# Striking to the Heart of the Matter

Selected Readings on Gender and HIV

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Atlantic Centre of Excellence for Women's Health

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# Preface

Despite the fact that HIV, the virus that causes AIDS, has been studied from a variety of perspectives for over 20 years, there does not appear to be any sign of a quick or final resolution to this health crisis. And as we continue to grapple with the impact of this virus we find ourselves revisiting questions related to the types of factors that continue to contribute to its further spread. Clearly, a myriad of biological, social, political and economic factors is implicated in the epidemic. One significant contributing factor, and the focus of this publication, is how gender impacts on HIV and risk behaviours. The manner in which men and women in Canada experience HIV/AIDS is not simply a biomedical fact, but rather a social reality, reflecting differential access to prevention, care, treatment, and support.

As the title of the cover art suggests, understanding gender issues related to HIV risk really does "strike to the heart of the matter". This publication is not an exhaustive overview of the issues of HIV/AIDS in Canada; rather it is meant to serve as a jumping off point for further study and discussion. Contributors to this collection have consequently traversed a wide range of research questions and issues in their efforts to deepen our understanding of the relationship between gender and HIV/AIDS. Colin Dodds and his colleagues, for example, make a compelling case for the economic imperative of a gender analysis of HIV transmission and AIDS management. When salient differences between women and men are ignored, prevention strategies and treatment programmes become less effective – and therefore more costly – than they might be.

Other authors expose the challenges of understanding the experiences of those at greatest risk of HIV/AIDS: women in marginalized or "forgotten" populations. Peggy Millson and her colleagues evaluate prevention strategies aimed at female injection drug users, while Lois Jackson analyses HIV prevention programmes for female prostitutes. Both studies document the differential impact of social and economic determinants, such as poverty, violence and discrimination, on the lives and risk behaviours of women as compared with men. Susan Judith Ship and Laura Norton similarly examine the experiences of Aboriginal women as they relate to HIV/AIDS. Historic subordination, cultural disruption, geographic and social isolation, racism, and poverty constitute an especially noxious mix that renders Aboriginal women more vulnerable than Aboriginal men or non-Aboriginal women and men. Equally important are the methodological issues raised by contributors. Articles by Millson et al, and by Jackson address the difficulties of assembling a "representative" group of women from within marginalized populations. Margreth Tolson and Stephanie Kellington also stress that researchers must enter into genuine partnerships with project participants if studies of "forgotten" populations are to produce results that are meaningful for community members as well as for those designing and implementing policies and programmes.

Although women relegated to the margins of Canadian society are most at risk of HIV/AIDS, the overall lack of gender-sensitive prevention and treatment strategies has profound implications for the health of all Canadians. Lynne Leonard and her co-researchers found considerable variation in the experiences of pregnant Canadian women offered HIV counseling. They conclude that HIV testing acceptance rates, which have the potential to reduce mother to child transmission rates, will increase only with the provision of more – and more appropriate – services. Donald Langille and his colleagues document differences between adolescent males' and females' perceptions of healthy sexuality and safer sex practices; differences that have the potential to modify risk of exposure to HIV.

It is hoped that the papers in this collection will not only provide insight into the types of research being conducted in Canada, but also will encourage further study of the impact of gender-related issues on the burden of HIV. Our responses to HIV/AIDS in the new millennium must highlight the importance of gender, particularly the underlying issue of power relationships between men and women, as it pertains to our understanding of HIV risk.

We would like to thank the contributors and the peer review panel for their time, energy, and expertise. We are also indebted to all those who assisted in the publication of this collection, including Susan Rolston and Barbara Clow for their patient editing. Lastly, we are grateful for the continued support of the Women's Health Bureau and the Centres of Excellence for Women's Health Program, Health Canada.

Jacqueline Gahagan Carol Amaratunga Deputy Director Excellence for Women's Health

# 1

# THE ECONOMIC COST OF HIV/AIDS IN CANADA

Colin Dodds Ronald Colman Carol Amaratunga Jeff Wilson

Until the 1980s, it was almost universally assumed that medical science was winning the battle against the worst infectious diseases. The HIV/AIDS<sup>1</sup> pandemic shocked the world not only because of the virulence of the disease and its automatic "death sentence", but because it challenged our basic assumptions and stereotypes about disease transmission and sexual relationships between women and men. Today, 20 years after the first Canadian AIDS death, the shock has been tempered not only by time, but also by changing trends and by the changing profile of the global epidemic:

 The "epidemic" nature of the disease appears more distant to the well-off and educated, both abroad and at home. HIV/ AIDS has afflicted one in twelve sub-Saharan Africans compared to 1 in 500 Canadians, and AIDS is now the main cause of death in Africa. The continued rapid spread of the disease has led researchers and policy analysts to revisit HIV/AIDS as a health issue and to view it from a broader interdisciplinary development perspective. HIV/AIDS is now viewed as a cross-cutting development issue which impacts on the security of the household as an economic unit, on food security, and on the overall stability of civil society.

 In Canada and elsewhere in the developed world, the rate of HIV infections, AIDS diagnoses and AIDS deaths has dropped dramatically, particularly in the last five years. Nevertheless, the rate of infection, particularly among young women under 30 years of age, continues to climb. According to Health Canada, as of 2001, more than 50,000 Canadians were HIV positive (Canadian HIV/AIDS Clearinghouse at <http:// www.clearinghouse.cpha.ca>).

In Canada, AIDS victims are now less likely to be middleclass gay men than in the 1980s, and much more likely to be vulnerable groups – Aboriginals, the poor, the unemployed, the homeless, and injection drug users. Those most likely to be newly infected with AIDS are already marginalized, and tend to come from populations which are excluded both socially and economically from mainstream society, including racialized minorities.

In Canada, the developed world, and globally, women are a growing proportion of HIV/AIDS sufferers. **Globally, more women than men are now dying of AIDS**. In spite of this fact, little is known about how gender, as a determinant of health, impacts on HIV prevention and transmission in terms of men and women's differential roles, expectations, values, sexual attitudes and behaviours.

Recently a number of international agencies, including the Joint United Nations Programme on HIV/AIDS (UNAIDS) (see <http://www.unaids.org>), the United Nations Development Fund for Women (UNIFEM) (see <http://www.unifem.undp. org>), the Commonwealth Secretariat (see <http:// thecommonwealth. org/gender>), and the Global Health Council (see <http://www. globalhealthcouncil.org>), have promoted HIV/AIDS as a national development and gender-based policy issue. The promotion and adoption of a gender approach to HIV/ AIDS helps to situate the pandemic as a broader development issue and raises key questions with respect to how the disease impacts upon women and men differently in terms of access to health care prevention and treatment services. A gender ap-

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proach, for example, ensures that public policies and services are designed to take gender and sex differences into consideration. A gender approach assists policy makers and planners to understand the shifts from personal to national security, and the impact of HIV/AIDS on national planning in terms of the delivery of services in education, health, food security, and socioeconomic programmes.

From a population health perspective, an understanding about the interplay among the twelve determinants of health,<sup>2</sup> i.e., including gender, culture, health services, physical environments, income and social status, and social support networks, further enhances the ability of governments to plan responsive and appropriate strategic public policy and programmes targeted at women and men in high risk populations.

The purpose of this paper is to find a meeting ground between the need for a gender approach to HIV/AIDS and the broader economic considerations.

- A cost analysis of HIV/AIDS in Canada shows clearly that prevention and education can markedly reduce HIV incidence. Parallel investment in other Commonwealth countries and among vulnerable groups would also likely be highly cost effective. The observation by the Canadian Strategy on HIV/AIDS that "the dollar cost of preventing a case of HIV/ AIDS is only a fraction of the cost of treating and caring for someone once he or she becomes infected" applies not only to Canada.<sup>3</sup>
- While there is still no known cure for the virus and the disease remains fatal, HIV is more successfully "managed" in Canada and the First World countries. Consequently, the lives of those with the infection are being significantly prolonged relative to those in the Second and Third World.

One of the limitations of this discussion is the fact that gender disaggregated HIV/AIDS economic data are difficult to locate. It is hoped that this preliminary discussion will encourage researchers to adopt gender-based approaches in both clinical trials and economic cost accounting studies.

#### GLOBAL AND CANADIAN HIV/AIDS TRENDS

AIDS killed 2.6 million people in 1999, including half a million children, an increase of more than 70% in just three years. It is now the fourth biggest killer in the world, after heart disease, stroke and respiratory disease, and kills more people than any other infectious disease. There are now more than 34 million adults and children in the world living with HIV/AIDS, nearly 70% of them in sub-Saharan Africa. Of those, 55% are women. The disease is spreading so rapidly that one in six of the 34 million AIDS victims became infected in 1999 alone (Matlin and Spence 2000: 1, 9-11).

The social and economic burden of the illness in Africa is devastating; 25% of Ugandan households are providing for an orphan. HIV infection rates of up to 40% are reported among teachers in Malawi, Namibia and Zambia. Twelve percent of all educators in South Africa are HIV positive, and one in 25 Botswana children have lost a teacher to AIDS (Matlin and Spence 2000: 11; Alben and Guinness 2000). An HIV/AIDS sufferer in Rwanda is 36 times more likely than the general population to use hard-pressed outpatient health services, and annual health care expenditures for HIV/AIDS patients are 21 times greater than for the general population. Because AIDS claims its victims at a young age, the indirect social and economic costs of lost productivity are enormous. A World Bank analysis of 80 developing countries estimated that a 15% HIV prevalence rate reduced per capita GDP growth by 1% (Alben and Guinness 2000).

By contrast, the rapid spread of HIV/AIDS in Canada and other affluent countries in the late 1980s and early 1990s has been dramatically reversed. There were 25.4% fewer HIV positive tests in Canada in 1999 than in 1995, reflecting the marked success of education and prevention investments. There were also 80% fewer AIDS cases, and 92% fewer AIDS deaths, reflecting the success of HIV-management methods that delay the onset of AIDS and prolong the lives of those infected (see Figure 1) (Health Canada 2000a: Table 16 at 29).

Nevertheless, Health Canada cautions that the bulk of the HIV and AIDS burden still lies ahead, even in this country.<sup>4</sup> That is because, even though new diagnoses are declining, the cumulative total load of AIDS cases continues to rise as existing HIV cases turn into AIDS. As of June 30, 2000, there had been a cumulative total of 47,000 positive HIV tests in Canada (Health Canada 2000a: Table 2 at 4). Of those, 17,165 have turned into AIDS, 20% more than the cumulative 1995 total. Of those 17,165. 70%, or 12,088 Canadians, have died of the disease.<sup>5</sup> According to these figures, there are currently about 35,000 Canadians living with HIV/AIDS. These figures are certainly an underestimate because they are based only on actual documented HIV positive tests. Health Canada estimates that there are an additional 15,000 Canadians who are HIV positive but who have not been tested and who are unaware of their infection (Health Canada 2000b). This means that about one in 500 Canadians has been infected with the virus.



Figure 1: The steep decline in new AIDS cases in Canada *Source*: Health Canada 2000a.

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These trends have implications for the cost assessments in the following section. They indicate that while the preventive and management investments of the last 15 years have stemmed the steep rise in health care and treatment costs that would certainly have occurred without these investments, the continuing cumulative increase in AIDS cases has not yet produced a significant decline in these costs. In terms of "return on investment," however, this "payoff" will soon occur. While cumulative AIDS cases in 2000 in Canada were still 20% higher than in 1995, they were only 10% higher than 1996, 7% higher than 1997, 4% higher than 1998, and 2% higher than 1999. In short, we are fast approaching the point in Canada where it will be possible to report an absolute decline in cumulative AIDS cases and consequently, dramatic savings in health care costs.

### THE CHANGING PROFILE AND GENDER DIMENSION OF HIV/AIDS IN CANADA

It has already been noted that 55% of AIDS sufferers in sub-Saharan Africa are women and, globally, more women than men died of AIDS in 1999. Gender-based studies of HIV/AIDS have noted that "women are more susceptible to HIV infection on each sexual encounter because of the biological nature of the process and the vulnerability of the reproductive tract tissues to the virus, especially in young women" (Matlin and Spence 2000: 11). Similarly one study notes that "young women are biologically at higher risk for infection because male to female HIV transmission ... is estimated to be several times more efficient than female to male" (Albert and Williams 1998: 13).

