living with HIV/AIDS consisted of a focus group lasting approximately two hours and selected interviews, each of which were an hour in duration, which served as the basis for a video and a resource manual, both entitled "Keepers of the Earth." The focus group and majority of the interviews were filmed. The focus group helped to delineate broad and general themes relating to multigenerational abuse, HIV risk behaviour and living with HIV/AIDS while individual semi-structured interviews with self-identified positive women willing to participate in the research allowed us to probe these general issues in more depth.

The Positive Women's Network, the Canadian Aboriginal AIDS Network and Healing Our Spirit were involved in finding participants for this research, arranging interviews and setting up the focus group, as well as reviewing the interview questions to ensure relevance, validity and screen out various kinds of potential bias. We interviewed eleven First Nations women living with HIV or AIDS, who are between the ages of twenty-six and thirty-nine years of age and who are from across the country. Two of the women were diagnosed with HIV over ten years ago while eight of the women had been diagnosed as seropositive within the last five years. One woman was in an advanced stage of AIDS. Sharing needles followed by unprotected sex appeared to be the main modes of HIV transmission. All but one live in Vancouver where dramatic increases in HIV/AIDS rates in general, among Aboriginal people, and in particular among Aboriginal women have been documented (Nguyen et al. 1997).

Limitations of This Research

Finding women willing to be interviewed on film proved challenging for a number of reasons. Given the highly sensitive nature of this research and the stigmas attached to HIV/AIDS, IV drug use and sex work, some HIV positive women and women on the street, refused to be interviewed on film or audio tape because they did not wish to be identified. The use of a male film crew posed an additional set of difficulties in

organizing interviews. Two women's organizations whose facilities we utilized provide a "safe space" for women and consequently do not allow men on their premises. Furthermore, some positive women expressed discomfort with a male film crew.

As it has become standard practice to pay research participants in the HIV/AIDS world, we were obligated to pay honorariums to the positive women and women in "hard-to-reach" communities in order to obtain their participation in the focus group and individual interviews. Financial constraints set limits on the number of women we could afford to interview and locations to which we could travel. While we can assume that remuneration for the interviews affected the research, it is unclear what the impact was or how this may have biased participant responses.

One of the difficulties encountered in the research was participants' reluctance to disclose the extent of their involvement in risky behaviours related to unprotected sex, sex work and sharing needles, an observation also made by some health professionals we interviewed who work directly with Aboriginal women in "hard-to-reach" communities. As such, it was difficult to obtain an accurate reading of the extent to which these women engage in risky behaviours.

Given the limited sample of respondents who were also self-identified and willing to be interviewed, this research can only be considered as exploratory rather than representative. Moreover, because this research was part of a larger project which included both the development of educational materials and training sessions, time constraints did not allow for the construction of a larger sample nor the development of standardized interview questions with adequate pre-testing. Although the results from our research cannot be considered hard data, the interviews with positive women generated important insights for further research regarding gender differences in living with HIV/AIDS.

First Nations Women Living with HIV/AIDS: "On the Hem of Life"

"We are fighting for a place in society, in our communities, to feel normal, just to feel accepted, and loved, and respected, let alone having to deal with...barriers such as sexual identity or childbearing."

Cultural Disruption, Residential Schooling: HIV and the Legacy of Abuse

The links between cultural disruption, residential schooling, the cycle of multigenerational abuse and grief, cultural and family breakdown and HIV are painfully clear in the lives of First Nations women living with

HIV/AIDS. Almost all of the positive women we interviewed told us that they came from families where one or both parents had attended residential schools, and where alcoholism was a major problem in the family. 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 streets, 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 these positive women 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 that 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 dealt with abuse."

"It was a violent sort of encounter; having someone on top of you, pulling off the condom and then finding out a month later that you are HIV positive from this person...then being abandoned."