These studies have also pointed to social, economic and cultural factors that increase women's vulnerability to HIV/AIDS. These include sexual coercion, less power to negotiate for safer sex, as well as greater likelihood of rejection, expulsion from the family home, and denial of care and treatment once the disease is diagnosed. Women also bear the main burden of caring for sick family members and often have less care and support when they themselves are infected (Matlin and Spence 2000; Gupta 2000a). While many studies have focused on Africa, a

culturally specific gender-based analysis is also critical in assessing the impact of HIV/AIDS in Canada. Indeed, without such analysis, the encouraging overall trends described above can be very misleading. While there has been an overall drop of 25% in the number of new HIV positive infections since 1995, the 1999 female infection rate is *higher* than it was in 1995, and has increased by 20% since 1997.

Men still represent 87% of the cumulative total of positive HIV tests in Canada, but the balance is changing dramatically. Between the period 1985-1994 and 1999, the female proportion of HIV positive tests increased from 10% to 25% of the total. Though the number of AIDS diagnoses has fallen for both sexes, women also represent an increasing proportion of AIDS cases diagnosed each year, from 9% of the total in 1995 to 21% in 1999. The proportion of new HIV infections due to male homosexual activity has dropped sharply from 75% of total infections in the period 1985-1994 to 38% today. Since 1995, there has been a 38% decline in the number of new infections attributable to male homosexual activity. In contrast, the number of new HIV infections due to heterosexual activity has more than doubled since the late 1980s and risen by 26% since 1995 (Figure 2). As a percentage of total cases, new infections attributable to heterosexual activity rose from 6% in the period 1985-1994 to 19% today.

As noted by Geeta Rao Gupta (2000b) the

public health discourse, as seen in scientific journals and forums, reflects definite progress in understanding the importance of both gender and sexuality. But because this increased understanding is fueled in large part by the need to interpret the dynamics of the AIDS epidemic, the analysis of gender and sexuality is situated firmly within a framework of disease. Sexuality, as seen through the public health prism, therefore, is still a potential determinant of ill health and little else. As a result, safer sex is the mainstream theme within this discourse, while sexual health, pleasure, and rights remain on the margin. Figure 2: Number of HIV positive tests due to heterosexual activity



*Source*: Health Canada 2000a. Trend line added to indicate percentage increase since 1995.

A U.S. study has linked HIV infection through heterosexual contact to injection drug use, based on indications that 80% of HIV positive heterosexual men or women who never used injection drugs became infected through contact with someone who did (Gould and Gafni 1997). This data would lead us to believe that injection drug use could possibly be responsible for more infections than the Canadian data indicates. Even without that apparent link to heterosexual infection, the percentage of new HIV infections attributable directly to injection drug use has risen from 9% of all cases during 1985-1994 to 28% in 1999 (Health Canada 2000a: Table 4C at 9).

Interestingly, and contrary to popular stereotypes, studies show that Canadian female prostitutes are no more likely to be infected with HIV or other sexually transmitted diseases than other women unless they are also injection drug users.<sup>7</sup>Other studies also note that in terms of sexual relations, sex-trade workers use condoms more consistently than other populations similar in age, race and sex.<sup>8</sup>

It is apparent that many high risk groups in Canada belong to socially and economically excluded and marginalized populations. As such, those at high risk of becoming HIV positive may represent "hard to reach" or "forgotten" populations that are excluded from the mainstream. As such, their isolation and social exclusion hinders the efficacy of conventional health prevention delivery strategies. For example, there has been a marked shift in rates of infection from middle class gay men to vulnerable populations, including the poor, unemployed, minorities, poorly educated, Aboriginal people, and those involved in "street activity" (Albert and Williams 1998: 9, 12, 14). Since 1984, the number of AIDS cases among Aboriginal Canadians has risen steadily, particularly among women and those under 30. Regrettably such data can inadvertantly contribute to and reinforce "victim blaming" stereotypes and marginalization of such groups.

Rates of infection in the Canadian prison population, which has a high proportion of Aboriginal people, are estimated to be at least ten times greater than in the general population.<sup>9</sup> With the advent of increased heterosexual and injection drug user transmission, First Nations communities remain at considerable risk within Canadian society.

Internationally, from a gender perspective, according to human rights agencies such as UNAIDS and UNIFEM, transmission from men to women is twice as likely as from women to men, and women and girls are frequently not sufficiently empowered to protect themselves from unwanted or violent sex. Around the world there are alarming trends that women are becoming infected at younger ages than men. Cultural views about masculinity and "machismo" further support sexual stereotypes. Such stereotypes promote greater gender inequalities with respect to who is entitled to access to treatment and, in some cases, who is entitled to receive anti-retroviral therapies.

The growing association of HIV/AIDS with social and economic exclusion indicates that continued reductions in HIV/ AIDS incidence in Canada will increasingly depend on alleviation of poverty and other underlying social causes. As in other countries, conventional disease-specific prevention and management frameworks will have limited effectiveness in reaching marginalized groups and even less impact in terms of reaching women and other high risk populations. One analysis notes:

New therapies should mean an improved quality of life for those living with HIV who have access to the therapies and sufficient income to procure adequate housing and nutrition to provide a healthy basis from which to manage the infection. It is not clear how helpful the therapies will be to marginalised populations, particularly street-involved people and injection drug users, who have difficulty complying with the stringent guidelines required to make the new therapies effective (Alberts and Williams 1998: 15).

It is now widely recognized that gender inequalities exist in terms of access to health and HIV/AIDS information, prevention and treatment services. Women often have low social status and limited access to health services. As the family unit disintegrates, the burden of care is transferred to young girls and/or to old women. The transmission of the disease is sometimes attributed unfairly to women as in the case of "vertical" transmission from mother to child. In short, HIV/AIDS affects family integrity, and the family as a social and economic unit. Around the world, and in Canada, HIV/AIDS continues to contribute directly to poverty and to reduce individual and collective productivity. Poverty in turn forces many marginalized groups, including women and girls, into risk taking behaviours. In addition, systemic violence against women and girls, including sex trafficking and prostitution, increase rates of infection. According to UNAIDS and UNIFEM, economic hardship contributes to increased incidences of sexual trade and crime, which in turn, impact upon society's ability to provide funding for social programmes and supports for women, children and families.

## THE ECONOMIC COST OF HIV/AIDS IN CANADA

Economic cost analyses demonstrate that the burden of illness is not borne by individual sufferers alone but is shared by society at large. Cost analyses also motivate policy actors to invest strategically in cost-effective prevention and management that can reduce the immense social costs of illness treatment and direct and indirect productivity losses. The application of gender-based analysis enhances the ability of planners and decision makers to define policy issues and outcomes, and to ensure that women's and men's experiences are considered in the identification of issues. When a gender approach is included in the design of an economic cost analysis of HIV/AIDS, society at large benefits. Such analysis contributes directly and indirectly to greater inclusion of the voluntary sector, strengthened civil and political rights for marginalized groups (including women), and greater personal safety and security for women and girls, men and boys.

#### DIRECT COSTS

Estimating the direct cost of HIV/AIDS is complex because the distribution of health care costs shifts dramatically as the disease advances. In addition, very little data is in disaggregated form by sex, and therefore our ability to estimate or approximate gender differences is limited. Early stages of the illness are characterized by a relatively high proportion of drug costs, primary and community care, and outpatient visits, while later stages are marked by longer in-patient hospital stays. Despite the high cost of drug treatments to manage the disease in its early stages, Table 1 clearly illustrates steadily increasing treatment costs as the disease progresses. The 44% of HIV/AIDS victims in the last two stages of the illness account for 59% of total health care costs, and the 25% with full-blown AIDS account for 38% of costs.

Table 1: Distribution of Annual Health Care Costs of HIV/AIDS in Canada, 1999 (CD-4 ranges in Row 1 refer to T-cell counts. The fewer T-cells, the more compromised the immune system; Total cost figures are in millions of 1999 dollars)

*Sources*: Hellinger 1993; Albert and Williams 1998; Health Canada 2000a; Statistics Canada (see footnote <sup>10</sup> for details).

In sum, the direct health cost of HIV/AIDS in Canada in 1999 was estimated to be in the range of \$560 million. To this must be added another \$42.2 million, largely from the public investment in the Canadian Strategy on HIV/AIDS, for prevention, research and support to national AIDS coalitions, Aboriginal communities, and correctional services, and other supports to HIV/AIDS victims that are not included in the direct cost figures cited in Table 1.<sup>11</sup> Total direct costs of HIV/AIDS are therefore estimated to be in the range of \$600 million a year.

The shift in 1996 to expensive HAART treatments (high activity antiretroviral therapies) that delay the onset of AIDS and prolong the lives of HIV patients has increased direct patient costs. Average monthly health care costs per person for the four HIV/AIDS stages described in Table 1 increased by 120% for

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the >500 stage, by 85% for the 499-200 stage, by 51% for the 199-75 stage, and by only 21% for AIDS victims (<75) following the introduction of HAART treatments (Albert and Williams 1998: Table III-6 at 32). A 1993 U.S. study estimated that the direct health care cost per person from HIV infection until the development of AIDS was US\$50,000, and from AIDS development to death about US\$69,000, for a total lifetime cost from time of infection to death of US\$119,000 (Hellinger 1993: 474-478).

#### INDIRECT COSTS

The economic cost profile of HIV/AIDS differs most markedly from that of other illnesses in the very high proportion of indirect economic costs attributable to the illness. As the immune systems of HIV/AIDS sufferers become increasingly compromised, they fall victim to more infections, take more sick days and longer disability leaves, and are increasingly unable to work. These indirect losses to the economy are amplified by the relative youth of AIDS victims, whose premature deaths are reflected in further production losses to the economy.

Indeed, the loss in "human capital stock" is greater for HIV/ AIDS than for any other cause of death, including car accidents, suicide, stroke and heart attack, because it claims its victims at a younger age (Hanvelt et al. 1994). For all illnesses, Health Canada has estimated that indirect costs are 54.3% of total disease costs in Canada (Health Canada 1997: Table 1 at 9). By comparison, using conservative production loss figures, this study conservatively estimates indirect costs at 2.4 times the direct costs of HIV/ AIDS in Canada.

This high ratio of indirect to direct costs exists despite the high direct costs of HAART treatments, and despite the gradual increase in longevity of AIDS victims, from an average age of death of 36 years in 1990 to 41 years in 1999.<sup>12</sup> If we draw a parallel from Transport Canada's estimate of \$1.56 million for the average life value lost in each road fatality, then the estimated ratio of indirect to direct costs would be much higher, or about 5:1.

The proportion of indirect to direct costs is also greater in

estimates of total cumulative illness costs because indirect costs due to premature mortality continue to accumulate even when direct costs cease at the time of death. Thus Albert and Williams estimate the **total economic burden of HIV/AIDS in Canada to date at \$36.3 billion**, of which \$29.9 billion are indirect costs and \$6.4 billion are direct costs (a ratio of nearly 5:1). They also estimate the **future economic burden associated with the current HIV population at \$27.3 billion** (reflecting a 4% discount rate), of which \$23.3 billion are indirect costs and \$4 billion are direct costs, a ratio of nearly 6:1 (Albert and Williams 1998: 36).<sup>13</sup>

The indirect costs of HIV/AIDS in Canada are estimated here on an annual rather than lifetime episodic basis, first by multiplying the number of premature deaths to date by the annual per capita gross domestic product of Canada. As the average age of death due to AIDS in 1990 was 36, it is assumed here that all AIDS victims would still be in the work force in 1999 had they not contracted the virus. Multiplied by the 12,088 AIDS deaths in the last 20 years, the indirect market loss to the economy of these premature deaths can be estimated at \$380 million for 1999.<sup>14</sup>

Unlike conventional accounting mechanisms that consider only market values, the Genuine Progress Index also counts the value of unpaid voluntary and household work. Using Statistics Canada estimates of the replacement value of voluntary work (\$16/hour) and household work (\$10/hour) in Canada, it is estimated that the lost unpaid work contribution for 1999 due to the premature deaths of 12,088 AIDS victims is \$347 million.<sup>15</sup> Total economic production losses due to premature deaths attributable to AIDS therefore amount to \$727 million for 1999.

Deaths avoided as a result of education and the successful prevention of new HIV infections as well as successful management of HIV, produce savings due to averted production losses and retained productive capacity. If AIDS deaths had continued at 1995 levels (1,427 for that year), there would be 3,906 fewer Canadians alive today. Multiplied by the per capita GDP, it can be estimated that the productive capacity of the Canadian economy is \$123 million larger today than it would be without the lives saved through successful prevention and management

of HIV.

In addition to indirect costs due to premature death, productive capacity is lost due to sickness and disability. For the purposes of this study, it has been assumed that all AIDS victims are absent from work and that 25% of the productive work time of HIV patients is lost due to the illness. On average, this would yield economic losses due to work absence, sick days, and long and short term disability of \$376 million. Lost volunteer time and unpaid household work time due to sickness and disability is estimated at \$343 million, for total disability losses of \$719 million. Added to production losses due to premature death, **total economic production losses amount to \$1,446 million for 1999 in indirect costs due to HIV/AIDS.** Added to the \$600 million in direct costs, it is estimated that HIV/ AIDS cost Canadian society more than \$2 billion in 1999.

# CONCLUSION: LESSONS LEARNED FROM CANADA AND BEYOND

As noted above, the Canadian experience is limited in terms of demonstrating gender differences in estimating the costs of HIV/ AIDS to Canadian society. However, the Canadian case demonstrates that "the dollar cost of preventing a case of HIV/AIDS is only a fraction of the cost of treating and caring for someone once he or she becomes infected."<sup>16</sup> In addition, it has been noted that successful management of HIV can prolong life and increase the quality of life of those with the virus, thus retaining productive capacity and reducing overall costs to the economy. As increased effort is directed to designing gender-sensitive education and targeted prevention campaigns for high risk populations, it is expected that the incidence of new HIV infections in Canada will continue to decline, thereby reversing the Canadian epidemic in a relatively short period of time. Successful management of HIV, particularly through HAART treatments, has even more dramatically reduced the number of new AIDS cases and deaths due to the disease. Because of the enormous economic burden of HIV/AIDS, these strategies are deemed to be cost effective over time, and will produce significant long-term direct

and indirect cost savings to the Canadian economy.

The enormous drain on the resources of developing nations, to say nothing of the immense burden of human suffering and premature death, demands that culturally appropriate genderbased strategies such as those developed in Canada be adopted where the need is greatest. Canadian case study economic analyses demonstrate that such investments can be highly cost effective, producing enormous savings in direct health care costs and retained productive capacity. Recent initiatives to apply gender-based analysis in cost accounting, such as the gender and economic costing project for HIV/AIDS and cancer palliative care pioneered by the British Columbia Centre of Excellence for Women's Health, Atlantic Centre of Excellence for Women's Health and Centre d'Excellence pour la Sante des Femmes will contribute to our understanding of such diseases and how they impact upon women and men differently. Other recent training and research initiatives such as those initiated by the Centres of Excellence for Women's Health, e.g., the International Design Workshop on Gender and HIV/AIDS, Halifax, January 16-19, 2002, will assist decision makers in Canada and abroad to adopt gender-based programmes and policies that address the experiences of those infected with HIV.

Closer to home, Canadians must recognize the changing profile of HIV/AIDS, particularly the increase in female infections and the escalating rates of infection among Aboriginal and marginalized populations. Education and prevention strategies that have worked successfully in reducing HIV/AIDS prevalence in the male homosexual population need to be continuously adapted to other populations increasingly at risk, e.g., injection drug users and the heterosexual population at large. It must also be acknowledged that disease specific HIV-management frameworks, including research protocols and programmes that focus only on men, when compared to gender sensitive models that address the interplay among the determinants of health, may be less effective in reaching vulnerable populations. Reducing social exclusion and advancing gender equality can be highly effective not only in combating HIV/AIDS among populations increasingly at risk, but in reducing the total burden of illness in Canada. Health Canada's *Second Report on the Health of Canadians*, 1999, emphasizes that poverty and poor educational attainment are the most reliable predictors of poor health. Programmes that are aimed at improving women's income security and redressing poverty can assist with HIV/AIDS reduction. The changing profile of HIV/AIDS in Canada demonstrates that this illness is no exception and is amenable to gender-based approaches and strategies – particularly strategies that address sexual relationships and relationships of power between men and women.

The challenge for governments will be to build national capacity in terms of gender and HIV/AIDS approaches, policy and programmes which address the differential experiences of women and men. Investment is required to package and disseminate new knowledge on gender approaches to HIV/AIDS, and to promote greater public understanding of the underlying issues of power, agency and autonomy in human relationships. Gender-based and economic cost analyses demonstrate that this is not only the "right" thing to do, but an excellent and costeffective strategic investment that can successfully reduce the enormous economic burden and suffering of HIV/AIDS. Ultimately, with "evidence" from gender-based economic costing studies, governments will be in a better position to target strategic investment in support of fair distribution of resources and more equitable public policy.

In summary, the HIV/AIDS story, particularly in the last five years, is both an account of unparalleled devastation in some parts of the world and innovative gender and population health management initiatives among targeted populations, particularly in high risk communities in Canada and elsewhere. The challenge in the years ahead is to bring those contradictory trends together by applying the "lessons learned" where the need is greatest.

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- 5. Health Canada 2000, Tables 13A and 13B, pages 20 and 21. These numbers have been rounded because 2000 Ontario data for HIV positive tests to June 30, 2000 were not available at the time of publication. The actual number of HIV positive tests reported in this document is 46,651, excluding the most recent Ontario data.
- 6. Gender breakdowns and homosexual/heterosexual attribution are from Health Canada, 2000a, Tables 3A, 3B and 4C, pages 5 and 9.
- 7. Bastow (1995), citing W. Darrow, "Prostitution, Intravenous Drug Use and HIV-1 in the United States."
- 8. Bastow (1995), citing P. Alexander, "Prostitutes and AIDS: Women as Alleged Vectors," *National Now Times*, February/March 1991.
- 9. Health Canada, <http://www.hc-sc.gc.ca/hppb/hiv\_aids>.
- 10. Percentage distribution of health care costs by stage of illness from Hellinger (1993: 480). Changes in treatments since that time have certainly altered this distribution but do not affect cost totals in this table, which are separately calculated from the monthly health and out-of-pocket costs per person estimated by Albert and Williams (1998: Tables III-6 and III-7, at 32) and which do take into account the new HAART treatments. 1999 HIV and AIDS patient numbers are estimated from Health Canada (2000a). Monthly per capita costs from Albert and Williams (1998) are annualized and converted to 1999 Canadian dollars using the Consumer Price Index, Statistics Canada, *CANSIM* Database, Matrix 9957, Table P200000.
- Health Canada, <http://www.hc-sc.gc.ca/hppb/hiv\_aids> (December 4, 2000) and cross reference to <http://www.hivnet.ubc.ca/background.html> (Canadian HIV Trials Network).
- 12. Dr. David Elliot, Medical Consultant and Epidemiologist, Performance Monitoring and Evaluation, Nova Scotia Department of Health,

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personal communication. Even though Dr. Elliot's figures monitor changes over time in Nova Scotia, they are used here to reflect changes in the country as a whole.

- 13. For detailed indirect cost benefit analysis see GDP per capita from Statistics Canada, *CANSIM* Database, Matrix M9219, "Canada - Selected Economic Indicators", Table D28609, "Gross Domestic Product per Person." It should be noted that GDP per capita includes the non-market-productive population (children, elderly, disabled, sick), and is therefore a conservative figure for the proxy estimation. Value of Statistical Life estimates based on "willingness to pay"/contingent valuation surveys yield much higher estimates, generally in the range of \$3-\$6 million per life.
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# CHANGING THE BALANCE OF POWER: THE LISTEN UP! RESEARCH PROJECT AND PARTICIPATORY RESEARCH WITH MARGINALIZED COMMUNITIES

Margreth Tolson Stephanie Kellington

In the Fall of 1998, AIDS Vancouver and the Positive Women's Network started development of the Listen Up! research project, a multi-phase qualitative research study designed to look at women's risk for HIV infection and illness progression.

We had seen that in much of the research on this topic, women's individual behaviours are often cited as the cause for their HIV infection or illness progression (for example, sex workers' use of condoms, substance-using women's injection drug use patterns). HIV prevention strategies using behaviour-change models would target these behaviours, often without exploring the larger factors that shape and inform individual behaviour.

Our research project sought to challenge this model, using two principles to guide our work:

- 1. Social and political factors form barriers to women's health, and should be explicitly explored along with potential strategies to overcome these barriers.
- 2. Dominant norms in research about whose voice gets heard and who is the 'expert' should be challenged.

Both these themes boil down to the same root issue, changing the balance of power:

- how a problem is defined and who defines it
- who determines the strategies for action and who takes action

# WHY FOCUS ON SOCIAL DETERMINANTS INSTEAD OF BEHAVIOUR?

Our focus on the political and social factors of women's risk was chosen largely in reaction to the continued focus in HIV research on women's behaviours. We understood that research focusing on behaviour could be useful for moving toward strategies in behaviour change. However, such research assumes that individuals have enough power in their society to be able to change their behaviour, that they have options, choices. While this may be true for some individuals in some groups, it is also true that for many people in marginalized groups, social conditions squeeze the options down to a very narrow range. We see the results of this squeeze in HIV statistics – it is the people who are at the bottom of the social and political hierarchy in their society whose risk for HIV/AIDS is greatest. For a woman in Vancouver, living on welfare in a dangerous area, using valium or heroin or alcohol to cope, her risks are determined not by the right personal selection of a healthy option, but instead by a socially-determined lack of options. There are numerous social and political barriers that prevent women from taking care of their health. Our participants clearly understood and articulated that it is the underlying social factors which determine risk:

*Facilitator*: "What are some of the things that have helped you stay healthy?"

Participant: "Not living in poverty!"

However, instead of researching the social conditions, it is women's behaviours that are examined and pathologized, made the focus of research and the target of prevention efforts. In looking at social barriers to health, our project hoped to re-orient

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the focus of research, pathologizing instead the socio-economic conditions and targeting social change in order to lessen the barriers to women's health.

# WHY WOMEN IN COMMUNITIES INSTEAD OF COMMUNITY WORKERS?

The other principle of our project was that of voice and determining who are the "experts". This focus was also chosen largely in reaction to research trends in Vancouver. Several recent AIDS studies and consultations asked service providers what they believed were the risks and solutions for marginalized communities, and asked members of marginalized communities only about their behaviours or lifestyle, not their ideas or suggestions for change. Many researchers came to poor neighbourhoods in our city or to the regional prisons to use community members in their research. They took the information out for their own interpretation and profit but did not leave information or skills behind for the community.

Our project wanted to work with groups who had been researched a great deal but who were not often involved in creating knowledge in a meaningful way. By sharing with women the tools and the means to do research, we hoped marginalized communities would have an opportunity to explore their definitions of the problems, identify solutions, and use the information to take the kind of action they wanted to see happen. Further, we hoped their research and advocacy efforts might influence health policy through collaborative work with sympathetic policy makers and health workers. If women from marginalized communities could use their research results as a tool to access decision-making bodies, perhaps they could find allies in these decision-making bodies to advance a vision of shared power and social change.

## Phase One

The purpose of Phase One was problem identification and, more importantly, gathering community interest and support. Rather

than "parachuting into" communities, the project coordinator partnered with workers and volunteers at community-based agencies who were already known to and trusted by community members. The communities these agencies worked with included:

- Spanish-speaking immigrants and refugees
- women with serious mental illness
- First Nations and Aboriginal women
- HIV-positive women
- current and former substance users
- lesbian/bisexual women

Workers and volunteers who partnered with the project contributed to the development of the initial questions and procedures for the groups (in order to ensure community relevance and appropriateness), identified potential participants and facilitated the actual group discussions. Focus group discussions were tape-recorded and transcribed by the Project Coordinator who wrote both a Report of Research Findings for Phase One, as well as a report to the community in pamphlet form, in consultation with the Project Advisory Group.