Nine of the eleven HIV positive women we interviewed have used alcohol and IV drugs extensively and some since their early teens. Five women admitted that they were still using IV drugs, mostly cocaine and to a lesser extent heroin, despite the fact that this is harmful to their health; as one woman said, *"It's scary knowing that cocaine is the worst thing for your HIV."* Some women still engage in risky behaviour such as sharing needles; an ex-addict pointed out, *"When you are 'jonesing' or 'whacked out', all you are thinking about is the next hit."* Almost all the women still drink and smoke pot. Drinking and using drugs are coping mechanisms to deal with abuse and HIV: they dull the intense pain they 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 stress. The pain is overwhelming."* Another woman relapsed back into heroin after she found out she was HIV positive: *"When I found out in 1994, I went into denial. I used drugs to kill the pain."*

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 one woman explained, *"I don't want my kids to have their spirit broken. I was sexually abused over and over again till I was eight."* Another positive woman conveyed a similar experience:

"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/AIDS Affects Women Differently from Men Single Mothers with Children Living Below the Poverty Line

Unlike gay men, many First Nations women with HIV or AIDS are parents, and most are single mothers, living on low incomes. Almost all the women we interviewed live *"in the East Hastings area of Vancouver, the poorest postal code in Canada."* With one exception, all the positive women we interviewed were receiving social assistance.

Women's social roles as primary caregivers and nurturers in the family means that they are responsible for caring for themselves, their children, partners and families, more often than not with fewer resources and supports. For First Nations women living with HIV/AIDS, their health and well being is last on the list of priorities. As positive women explained,

"I think for a lot of women, it is scary because when you find out (you're positive), you're responsible for the whole world. You're responsible for your children. You're responsible for your man. You're responsible for your home, for everything."

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

Life is a daily struggle because many positive women experience difficulty providing for basic needs - food, shelter, clothing and transportation – for their children and for themselves. Many women cannot afford expensive treatments and difficult choices are often made between purchasing medication for themselves and basics for their families. Many financial supports are geared to the needs of single men or single people, and most women do not have adequate housing for themselves and their families. One single mother explained,

"A lot of women who I know are single moms like me. Your child is your first priority. 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, whether that be money, time out or a 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 take on a greater importance than their own needs, health and well-being. A universal primary concern is who will care for their children if they get sick and after they die: *"The first thing that popped into my head when I found out was who is going to take care of my children."* Many women expressed anxiety and guilt about how their children were coping with knowing that their mother was HIV positive, particularly regarding discussing their illness and its impact on their children's well being. Some women worry that their *"children are too sensitive"*, *"carry an added burden"*, *"grow up too fast"*, *"have too much to worry about"* or *"may not be strong enough to cope."* This woman explained, *"My daughter worries about me, and she is only nine. That stops me from showing pain when I feel pain because I don't want to worry her."*

Deciding when and how to disclose their HIV status to their children and to which children is a difficult, complex and stressful process for HIV positive parents but particularly so for single mothers with little emotional and social support. Some women chose to tell their children at an early age. These women felt it was important that their children know the truth and have the opportunity to work through their feelings, including coming to grips with grief, loss and death.

“I know that children at different ages deal with grief, loss and death differently. One of the things I have tried to do; it becomes emotional to talk about it, she’s my baby and I would like to protect her. But one of the things we’ve started doing is seeing a grief counselor. My daughter goes to an art therapist and this is a way for her to understand these changes in our lives and accept that these losses happen. We have to deal with them and we have to accept them.”

But children are also a source of joy, hope, support and a primary motivation for First Nations women to find strength and 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 feel that their own lives have been shattered, their hopes and their dreams are for their children.

Gender Discrimination as HIV Positive Women

Many positive First Nations women live in secrecy because of the multiple forms of stigma associated with HIV/AIDS; one woman living with AIDS explained,

“It’s the stigma that goes with it. It’s not the death part. It’s how you got it. You must be homosexual. You must have used IV drugs. You must have done something wrong. That’s the fear for me, the rejection because of stigma.”