Each group looked at how three specific social factors impact on their risk for HIV infection and illness progression:

- 1. Income
- 2. Power in intimate relationships (meaning friends, partners, family)
- 3. Relationship with health care providers and health institutions

A total of 57 women joined the focus groups, talking about how the three determinants affected their risk for HIV. After the focus groups were completed, the Project Coordinator had established enough trust with women in these communities to begin Phase Two.

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## Phase Two

Phase Two involved the recruitment, training and support of peer researchers in order to further identify community needs and preferred strategies for change. After 12 women had been recruited from the six partnering communities to act as peer researchers, a community-based educator familiar with simple, accessible participatory methods was hired to work with the peer researchers. The educator focused not only on developing research skills, but on fostering bonding, communication and sharing between peer researchers, contributing to their empowerment as a group. After receiving training in one-on-one interviews and focus group facilitation, peer researchers took the information from Phase One back to other women in their selfidentified home communities. The peer researchers asked women what changes they wanted to see happen in order to reduce barriers to their health, as identified in Phase One. There were 44 one-on-one interviews and six focus groups conducted in Phase Two. The following sections look at some of the findings and recommendations from both phases.

#### INCOME

Regarding income (or what quickly became called poverty), our study, like many others, found significant barriers to personal health and safety due to poverty. However, women talked not just about the lack of access to food and housing, but also about the discrimination they experience for being poor as a barrier to their health.

One goes hungry sometimes because one doesn't have a penny. I feel embarrassed to ask people for help, very embarrassed ... I asked people for help but I went hungry many times because I didn't want to burden other people.

...there are stereotypes and [mis]-conceptions about what it means to...not have money...the assumptions that go with that: fault-finding and blaming.

In our country, the poor are shamed and made to feel as though they must have done something wrong and deserve to suffer. For many, it intensifies the guilt they already feel so they do not ask for services that are rightfully theirs. It is this class discrimination which erects additional barriers for those already living in poverty and further limits their health options.

Policy-makers must begin to see and understand that the standard of living maintained by welfare levels in Canada creates health risks, not only due to material deprivations, but also due to the internalized and externalized shame of being poor in a wealthy land. Construction of affordable housing and provision of sufficient money for the purchase of good quality food are two examples of material benefits that would greatly reduce the risk many participants talked about experiencing. Two HIV positive women described some of their poverty-related challenges to staying healthy as follows:

It's the fresh produce that I find really hard [to afford], the veggies and the milk.

I get \$756 per month and my rent is \$725 for a two-bedroom apartment. Imagine having to provide for your children [on that]!

#### POWER IN INTIMATE RELATIONSHIPS

Power in intimate relationships was the second determinant of health we examined. We found, as have numerous other studies (for example, Kahn 1998; Weiss and Gupta 1998), that historical and current experiences of abuse were linked with increased risk for HIV infection. Women also linked their experiences of abuse to ongoing poor health and shortened life spans. For example, an AIDS defining illness may not be the most significant health risk for an HIV positive woman in these communities: it may be a violent partner who assaults her; it may be a long-standing drug addiction as a means to cope with memories of childhood abuse; it may be an inability to leave her home for weeks or months after a rape in order to seek medical treatment; it may be some combination of all three, and health risks of this type can form a web of barriers that present more of an immediate danger than the long-term risks of developing an AIDS defining illness.

One woman, HIV positive, street-involved and recovering from a long-standing heroin addiction, talked with articulate and painful clarity about the role drugs had played in helping her cope with memories of childhood sexual abuse as well as the after-effects of a recent acquaintance-rape:

[I had] so much fear and anxiety that I had ulcers and that and I've been hospitalized because of it. And now I'm on anti-depressant pills...It's been really hard when you're trying to stay clean and you have things like that going on.

Another woman described how violence and HIV had intersected in her life:

... a couple of years ago I was living with one individual and he became [HIV] positive he said ...And he was a very violent person and I found that [contracting HIV from me] was one of the things that he wanted to use against me in order for me to stay with him.

Despite the innovative work done by some groups in Canada to document and take action on these issues, there is still a need to raise awareness in the public consciousness. Policy-makers and public health educators have a potentially important role to play in helping to investigate and publicize the links between relationship abuse and HIV. As well, provision of adequate longterm resources for women leaving abusive relationships (especially in rural areas) needs to be more actively linked to HIV prevention and support strategies.

#### **R**ELATIONSHIP WITH HEALTH CARE PROVIDERS

The third social determinant we looked at was the relationship with health care providers and health institutions. There were stories of healthcare providers whose sincere caring had made a life-saving difference for women.

My doctor, she said, 'I don't want you to die needlessly' and

that was just wonderful to hear. Like that's a big ego-boost - my doctor likes me and want me to live!

There were also stories of appalling discrimination and the life-threatening consequences of inferior treatment.

Finally after four years of complaining about stomach ailments, I got to see a specialist and found out that I have severe liver damage from the [psychotropic] medication they give me here. But nobody listened to me before because I'm a mental patient.

This doctor told me, once he learned I was [HIV] positive, he didn't want me in his office. He said I would infect his staff.

These examples point to the long-standing need to develop policy initiatives that will encourage ongoing training for health care providers:

- 1. Regarding structures of power, privilege and oppression, in order to reduce discrimination against marginalized groups.
- 2. Providing up-to-date HIV information for non-specialist doctors so they are more comfortable with providing care and support to HIV positive people.

Another barrier identified by women across the research phases was the lack of support by the mainstream medical establishment for access to alternative medicine and complementary therapies. HIV positive women condemned the close ties between large pharmaceutical companies and HIV treatment research. They perceive the pharmaceutical industry as controlling the treatment and research agenda of the "AIDS establishment". We were particularly alarmed to discover that women were sometimes taking their free prescription medications and selling them on the street in order to earn enough money to buy herbal or other alternative medicines.

Women and men will continue to use alternative and complementary therapies with or without their doctor's support or knowledge. By refusing to acknowledge the benefits of such medicines and include alternative practitioners and medicines in our socialized healthcare system, the mainstream medical establishment forces people to go "underground" for their self-

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medication practices in order to accommodate their preferences. Therefore, it is strongly suggested that:

- 1. The mainstream medical profession be encouraged to work with alternative and complementary health care professionals, integrating such research and information into their practise.
- 2. The Canadian public health care system be amended to include the provision of alternative health care services and medicines.

#### CHALLENGES

As the group did this research work, becoming more confident and empowered, the balance of power was shifting in new ways and questions started to arise about several separate issues, all rooted in the issue of power. For example:

- 1. Who would write the funding proposals, and who would prioritize how funding is used?
- 2. What is acceptable research practice and what is not?
- 3. Who would speak about the project in public (for example, at conferences) and who would write about it?

This negotiation between the needs of the community agencies and peer researchers has required constant mutual education about different goals and ways of working. Sometimes the work gets messy when people do not understand each other's motives and choices, or when differences in assumptions (due to class and culture particularly) become apparent. The challenge has been for all to compromise. Partnership has meant learning to listen in sometimes very challenging circumstances, and always re-negotiating the balance of power.

This paper has focused on the findings of Phases One and Two of the Listen Up! Project, and how power balances were questioned and altered through de-mystifying and opening up the research process to participants and community members. The next phases of the project (Phase Three focused on reporting back to the local community in Vancouver and Phase Four, in process, focuses on province-wide mobilization) continue to bring their own unique challenges, not only to this research project, but also to the relationship between the agencies and the communities within which they work.

#### RECOMMENDATIONS

What has this project taught us about our communities and our research work in communities? As well as the key findings and recommendations of the research report, some of which are noted above, we feel the project provides valuable lessons about what community ownership of the research, programming and policy development process might look like. The following suggestions seek to encourage power-sharing with communities, and can be implemented at local and national levels.

#### NETWORKING

It is important to utilize links with other community agencies in order to share information and resources, share the workload, and involve the greatest possible number of community members. In this way, the project and its results do not become the "property" of one agency. This can be a challenge when agencies have different agendas and perhaps also compete for funding. Members of the community are well aware of 'grudgefights' between agencies or government departments, and the obvious hypocrisy if we cannot "walk it like we talk it". By involving other agencies in meaningful ways, the sharing of power is then also role-modeled in the community itself.

As well, if the work is to "stay honest" and keep improving, it is helpful to have a wide range of people involved. A mix of people (e.g., from the community, local government, health professions, agency staff) will challenge different pieces of the project, ensuring mutual education and increased potential for project integrity.
#### INVOLVING MEMBERS OF THE COMMUNITY

If a community (clients, patients, consumers) is to increase its voice and power, then people must have a place in the decisionmaking process. However, the trap of tokenism can arise due to differing levels of power. One of our mistakes in Phase One was to reserve only two seats for community members on our advisory board – the other six were for agency staff and health professionals. The two HIV positive women sometimes felt intimidated and silenced. There must be awareness of and sensitivity to these dynamics, as well as a commitment to seek and to develop innovative methods to solicit community involvement beyond the usual advisory boards and "special commit-tees".

#### WORKING WITH AND WITHIN THE COMMUNITY

In order to facilitate community involvement and networking, we found that outreach services and sharing of resources are both important. Service providers need to get out of their offices and take their services to where women spend their time – the laundromat, the community centre, the church, the street – rather than expecting women to be able to come to their agencies. Outreach workers are crucial to a program's link with a community, facilitating the community's communication of its needs.

As well, communities need resources in order to facilitate the communication of their needs and vision. Peer education and skills training, combined with encouragement to develop strong political analysis, give marginalized groups the tools to participate fully in the processes of learning about their needs and opportunities, and then taking the action required to address them.

Increased awareness and education can be shared between all members of our communities. This is the very essence of changing the balance of power.

## Some Last Points About Approaching the Work

When we talk about changing the balance of power, working toward community empowerment, and challenging political and social systems, we are asking ourselves to change the very nature of the systems within which we work. This is a very tall order to fill! Hence, it can be helpful to remember:

#### INVEST IN THE LONG-TERM

In-depth work with a community takes time and commitment. Prepare for this from the outset, putting in the supports and resources necessary to sustain staff and community members. If work is done too quickly (i.e., to meet a funder's short-term project goal), this can leave the community in worse shape than before the project started.

#### PREPARE FOR CONFLICT

Conflict will naturally arise when different groups are brought together. Skilled facilitation is required to work through conflict, not around it.

#### WHOSE NEEDS ARE BEING MET?

The agency's priority may not be the community's priority. When community members are asked to define their priorities, they may want to act on needs other than those identified by funders, agencies or academic institutions. Empowerment means letting the marginalized communities take the lead, and giving them the skills and resources to do so.

## CONCLUSION

What we are all learning in our research project is that truly representative community consultation and mobilization is a slow and complex process. In taking the time to develop community voice and listen for what is being said (not just what we want to hear), the sense of ownership and empowerment felt by all members of the team, and the depth and diversity of information gathered has created a very rich research project.

We have already started to see the impact of this work in some of the peer researchers as individuals:

This project has played a big part in lifting my self-esteem, in getting me out there and getting a job and accepting a position in the helping field — it's boosted my confidence and made me feel comfortable expressing how I really feel.

Our hope is that by targeting barriers in our social and political systems, and supporting community empowerment, we are contributing to a process that will continue long after our project is finished, and will sustain real change in the health and dignity of marginalized communities.

#### ACKNOWLEDGEMENTS

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## GENDER, INJECTION DRUG USE AND HIV RISK IN ONTARIO, CANADA

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Injection drug use has been a longstanding issue in Canada, but has been brought to the attention of the broader public health community because of its association with bloodborne infections, particularly HIV and Hepatitis B and C. As a result of concern about these problems, research into the epidemiological and socio-behavioural aspects of injection drug use has been undertaken in several cities across Canada over the past few years. One consistent finding has been that the population of injection drug users (IDU) accessed in these studies are predominantly male, although the male:female ratio has varied from about 56:44 to 87:13 (Health Canada 2000; Millson et al. 1999) depending on the place and the methods of recruitment. This paper briefly outlines some of what we have learned about these IDU women and the ways in which gender is relevant to their drug use and risk-taking behaviour. Based on this analysis, we make suggestions on aspects of service provision for these women and highlight further research needs.

Before 1995, adult women represented 9.6% of all positive HIV test reports with known age and gender in Canada. This proportion has risen to 23.9% in 2000. Though the proportion has been variable, injection drug use has always been a major contributing risk amongst women testing positive in Canada (Health Canada 2001). The proportion of positive HIV tests among women attributable to injection drug use was 31.9% prior to 1994, rising to 53.6% in 1995. In 1999, 47.5% of all positive cases in women with a known risk factor were attributable to injection drug use.

Findings about the characteristics of injection drug users depend very much on how one identifies participants for study. Since drug injection is a stigmatized and relatively hidden behaviour, populations who inject drugs cannot be readily defined and systematically sampled. The drug users who are the most accessible to study may be those who have entered treatment, yet once they are in treatment their current behaviour usually no longer reflects active drug use. Active drug users may be accessed through helping services such as needle exchanges, shelters and drop-in centres, community health services, etc. Many of these services are likely to see persons who are relatively needy and unable or unwilling to access care through other venues. Thus, any conclusions we draw from research findings about this population must be tentative and must acknowledge that they may be based on persons who are at least partially unrepresentative.

## INJECTION DRUG USER STUDIES

With these caveats in mind, we will outline findings from studies of injection drug users which we have carried out in Toronto and, more recently, in other Ontario cities. The studies include a 1991-94 collaboration with several other cities around the world sponsored by the World Health Organization (WHO), the WHO Multicity Study of Injection Drug Use and Human Immunodeficiency Virus (HIV), and a 1997-98 study of injection drug use and risk of bloodborne diseases in Ontario needle exchange attenders. Both of these studies were sponsored by Health Canada through the National Health Research Development Programme (NHRDP).

The WHO study consisted of annually repeated crosssectional surveys of women and men who were active injection drug users (within the past two months) or who were new entrants into drug treatment (less than one month), and who had injected in the two months prior to entering treatment. The outof-treatment group was recruited through a broad recruitment strategy that included posting flyers and giving out information cards at needle exchanges, community/drop-in centres, street youth agencies, and community health centres, at both fixed sites and during street outreach. Additionally, participants recruited others through word of mouth. Participants called a study telephone number to set up an appointment, or in some cases were recruited by an on-site interviewer; all received \$20 compensation for their time in participating. Participants completed a 30-90 minute interviewer-administered questionnaire, and provided a blood and/or saliva sample for HIV testing. Participants remained anonymous, and those wishing to know their HIV status were referred for counselling and testing. A total of 1,045 different men and 260 different women participated over the course of the study.

The second study recruited participants during 1997-98 through needle exchanges in several Ontario cities: Windsor, London, Hamilton, Niagara (including St. Catherines), Toronto, Sudbury, Thunder Bay, Oshawa, and Kingston. Needle exchange staff did the recruitment, and the questionnaire could be selfcompleted or completed with staff assistance. Compensation was paid to both participants and the needle exchange programmes for their assistance; the needle exchanges used the money they received to provide extra services for their clients. One hundred and twenty-eight women and 414 men participated in this study. Both of these studies received ethics approval from the University of Toronto's HIV research ethics review committee.

## STUDY FINDINGS

In both studies, the women recruited were younger than the men (mean 30.6 years vs. 31.7 in the first study, and 33 vs. 34.8 in the second, although the latter did not reach statistical significance). Age of first illegal drug use was asked in the second study and did not differ significantly by gender; for women the mean age was 13.7 years (with a range from 5-35). In both studies, mean age of first injection was comparable for both genders, about 19 years of age. This raises the question of whether the women recruited were younger because, on average, they do not continue injection for as long as their male counterparts. If this is the case, it could be for a variety of reasons, including a higher rate of discontinuing injection, either because of entering treatment, changing to non-injection use, or ceasing use without treatment. Both male and female IDU may also leave the population of users available for study because of death or incarceration. However, the limited evidence available does not suggest that these are more frequent for females. For example, in these studies a smaller proportion of females (61.5%, 62.6%) vs. males (79.8%, 75.7%) reported having ever been in jail.

The first study also suggested that female IDU were on average slightly more educated than the males (11.4 years of education vs. 11.0); in the second study, educational level did not vary by gender. Female IDU also differed significantly from males in their relationships. They were more likely to be married (27% vs. 9%) or living with a sexual partner (42% vs. 19%). Significantly more women had children living at home, 36% vs. 11% of men. In the first study, female IDU were more likely than males to have a sexual partner who also injected drugs (74% vs. 43%, p = 0.001). The implications of this for risk of bloodborne infection are discussed below. A significant proportion of female IDU also self-identify as lesbian or bisexual in our studies (5% and 22% in the second study), whereas a much smaller proportion of male IDU self-identify as gay or bisexual (2% and 6.5%).

The first study asked about sources of income. Responses indicated that only 10% of females and 12% of males were le-

gally employed. In both studies, a sizable proportion of female IDU were engaged in sex trade work (37.6%, 35%). The design of these studies does not allow for conclusions about the time sequence, i.e., whether persons who begin to inject drugs then participate in the sex trade to support their drug use, or whether persons who engage in the sex trade then become involved in drug use, or whether both occur simultaneously. Although a significant proportion of males who engage in sex trade with other males self-identify as gay, this was not true for the women; sex trade work was equally likely for women who self-identified as heterosexual or bisexual (only a very small number of women self-identified as lesbian).

With respect to drug use behaviours (see Table 1), women in the first study were more likely to have used heroin, barbiturates, and tranquilizers in the preceding six months and less likely to have used cocaine, crack, alcohol, or cannabis than men. In the second study, there was no significant difference in reporting use of heroin, cocaine, or both by gender. A majority of women in the second study had experienced at least one drug overdose (65%), a rate comparable to that of the males. In both studies, women were more likely to have received drug treatment in the past. They were also more likely to both take and give needles and syringes previously used by others, more likely to share other injection materials (water, cotton, cookers), and were more likely to report sharing of needles and syringes with a sex partner and less likely with friends. In the second study, a much higher proportion of women reported always cleaning previously used needles prior to injecting with them. This study also asked about the numbers of persons with whom injection equipment had been shared in the previous six months. The majority of those who had shared did so with only one other person; this did not differ significantly by gender.

These findings suggest the importance of relationships and networks in HIV risk for both genders, and also make it seem likely that these may differ by gender. It appears that women share as much or more than men, but that their sharing may be more often in the context of a sexual relationship with another injector. Other studies have also found this pattern of female Table 1: Risk behaviour and service use comparison

injectors being likely to have regular sexual partners who also inject (Donoghoe 1992; Klee 1993), and more likely to obtain used equipment predominantly from a sexual partner (Davies et al. 1996). Clearly the degree of risk in this scenario is greatly influenced by the likelihood that the partner is HIV infected, which in turn depends on the sharing and sexual behaviour of the partner. A monogamous sexual relationship in which both partners are HIV negative and never share any injection equipment with anyone else is essentially risk-free, even though these individuals will report sharing injection equipment when asked. Sharing of drugs and injection equipment within a sexual relationship may also involve one partner injecting the other. It is reported that some women IDU do not learn how to inject themselves and rely on their male partner to inject them. They may thus be particularly vulnerable to their male partner's risk taking if he injects with others. Clearly, efforts to address risk and risk modification in such a context require addressing the relationship and the issue of caring for one another both emotionally and practically.

Sexual risk taking among injection drug users must be considered in its context. Most IDU report being sexually active with the opposite sex in the past six months (in the first study, 98% of women, 90% of men; in the second study, where the question asked about sex in the past six months and gender of partner was not specified, 86% of women, 85% of men). In the second study, numbers of partners in the past six months were specified, with 53% of women reporting sex with men having one partner only. Sex trade work, as discussed above, was common; a high proportion of women who engaged in the sex trade reported always using condoms with clients. About one quarter (26%) of the women in the second study reported exchanging sex for crack. We are not able to distinguish condom use behaviour for this group from the overall report of condom use with clients.

Only a very small proportion of women IDU report always using condoms with regular partners; a larger number, but still a minority, report always using condoms with casual partners. For men, the proportion using condoms in the sex trade appears somewhat lower (but these are based on very small numbers); the proportion always using condoms in regular and casual partnerships are somewhat higher than for women, but the pattern is the same. It may well be that women do not use condoms with regular partners with whom they also share injecting equipment, perhaps considering this an indication of trust or of having already accepted whatever risk of infection this partner poses.

Almost half of the sexually active women in the second study reported more than one male partner in the past six months, ranging from 2-150, with a median of 3. Of these, about half reported being paid for sex, for whom the median number of partners was between three and four (range 2-150); for the other half, who reported not being paid for sex, the median number of partners was two (range 2-10). This indicates that there is a group of women IUD who have multiple male partners but do not self-identify as being sex trade workers. These women may require particular approaches to risk reduction with respect to sexual behaviour which may differ from those aimed at women engaging in the sex trade. A better understanding of the sexual networks of women IUD would help to identify issues in sexual risk taking for different women and risk reduction strategies which might be used by these women.

As part of both studies, we obtained anonymous, unlinked HIV testing as a measure of the impact of risk behaviours. In the first study, the overall prevalence of HIV among male participants was 6.4%, and for females, 2.8%. In the second study, 5.8% of males and 9.4% of females were HIV positive. The rate difference between the genders was statistically significant in the first study, but not in the second. However, these findings do suggest that the relatively high rates of risk behaviour among female IDU are resulting in a prevalence of HIV which is at least comparable to males.

## SERVICE IMPLICATIONS FOR IDU

These studies also collected information on use of services by participants. As indicated, the second study recruited through needle exchange programmes. However, many of the participants had never actually used the needle exchange or were using it for the first time. This was significantly more likely for males than females (37% vs. 19%), indicating that most of the women identified in this study were established needle exchange

attenders. Twenty-one percent of the women interviewed attended the needle exchange more than once per week, 74% of them got more than half their needles from the needle exchange, and 49% reported getting all their needles from the needle exchange. With respect to other services, 83% of the women in the second study reported having a family doctor (vs. 67% of the men).

As indicated above, more women than men had previously tried drug treatment; in the second study, significantly more women had ever taken methadone. Although the IDU in the second study were all recruited through needle exchanges, 19% of the women and 12% of the men were currently taking methadone. This may be in part related to the presence of low threshold methadone programmes in some of the needle exchanges; we did not obtain specifics of what type of methadone treatment the participants were receiving.

We did ask those who were not currently receiving methadone whether they would enter a methadone programme if one were immediately available. Fifty-one percent of women (and about the same for men) indicated that they would, with 70% of these indicating that they would be seeking to discontinue other drug use, and the remaining 30% indicating that they would intend to continue using other drugs. We interpret this as a demand for further methadone programmes beyond those already present in these communities. In particular, there is a desire for more low threshold programmes. These programmes do not require an immediate commitment to abstinence. Rather they attempt to decrease harms related to opiate use by substituting legally accessible methadone while, at the same time, accepting the continued use of other drugs if this is the current choice of the IDU.

The opportunity to interact regularly with these injectors in a helpful and non-judgmental way provides an important chance to decrease their marginalization and to begin a process of trying to provide them with the means to begin improvements in their lives according to their own needs and choices. The evidence which we have about relationships for many of the women suggests that this is a key issue to be addressed in harm reduction. Conventional abstinence-oriented treatment programmes may attempt to remove the client undergoing treatment from their former life in order to improve chances for successful treatment. Harm reduction oriented approaches must take into account that this very loss of relationships may be considered by some IDU as a greater threat than continued drug use; this may be particularly so for women IDU whose intimate partners are also injectors. Options which try to provide support for the partnership, especially if there are children involved, need to be examined. It is essential to the philosophy of harm reduction that the IDU be treated with respect and caring, and allowed to identify their own goals over time and with support, starting from where they currently are in their lives.