In addition to the multiple stigmas associated with HIV, First Nations women living with HIV/AIDS suffer from gender discrimination because as women they carry the additional stigma of being branded *“promiscuous”*, *“bad mother”* and *“deserving of HIV/AIDS.”* Secrecy is perhaps a bigger issue for positive women because of a need to protect not only themselves but also their children. *“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 also particularly for their children. One positive woman said,

"It's hard being a woman with HIV in a society that rejects women who are HIV positive, that frowns upon mothers who are HIV positive and that rejects the children..."

It's still hard being a woman with HIV because of the 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."

As a consequence, many First Nations women living with HIV/AIDS under-utilize both First Nations and non-Aboriginal services. *"If I go there, I might see one of my relatives and they are going to go around and say they saw so-and-so here. There are a lot of questions about whether you should come out and disclose your HIV status in the community."*

Multiple Barriers to Services

First Nations women encounter multiple barriers based on gender, racism and class in accessing a broad range of services. Gender barriers persist in women's access to treatment and clinical drug trials; one woman noted, *"I think in the AIDS world we've been at the bottom of the ladder in terms of treatment and clinical trials because of our reproductive capacities."* Moreover, 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 service organization for women. All the rest are 90% for men. They don't discriminate against women, but there is really no place for them."

In addition to gender barriers and stigmas around HIV, some positive women acknowledged encountering subtle forms of racism in their interaction with non-Aboriginal, mostly white, health professionals. As well, women noted the lack of culturally appropriate services and counseling for First Nations women living with HIV/AIDS. Many health professionals and service providers need to improve their understanding of First Nations cultures and traditions. Almost half the women we interviewed expressed the need *"for more Aboriginal counselors, particularly who know street life."* Some women felt it was important to

combine traditional healing and western medicine. One positive woman explained, *"HIV/AIDS takes your spirit away. We need to find a way to use the sweat lodge and the white man's medicine."*

Pregnancy, Reproductive Choice and Sexuality

A number of women we interviewed discovered they were HIV positive when they were pregnant, either as a result of a routine check-up or because they were experiencing difficult pregnancies. While some women felt they received adequate counseling, information and support, other women reported less than satisfactory treatment. One woman reported,

"When I first found out I was HIV positive, I was five months along going into six. I was having a lot of problems...Back at home, my doctor was quite ignorant of HIV. The way I found out was very bad because he was so overwhelmed by the results that he didn't know how to tell me. He left his door wide open and he was practically shouting at me and waiving the piece of paper...he stood across the other side of the room and talked to me. The whole time he had his rubber gloves on."

Women who are HIV positive or who have partners living with HIV have often been discouraged from becoming pregnant. Many women have been counselled to avoid pregnancy, delay or abort. In addition to worrying about their own and their baby's health, positive women desiring to have children have to come to grips with the stigma associated with pregnancy and HIV. One positive woman explained,

"I was just trying to be a normal pregnant woman without having to worry about whether I was going to be responsible for infecting my child. The judgement was that if I was an HIV positive woman making a choice to have a child, I was treated differently than if I was just an innocent victim happening to find out that I was HIV positive."

If reproductive issues are fraught with difficulty, sexuality and intimate relationships for positive women are as well. Violence can occur when women ask men to use condoms: *"It's just hard to be a woman and to be having to ask to use a condom. It can get abusive to ask your partner to use a condom...abusive physically, emotionally and verbally."* Disclosure

of HIV status to a potential partner or mate is stressful, but positive women run the risk of encountering violence consequent upon informing a sexual partner of her seropositive status.

"There were some women who experienced violence in their relationships because the men didn't know they had the virus and found out later...I was too scared to say that I was living with the virus because I was afraid of the violence that comes with the men knowing when you tell them that you are HIV positive."