There are a number of specific issues which services may encounter in seeking to serve women IDU. It may be difficult to provide education and support to women who do not attend services such as needle exchange directly, for example when their male partners carry out exchanges on their behalf. Services need to consciously assess their service and outreach to women, recognizing that women's needs may differ from men's. They should assess the need for and feasibility of specific outreach to women, women's support groups, services which may attract women such as opportunities to obtain food and clothing for their children, parenting advice and support groups, family counselling, etc. The fact that most women IDU report having a family doctor may indicate another potential avenue for contact and outreach through family physicians who could refer their patients for services, or could at least display information in their waiting areas for women who may not have revealed their drug use to their doctor.

## FUTURE RESEARCH NEEDS

Our research unit has identified a need for more extensive, qualitative research aimed at a more in-depth understanding of the issues involved in ongoing injection drug use and the service needs of users, as well as a need for further research into the social networks of both male and female IDU – these studies

are ongoing. There is also a need to evaluate a variety of harm reduction interventions for IDU in the Canadian context. These interventions include a broader range of drug substitutions for those who cannot or will not use methadone, including a trial of heroin prescribing similar to that which has been undertaken in Switzerland, safe injection facilities, and harm reduction housing (i.e., housing aimed at those who are homeless or underhoused which accepts ongoing substance use while seeking to minimize harm to the user). In addition, interventions aimed specifically at HIV-infected IDU to enable them to effectively undertake antiretroviral drug treatment regimes should be undertaken and evaluated. All research should include a careful examination of how these services work for both female and male injectors and an assessment of the need for specific services or modifications of services to meet the particular needs of female IDU and of couples who both inject.

In order to broaden our understanding of the relationship between gender, injection drug use, and HIV/AIDS, research is also required related to the broader health issues of violence, poverty, and abuse in the Canadian context. The role of parenting in the lives of IDU women must be examined; it may be that fear of losing their children inhibits many IDU women from revealing their drug use and seeking the help which they need.

## CONCLUSION

There is evidence that gender is an essential component of injection drug use behaviour in general, and of behaviour related to HIV risk in particular. This in turn implies that, in the same way as we are seeking to move beyond male-only research in other areas of health, it is essential that gender be considered in all examinations of HIV risk among injection drug users and in developing further preventive strategies. Evidence of the deep and multiple roots of dangerous drug using behaviour and the infections with HIV and other bloodborne viruses which are occurring as a result (Spittal and Schechter 2001) must lead Canadian society to address these underlying causes if we are to move closer to caring for all our citizens as they need and deserve.

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## 4

## HIV/AIDS AND ABORIGINAL WOMEN IN CANADA

Susan Judith Ship 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. 1997). Epidemiological data for 1998-1999 shows that Aboriginal women constituted 49.6% of newly diagnosed HIV cases among Aboriginal people, while non-Aboriginal women comprise 20% 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 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 mother to infant among Aboriginal women is increasing (Health Canada 2000a). Despite these alarming trends, Aboriginal women continue to remain invisible in HIV/AIDS research and policy, and they face numerous barriers in accessing services (Ship and Norton 2000: 75).

## 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 1994: 138). 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 dispossession of Aboriginal women's rights and the devaluation of women's social roles (Shawanda 1995). 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: 74).

Employing a culturally sensitive gender perspective in order to capture the unique aspects of Aboriginal women's experiences, our research with First Nations and Inuit women explored two themes: how cultural disruption, residential schooling, family and cultural breakdown, and the legacy of multigenerational abuse affect 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 1997: 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 1996). High rates 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 ten Inuit women involved in the sex trade in Montreal who we interviewed<sup>1</sup> left their communities as a result of sexual and physical abuse they suffered within the family or at the hands of a partner. (Although it is not wellpublicized, 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 are Inuit people in Montreal. While these women pointed out that the Inuit community in Montreal is growing, the people are spread out and there is no 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, and unable to speak French, these Inuit women found themselves in very precarious situations, ending up on the streets in sex work to survive and living in a spiralling 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 programme 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 the sex trade suggested that the actual use of condoms was far less frequent than the women themselves reported. We were told that many Inuit women still do not 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-test 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 do not usually use condoms when they are involved with 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 intravenous 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 the 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 - either 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 to 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 these Inuit women were HIV positive at the time of the interviews, they are at high risk for HIV, as evidenced by the following stories of their First Nations sisters on the streets of Vancouver, now living with HIV/AIDS.

## FIRST NATIONS WOMEN LIVING WITH HIV/AIDS

# Cultural Disruption and Residential Schools: HIV and the Legacy of Abuse

Our interviews with 11 First Nations women in Vancouver 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 spiralling cycle of abuse which includes alcoholism, drug addiction, prostitution and violence; a cycle which places them at greater risk for HIV. For some, this spiralling 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 dealt 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 intravenous drugs, mostly cocaine and to a lesser extent heroin, despite the fact that they know it is harmful to their health; some still engaged 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,

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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 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 a difficult, stressful and complex process for HIV positive parents, but particularly for single mothers with little social and emotional support. But children are also a source of joy, hope, and 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 feel 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 with HIV/AIDS live in secrecy because of the multiple forms of stigma associated with the illness. 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 underutilize First Nations and non-Aboriginal services for fear that their community 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 women 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% 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 HIV positive women we interviewed live in urban and metropolitan centres, far from their home communities because the city provides anonymity, and they felt there is greater acceptance of HIV positive women.

Many HIV 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 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 while others are far less accepting as lack of knowledge and fear predominate. One positive 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."

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.

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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. I want them to grow up, to be good people and to be good women. I want them to be able to go home some day because I do have land and a house back home.

# 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 overwhelming 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, community health representative (CHR), community health nurses (CHN), 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 than men to be primary caregivers to people living with HIV/AIDS and to commit themselves to the very end. We were moved by the strength and depth of the commitment of the female caregivers we interviewed.

The needs and the concerns of female caregivers tend to go largely unnoticed and unattended to. Caregiving is seen as the "natural role of women" but, at the same time, "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 and with the health of the family; their own health is the least important priority. Many caregivers need to learn how to take better care of their own physical, mental-emotional, social, and spiritual needs and to 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.

#### **I**SOLATION 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, reinforces 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 as 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 non-existent. 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 as do the people living with HIV/AIDS they are caring for. As this woman explained,

*I* went through much of the same things my daughter went through – the grieving process, the denial, the anger. I tried to be supportive of her but it was much harder for her.

The family as a whole needs support and counselling in working through complex and contradictory feelings throughout all stages of the disease and with respect to making difficult decisions. Some caregivers also talked about the difficulties they experienced in watching loved ones with AIDS die a slow death. 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, the Halifax-Dartmouth region, are inadequate. Getting appropriate information and accessing services as quickly as possible can be difficult. We were told about a young man who had come home to his reserve to die, was growing progressively sicker and, because it was Good Friday, found 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

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because they may have experienced racial discrimination. 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 present 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 – 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

Aboriginal women at greatest risk for HIV are most likely to be products of families and communities devastated by spiraling cycles of multi-generational abuse, the long-term effects of the legacy of cultural disruption and residential schooling. Gender plays an important role in shaping distinct women's experiences and perspectives with respect to HIV. Aboriginal women living with HIV/AIDS experience gender discrimination as women in addition to the stigma that seropositive men face. Women's social roles as primary caregivers and nurturers in the family constitute a fundamental difference in their experience of HIV/AIDS when compared to men.

The over-representation of Aboriginal women in HIV/AIDS statistics demands that we place them on research and policy agendas. In addition, we must develop 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.

#### **ACKNOWLEDGEMENTS**

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1. The interviews were conducted by Laura Norton with the assistance of Susan Judith Ship during the fall of 1998 as part of a larger project for the National Indian and Inuit Community Health Representatives Organization.

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## HIV COUNSELLING AND TESTING AMONG PREGNANT WOMEN IN CANADA: BEST PRACTICES

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In Canada, women of childbearing age (15-44 years) accounted for approximately 80% of the total AIDS cases among adult women reported to the Centre for Infectious Disease Prevention and Control, Health Canada, to 31 December 2000. Of the 189 paediatric AIDS cases with identified exposure categories reported by that date, the majority (84%) were attributed to mother-to-child transmission (MTCT) of HIV<sup>1</sup> (Health Canada 2001).

Despite these facts, offering HIV voluntary counselling and testing (VCT)<sup>2</sup> to pregnant women was not a public health policy objective to prevent mother-to-child transmission of HIV prior to 1994. Prior to this date, HIV testing among pregnant women was provided either at the request of the pregnant woman herself or on the judgement of her physician. The publication of the results of a randomized clinical trial (PACTG 076) of antiretroviral medication (AZT) provided to pregnant women during the second or third trimester and during labour and delivery and to their newborns for six weeks which showed a two-thirds reduction in MTCT, led to a reconceptualization of

the role of HIV counselling and testing in pregnancy (Connor et al. 1994). More recently, Canadian studies have shown antiretroviral therapy to be effective in reducing MTCT rates to even lower levels than the eight percent achieved in PACTG 076 (Forbes, Burdge and Money 1997; Lapointe 1998). Although increased attention has been focused on the issue of the prevention of MTCT, most studies in the area have been quantitative in nature and have been concerned primarily with determining the discrete variables associated with the uptake of HIV testing by pregnant women. Little work has been done to investigate pregnant women's experiences with prenatal HIV counselling and testing from a qualitative perspective.

The present study was developed to attempt to explain some of the gaps in current knowledge regarding HIV VCT among pregnant women in Canada. More specifically, the goal of this national study is to provide timely information from pregnant women to inform a federal position on an effective prenatal HIV counselling and testing policy for Canadian women. This goal will be achieved by documenting pregnant women's experiences of HIV testing in pregnancy and, based on these experiences, their perceptions of best practices regarding HIV counselling and testing.

Additionally, this national study will allow for a comparison of the application and acceptability of the different approaches in providing HIV VCT currently practised in Canada. In Canada, HIV testing programmes are the responsibility of provincial and territorial governments. There are no national recommendations or policy guidelines to inform these governments in their efforts to address the emerging issue of the implementation of HIV VCT programmes for pregnant women. As a result, there exists a range in formal or informal counselling and testing policies in each of the provinces and territories.

Alberta, Ontario and Nova Scotia were selected for this study based on their differing provincial policies related to HIV counselling and testing among pregnant women. In Alberta, the provincial policy is broadly defined as an "opt out" option. All pregnant women are routinely tested as part of the province's prenatal screening programme unless they specifically request
not to be tested for HIV. In contrast, the provincial policy in Ontario states that all pregnant women and women contemplating pregnancy are to be offered the opportunity for HIV counselling and testing. The situation in Nova Scotia is currently somewhat more fluid as the provincial guidelines have recently changed from a policy that suggested HIV counselling and testing be at the discretion of the physician to a policy that states that HIV counselling and testing should be offered to all pregnant women.

# METHODS

A total of 105 pregnant women, 35 each from Alberta, Nova Scotia and Ontario participated in personal interviews with experienced women researchers to describe and discuss their prenatal HIV counselling and testing experiences. The stratified sample of women in each of the three provinces included Aboriginal women, women from HIV-endemic countries, visible minority women, women who would be considered to be at higher risk of HIV infection, women considered to be at lower risk of HIV infection, and women who inject drugs. With the woman's consent, each interview was audio taped and then transcribed and subjected to thematic analysis to determine the types of issues women experience in relation to HIV counselling and testing during their pregnancy. The interview followed a guided conversational format which allowed the pregnant women to elaborate on a number of key, interrelated issues, including whether HIV testing had been offered, how it was offered, and the women's assessment of best practices for HIV counselling and testing grounded in their own experiences.

# RESULTS

Based on the preliminary findings from the ongoing analysis of the transcribed interviews, there is clear evidence that the established Canadian principles of HIV counselling and testing, which require HIV testing to be carried out only after the person has given their voluntary informed consent in the context of pre- and post-test counselling , are not always maintained in the context of programmes that offer to test women during pregnancy. While the majority of the women interviewed did accept testing when it was offered, many reported that they did not experience the offer to test as voluntary and did not feel that they had given their specific informed consent to be tested. Many women interviewed also reported not having been given adequate information to assess the risks and benefits of HIV testing for themselves or for their unborn child.