Emotional and Social Isolation

As a consequence of multiple stigmas and barriers to services, First Nations women living with HIV/AIDS have little, if any, emotional and social support. Many women live in extreme isolation. The positive women we interviewed live in urban or metropolitan centers, far from their home communities because the city provides anonymity and because they feel there is greater acceptance of HIV positive women in the city: *"Vancouver has a good sense of community for women with HIV"* ... and, *"better access to services: "It's better for me to stay here. In my community, there aren't enough services and it is more open in Vancouver."*

All of the women we interviewed go regularly to the Positive Women's Network (PWN), which has a mandate *"to provide a safe environment for Aboriginal women."* PWN provides baby-sitting and transportation money to women who come in to access the food bank or to have lunch. In addition, individual counseling is available for women if they so desire. One woman expressed, *"It is there that I feel safe. I'm not alone. I get to be with other women. We are there for each other."* For other women, it is a place to *"make friends with other positive women who have children"* or *"for support for children living with people who have HIV."* But, many First Nations women are *"afraid to come to PWN"* for fear of being identified.

Many positive women desire and need to return home. One woman stated, *"I know a lot of people who live with HIV that have no sense of family or community and they die really quick."* However, many women fear isolation, rejection and discrimination should 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. One woman reported, *"Last spring I had a really good experience. I got to go home and I had 200 of my community, family, friends and extended family come and have a celebration with me."* Other communities are less accepting. One woman said, *"My family was*

isolated because I was home. People are afraid. They think you can catch it - through the air.” Some women were forced to leave their communities: “When people found out, they reacted very badly. It wasn’t safe for me to stay. It’s a small community. Everyone knows everyone. I am the first person in the community to test positive.”

For First Nations women with HIV/AIDS who are living far from home, family, culture and community, their hope is that their children will one day be able to go home, as this woman so poignantly expressed,

“I have been told by my doctor that I am dying and I have to go on anti-virals. It’s a hard choice but I’m doing it because I want to live. I have two daughters. I want them to grow up, to be good people and to be good women. I want them to know their culture and to be able to go home some day because I do have land and a house back home.”

Conclusion and Recommendations

Our interviews with First Nations women living with HIV/AIDS reveal how gender plays an important role in shaping their socially distinct experiences as women and as mothers. Women’s social roles as caregivers and nurturers mean that they are responsible for caring for themselves, their children and their families. Providing for their basic needs and the needs of their children is a daily struggle for low-income single mothers living with HIV/AIDS who have few resources and little, if any, emotional and social support. Services and supports need to be geared to the needs of positive women and their children. Access to affordable, comfortable housing and income supplements for medication, alternative therapies and treatments, food, transportation, home support, daycare and babysitting services would go a long way to improve the quality of positive women and their children’s daily lives.

Gender discrimination, racism and socioeconomic disadvantage impede the access of First Nations women living with HIV/AIDS to a range of medical and social services and supports which could enhance their own and their families’ health and well-being. A greater range of culturally appropriate, gender-specific services, supports and counseling; particularly around accepting and living with HIV, sexuality, reproductive choice, sexual and physical abuse must be made available to First Nations women living with HIV/AIDS. Enhanced networking would help positive women who wish to connect with other women living with HIV and AIDS, reduce their sense of isolation, gain mutual support and share information.

Some positive First Nations women indicated to us that there is a need for more comprehensive family services in particular, family counselling, to help them and their family members work through and validate complex and contradictory feelings as well as learn new coping mechanisms. They also felt that family counselling to teach how to disclose HIV status, particularly in small communities, would be very helpful to all family members. Other women also wanted enhanced services for their children, such as grief counselling, on-going support and support (which could be extended to the entire family) in the event of the death of the parent living with HIV/AIDS. Some positive women felt their children may also need retreats to get away, to have fun and to be children.

Placing First Nations women living with HIV/AIDS on research and policy agendas as well as improving access to a range of health and social services and supports are essential if we are to more effectively meet the physical, mental-emotional, social and spiritual needs of First Nations women living with HIV/AIDS and their children so that they may live positively.

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