In Alberta, all pregnant women are routinely tested for HIV as part of the prenatal screening programme or other pregnancyrelated tests, with the option to opt out or to decline to be tested. Only 2.4% of pregnant women in Alberta declined testing during the second year of the routine testing programme. None of the women interviewed for this study had declined testing. However, many of the women either had no prior knowledge that they would be tested for HIV or were not informed about the test. If they were informed about the test, they did not remember being presented with the option to decline. Nevertheless, all of the women indicated that they were pleased that their doctor had included the HIV test among the prenatal tests that were ordered and would have agreed to the test if they had been given the option. They added that they did want to know about the testing even though it was routine. Furthermore, many of the women who participated in the study had had previous HIV testing, and although they believed that they were still HIV negative, they agreed to have the test since it was routine.

In Nova Scotia, where it is recommended that testing be offered to all pregnant women, there were very few refusals of the test among study participants. This may reflect the fact that some women are being testing for HIV and either do not know it or do not feel comfortable asking their physician why the test is being offered to them. In addition, women who perceived themselves to be knowledgeable about HIV risk tended to decline testing when it was offered since they felt they knew their risks better than their physicians. We found variability in the offer of testing by social class or ethnicity in Nova Scotia. For example, rural Aboriginal women were more likely to have been tested than were white women. As well, very few women interviewed in Nova Scotia felt that they had been given adequate pre- and post-test counselling or information regarding the use of the test results. Several women commented that they had wanted to do whatever their physician suggested regarding prenatal blood tests, believing that they were doing what was best for the baby. As well, some women commented on how they did not feel comfortable questioning or refusing the recommendations of their physicians to undergo the test for fear of possibly receiving sub-standard health care from their physician at subsequent appointments.

In Ontario, where all pregnant women and women contemplating pregnancy are to be offered the opportunity for HIV counselling and testing, some women participating in the study did decline the offer of the test. Reasons for declining the test when offered centred on a prior history of accessing HIV testing outside of pregnancy, their concerns regarding the use of the test results and on their self assessment of their own low personal risk of acquiring HIV. For example, some women declined testing, as in Nova Scotia, based on their own assessment of their behavioural susceptibility to HIV infection, often confirmed by previous negative results, others declined simply because they were regularly tested either as blood donors or as part of their annual physical examination.

The reason most frequently cited by Ontario women for accepting the offer of the test was to ensure the safety of the babies the pregnant women were carrying. For many women, their own health care needs, the likelihood of themselves being infected and everything that might entail were not part of the discourse. In fact, concern for the baby's health often overshadowed the woman's assessment of her own susceptibility to HIV infection. Some women accepted the offer almost as a matter of routine, perceiving themselves at low risk of HIV infection and thus attaching little significance to the outcome. Other women however, accepted the offer as they perceived there was some chance that they could have acquired HIV infection either through their own or their partner's injection drug use or sexual practices.

#### DISCUSSION

Grounded in their own personal experiences, the women participating in the study recommended developments in policy and practice that will work towards ensuring that prenatal programmes address HIV counselling and testing in a manner which is sensitive to the needs of the pregnant woman as well as maintaining the objective of the prevention of HIV transmission. Several women remarked on how the focus for HIV testing during pregnancy is related to the foetus and not to the pregnant woman's well being per se. In addition, a number of women thought that removing the exceptional nature of HIV testing during pregnancy may help to reduce the stigma that is still often associated with HIV testing at other points across a woman's lifespan.

In terms of best practices, most of the women interviewed in Nova Scotia felt that their physicians were the best-suited individuals to offer HIV testing in their pregnancies. However, they also pointed out the need for greater standardization of preand post-test counselling to reduce the variability in the way the test is offered to pregnant women and under what circumstances. While some women interviewed felt that they either had sufficient levels of HIV knowledge prior to their physician suggesting the test or were given this in the course of their prenatal care, several others felt that more emphasis ought to be placed on providing information on the treatment options for women who are found to be HIV positive during pregnancy. Very few women commented on having access to any information on antiretroviral prophylaxis to reduce the risk of transmission to their baby. This led some women to report that they would abort the foetus rather than risk carrying the foetus to term and potentially giving birth to an HIV infected baby. There was strong consensus among those interviewed that preventing MTCT is an important issue, and that additional information and resources could be used to increase the visibility of the purpose, the procedure, and the use of the test results. In addition to the pamphlet produced by the Canadian Public Health Association on women and AIDS, it was felt that other pamphlets, videos, websites, or toll-free hotlines are needed, particularly for those women who live in more remote areas of Nova Scotia.

In Ontario, most pregnant women, in discussion with the researcher, supported the provincial policy and saw the offer of an HIV test in pregnancy as the first step in accessing, if necessary, the choice of treatment interventions for themselves and the range of preventive interventions to reduce transmission to their unborn children. However, many women were very clear that pregnancy was not the most appropriate time to raise the issue of HIV infection with women or to offer testing. Preconception, before deciding on pregnancy, at the time of an annual pap smear or physical examination, for example, were favoured by many women for the offer of HIV testing as knowledge of their HIV status would have been a factor in their decision to become pregnant. Other perspectives on the timing of the offer of prenatal HIV testing included the provision that the issue should be raised early enough in the pregnancy to allow the pregnant woman access to a range of options which may include termination. Further, the discussion around the offer to test for HIV should be carried out over several visits allowing for personal reflection and discussion with the woman's family and partner as appropriate. An issue of particular importance for women in Ontario was the recommendation that HIV testing should be the focus of a pre-natal visit and not combined with other routine tests offered in pregnancy, in particular the offer of maternal serum screening.

As in the two other provinces, for most Ontario women, their doctor was their first choice to raise the issue of the opportunity to test for HIV in pregnancy. For some women, their doctor was their preferred health care professional as they perceived that the discussion around HIV testing would remain confidential, while for others, it was because they had an established relationship with their doctor based on trust. However, some women would choose the health care provider who is most accessible to them in terms of the time they have available and suggested the nurses attached to physicians' practices, public health nurses and midwives.

Finally, most of the women in Ontario, as documented in the other two provinces, wanted much more information than was offered to them before they took the test. Each of the women in Ontario reflected on their experiences to suggest items and topics that needed to be covered in the pre-test counselling session, including the necessity of preparation for a positive result. Similarly, they gave the researcher concrete suggestions as to how the post-test session should be conducted both in terms of process and content. In addition to describing the information they needed from their health care provider, the pregnant women also made comprehensive suggestions for the contents of a new and revised brochure to be made available in Ontario to every pregnant woman or woman considering pregnancy. They also made specific suggestions around information distribution points, for example, the inclusion of the women's brochure at the point of sale of feminine hygiene products and pregnancy home testing kits.

In Alberta too, women's responses provided further insights into best practices for HIV counselling and testing. A few women identified nurses, in addition to physicians, as possible people to deliver HIV VCT because they felt that nurses had the time and would be more accessible than physicians, particularly in remote areas of the province. As well as treatment information, women wanted information regarding how women can contract HIV and how it is transmitted to the foetus. Although Alberta has produced brochures with this information, most of the women in the study had not seen them. The majority of the women in Alberta supported the routine testing programme and several advocated mandatory testing. They noted that the routine nature of the testing resulted in less stigma because the test is less stressful and embarrassing than having to request the test. However, many women said they would ask for an HIV test if they had concerns.

In order for pregnant women to increase control over their own health and that of their unborn children, there is clear value in all pregnant women being afforded the opportunity to know their HIV status. However, in efforts to reduce MTCT, it is essential that a pregnant woman's needs and rights to best practices in HIV counselling and testing are protected. Failure to attend to the quality or variability of the experiences of HIV counselling and testing in pregnancy will result in programmes that fail to increase testing acceptance rates and fail to provide women with the resources they need to make the best decisions for themselves and for their children.

#### ACKNOWLEDGEMENT

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- 1. Mother to child transmission of HIV can occur in the uterus prior to birth, during birth at the time of labour and delivery, and following birth through breastfeeding. Co-factors associated with the risk of transmission include: maternal viral load, mode of delivery, timing of delivery after rupture of membranes, and length of time breastfeeding.
- 2. While adopting the United Nations AIDS terminology of voluntary counselling and testing (VCT) in this paper, it is clear that in this study, HIV counselling and testing were not always perceived by the pregnant women to be voluntary.

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# 6

# Gender Differences in Results of a Programme to Promote the Sexual Health of High School Students in Nova Scotia

Donald B. Langille Jacqueline Gahagan Gordon Flowerdew

#### GENDER AND SEXUAL HEALTH

Blonna and Levitan maintain that sexual health requires not only appropriate levels of knowledge about sexuality, but also the capacity to develop fully one's potential for sexual expression (Blonna and Levitan 2000). Such capacity is particularly important for adolescents and young adults as they begin to explore issues of sexuality and sexual activity. With sexual exploration comes the very real potential for unintended pregnancies as well as exposure to sexually transmitted infections (STIs), including HIV (Dryfoos 1990; Makinson 1985). While many efforts to reduce the incidence of STIs and unintended pregnancies among adolescents have been undertaken, the significance of gender role socialization is often at odds with the types of healthy sexuality messages targeted at this population (Andersen 1997; Bonvillain 1998; MacKie 1987). For example, many healthy sexuality programmes for adolescents place a significant emphasis on contraceptive choices for pregnancy prevention that may have

the effect of inadvertently shifting these messages from both males and females to an issue for females alone (Forrest 2000; Radcliffe-Richards 1993). Further, differing definitions of healthy sexuality and differences in areas of sexual interest between young males and females may serve to reinforce traditional gender stereotypes and sex roles that portray females as passive and males as active sexual beings (Stoltenberg 1989).

#### INTRODUCTION TO THE AMHERST STUDY

Students in Cumberland County, Nova Scotia, including the county's largest town, Amherst, are as sexually active as their counterparts in the rest of the province (Beazley, King and Warren 1988; Langille, Beazley, Shoveller and Johnston 1994) and throughout Canada (King, Beazley, Warren et al. 1988). Since 1996, the community of Amherst has been making efforts to help its youth with this aspect of their lives through health promotion efforts targeted at prevention of sexually transmitted infections and unintended pregnancy. During that time, the Amherst Association for Healthy Adolescent Sexuality (AAHAS), a voluntary non-profit organization, has been engaged in this process, based on theories of social-ecology (Stokols 1992, 1996), social learning theory (Bandura 1991), and social marketing (Adreason 1995), and has relied on the multiple community intervention strategies felt to hold a great deal of promise for promotion of sexual health (Vincent, Clearie and Schuluchter 1987; Koo, Dunteman et al. 1994). AAHAS' efforts include community education, largely through a campaign making use of local media, workshops for parents, and continuing professional education. All of these efforts are directed at attaining its goal: "To bring the community of Amherst together, through the use and enhancement of existing community resources, to improve the sexual health of Amherst's adolescents." A health centre located in Amherst Regional High School (ARHS) has been established to provide educational and clinical services to students through a nurse-educator. These services include contraceptive and sexual health counseling and referral, and the provision of condoms free of charge. This report outlines gender differences in response to all of these efforts.

## METHODS

*Student Surveys.* Students at ARHS were asked to complete self-administered questionnaires at baseline in November 1996 and again in November 1999. Students were asked about their sexual health knowledge, their attitudes towards various aspects of sexuality, and the use of barrier protection and oral contraception. Questionnaires were administered in the classroom setting, supervised by teachers. Students were informed of the purpose of the study and of their right not to participate.

*Knowledge*. Sexual health knowledge was assessed using a 29-item knowledge test to which students were asked to respond "true", "false" or "don't know". A score of one was assigned where the answer was correct, and zero where the answer was incorrect or where students indicated not knowing the answer. Total scores were summed. The knowledge scale was internally consistent with a KR-20 of 0.77 (Langille, Beazley, Andreou and Delaney 1998).

Attitudes Towards Condoms. Attitudes were assessed using attitudinal scales developed and tested for reliability and validity by other investigators. This report analyzes results for the modified Attitudes Towards Condoms Scale which has an alpha coefficient of 0.78 (Brown 1984).

*Normative Beliefs About Condom Use.* The Social Normative Beliefs Regarding Condom Use Scale, which examines how respondents feel about the acceptability by peers, parents and professionals of condom use by adolescents, was used to assess changes in students' beliefs about such support. This scale has an alpha coefficient of 0.62 (Richardson, Beazley, Delaney and Langille 1997).

*Behaviours*. In addition to asking about sexual intercourse, the survey included questions about the degree to which barrier protection (condoms) and oral contraception were used at last intercourse.

**Data Entry and Analysis of Surveys**. Data were double entered using Epi-Info<sup>®</sup> Version 6.1. Analysis was carried out using SPSS<sup>®</sup> Version 7.5 for Windows. Tests of proportions were carried out using the  $X^2$  distribution, and tests of means using

student's t-test. Statistical independence between the two years 1996 and 1999 was assumed for analysis of knowledge and attitude items, since those who were age 14 and 15 in November 1996 would have been 17 and 18 in November 1999.

*Calculating Pregnancy Rates.* Pregnancy data were collected using the Population Health Research Unit (PHRU) database which contains information on all pregnancies (i.e., pregnancies of any type) receiving care at any hospital in Nova Scotia.<sup>1</sup> Amherst is very close to the province's border with New Brunswick. Data for Amherst women were therefore also collected from the Reproductive Care Programme of Nova Scotia, which examines births to Nova Scotia women at hospitals in New Brunswick.<sup>2</sup> Data on abortions for Amherst women aged 15 to 19 were provided by Nova Scotia's only private clinic. Thus, pregnancy counts are as comprehensive as is possible.

Denominators for pregnancy rates are based on the province's Medical Services Insurance (MSI) registration data. MSI covers physician and hospital services for all residents of Nova Scotia. Age standardization was carried out using the 1995 Cumberland County adolescent population as the reference group.

*Analysis of Pregnancy Rates.* We used a multiple logistic regression model to evaluate the effect of the health promotion project, controlling for baseline (1995-97) pregnancy rates, age effects, and a possible provincial time trend. It was assumed that if the interventions carried out in Amherst had in fact been beneficial, the impact on adolescent pregnancy rates would have begun to be seen in 1998.

#### RESULTS

Table 1 summarizes responses to the surveys. The response rates were excellent, with approximately 80% of eligible students completing surveys in both survey years (the denominator includes those students who were not in attendance at the school on the days which surveys were carried out). The mean ages of students by gender were very similar, as were proportions of eligible males and females responding. Table 1 also gives proportions of students who indicated that they had ever been sexually active (i.e., they had had vaginal intercourse on at least one occasion). Sexual activity was similar in 1996 and in 1999 for males and was seen to decrease slightly in females.

*Sexual Health Knowledge*. Knowledge scores increased in both age groups in each gender, both overall and in those who were sexually active. Absolute differences were similar for females, both overall and for those who were sexually active. Males who were sexually active had a smaller increase in knowledge than that seen in males overall (see Table 2).

Table 1: Characteristics of respondents in survey years

Table 2: Overall knowledge scale scores, by age group and gender\*

\* Higher scores indicate greater knowledge. Total possible score=29 \*\* Significantly different in two survey years; p <0.05 *Attitudes Towards Condoms*. For this scale, lower levels of agreement indicate a more positive attitude towards condoms. For males overall, scores remained the same from 1996 to 1999, but for sexually active males they increased, indicating a less positive attitude. Females in both groups showed more favourable attitudes than males (see Table 3).

*Social Normative Beliefs About Condoms.* For the items in the scale, higher levels of agreement indicate an increased perception of social support for condom use. Table 4 indicates changes in overall scores for the Social Normative Beliefs Regarding Condom Use Scale. Females had significant increases in this measure of their perception of support for their use of condoms, while males indicated decreased perception of such support.

Table 3: Overall condom attitude scale scores, by age group and gender\*

\* Lower scores indicate a more positive attitude towards condoms. Total possible score=40

\*\* Significantly different in two survey years; p <0.05

Table 4. Normative belief scale scores, by age group and gender\*

\* Higher scores indicate a more positive perception of social norms concerning condom use. Total possible score=30

\*\* Significantly different in two survey years; p <0.05

*Protective Behaviours.* Results for use of condoms and oral contraception for both survey years are presented below. Use of a condom at last intercourse increased significantly in females from 1996 to 1999, but was essentially unchanged in males (see Figure 1). Females' use of oral contraception at last intercourse increased from 49% to 58%, though this was not statistically significant (see Figure 2).

Figure 1: Proportions of students using a condom at last intercourse

Figure 2: Proportion of female students using oral contraception at last intercourse *Pregnancy Rates.* During the period 1998-99 there was a sharp reduction in pregnancy rates in Amherst compared with the province overall, which approached statistical significance (p =0.09, 2-tailed). Failure to achieve statistical significance may be due to the small population size in Amherst. If the reduction is sustained in future years, and especially if it is even more marked, the statistical evidence of decreased adolescent pregnancy will be more compelling (see Figure 3).

Figure 3. Age-adjusted pregnancy rate per thousand, ages 15-19 years, Amherst and Nova Scotia,1995-98

# DISCUSSION

The changes in young women's sexual health attitudes and behaviours, and in rates of pregnancy observed in association with this programme, are very encouraging. Young men, however, did not show much in the way of change over the three-year course of this health promotion effort. Though males showed increased knowledge, changes in attitude towards condoms and perception of societal support for their use were essentially the same in both years, and their attitudes to condoms in fact became less positive. These conclusions were reflected in the finding that males' condom use at last intercourse remained unchanged. Despite the efforts made to include both male and female students' needs in sexual health promotion messages in both school-based and community programmes, female students responded more favourably to these messages than did their male counterparts, a finding which is similar to those seen in other investigations (Gupta, Weiss and Mane 1996).

These findings can be interpreted in several ways. Some authors suggest that such results may be related to differences in levels of maturity between adolescent males and females. Others argue that this is a reflection of a sexual double standard, whereby young females are socialized to accept a greater degree of responsibility for sexual and reproductive outcomes than are their male counterparts (Blonna and Levitan 2000; Gorna 1996; Nevid, Fichner-Rathus and Rathus 1995). It also could be the case that the community's health promotion efforts may not have taken into account sufficiently the needs of the young men it was attempting to reach. Efforts to reduce the spread of STIs, including HIV, as well as unintended pregnancies, must acknowledge the variability of high school aged individuals' sexual experiences in addition to the gender differences in sexual socialization between young males and females. Additional sexual health promotion programming efforts in this community will need to take measures to ensure that young males feel a sense of 'buy in' with such efforts and do not feel as though they have been written out of the safer sex discourse.

Perhaps negative attitudes seen among the males in this study are a reaction to a new sense of empowerment on the part of young women in Amherst. Culturally dominant ideas or gender stereotypes regarding sexual roles and responsibilities for high school aged individuals can present formidable challenges in the prevention of STIs, HIV, and unintended pregnancies, and should be considered by those involved in such efforts. Further research should be carried out, using a wide range of investigative techniques, to ascertain the gendered factors behind these different responses to sexual health promotion in this Nova Scotia community. Providing set

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Providing sexual health information may be less than optimally meaningful for youth without also providing the means to change such behaviours in the context of their own unique social and cultural frameworks (Stokols 1992, 1996). As Kowalewski et al. (1997) point out, the decisions made by youth regarding prevention in the area of sexual health are often informed by social and cultural values that reflect the social arena in which more general decisions regarding sexuality are made. Several authors have pointed to the need to go beyond simply attempting to increase awareness of risks to sexual health to also including reference to the context in which youth engage in their daily lives (Schieman 1998; Poppen and Reisen 1997; Smith and Katner 1995). Further health promotion work in this area should recognize these complex aspects of adolescent sexuality and incorporate ways of addressing them in programme planning.

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# 7

# HIV PREVENTION PROGRAMMES AND FEMALE PROSTITUTES: THE CANADIAN CONTEXT

#### Lois Jackson

# MISTAKEN BELIEFS ABOUT FEMALE PROSTITUTES AS "VECTORS OF TRANSMISSION"

During the earliest days of the HIV epidemic, female prostitutes1 were conceptualized as "vectors of transmission" (Alexander 1988; Campbell 1991; Padian 1988; Rosenberg and Weiner 1988). Many believed that female prostitutes would be the human mechanism through which HIV would spread from the gay community to the heterosexual community (Barnard 1993; Scambler et al. 1990). There were calls to quarantine female sex workers, or at the very least to clamp down heavily on solicitation in an attempt to control the disease. A form of 'moral epidemiology' was advocated, or a process of attempting to control the spread of the disease through the law. In some centres there were calls to license prostitutes and to have the license tied to being free of sexually transmitted diseases (STDs), including HIV. However, there was much opposition to such demands, particularly from prostitutes' rights organizations who strongly disagreed with the portrayal of female prostitutes as the problem (Jenness 1990). According to Jenness, "As the AIDS epidemic reached alarming proportions, prostitutes' rights organizations became a link between public heath agencies and sex workers as well as a watchdog organization to counter assertions that prostitutes were spreading the disease" (Jenness 1990: 404).

The belief that female prostitutes were "vectors of transmission" was based on the assumption that multiple high-risk sexual services were being provided without the use of condoms. However, numerous studies conducted in the 1980s and early 1990s began to show that most female prostitutes in North America (as well as parts of Europe and Australia) typically use condoms with clients (Darrow et al. 1990; Hancock 1998; Jackson et al. 1992; McDonnell et al. 1998; Padian 1988; Seidlin et al. 1988; Ward et al. 1999). Some suggested that there was relatively widespread use of condoms even prior to the development of HIV because of female prostitutes' concerns about protecting themselves against sexually transmitted diseases in general (McLeod 1982). A number of HIV seroprevalence studies conducted at this time also began to document low rates of HIV infection among noninjection drug using prostitutes (Kinnell 1991; Padian 1988; McDonnell et al. 1998). A study of HIV prevalence among 78 New York 'call girls', for example, reported that, "One of the six women with a history of drug abuse and none of the 72 nondrug abusers were seropositive for HIV"(Seidlin et al. 1988). Likewise, Darrow et al. (1990) reported that of the 57 non-injection drug using prostitutes tested in 1990 in San Francisco, only one tested positive for HIV compared to six of the 40 injection drug-using female prostitutes. Of 11 adolescent prostitutes tested in Montreal, Quebec (Canada), only one female prostitute was found to be HIV positive, and this woman was also an injection drug user (Frappier et al. 1994).

#### Female Prostitution and the Double Standard

The focus on female prostitutes – rather than male clients – as the problem in the potential spread of HIV mirrored the general focus on stigmatization of and discriminatory treatment of female prostitutes. In much of North America there is a dominant moral disdain for the selling of one's body to multiple customers, which is represented in the criminalization of activities

associated with sex work (including "communication in a public place for the purpose of prostitution" and "keeping or being found in a common bawdy-house") (Federal/Provincial Territorial Working Group on Prostitution 1998; Maticka-Tyndale and Lewis 1999). However, it is female prostitutes rather than the male clients who suffer the greatest consequences of this disdain. Women who engage in the sale of sexual services constantly have to guard against police arrest, especially if they are street prostitutes, the most visible form of prostitution (Jackson et al. 1992). Clients of female prostitutes, in contrast, typically do not undergo constant police scrutiny. In some centres some clients have been arrested and sentenced to 'John' school, which is a programme that is intended to reform clients to deter them from purchasing the services of female prostitutes, and offers them an alternative to entering the criminal justice system (Federal/Provincial Territorial Working Group on Prostitution 1998; Jones 1998). However, it is still more common for the female prostitute to be stigmatized and punished, not her male clients.

According to Shaver (1996), Canadian Department of Justice statistics from the three year period following the 1985 enactment of the communicating section of the law - which was designed to be non-sexist in nature and to criminalize both prostitutes and customers - indicate that in four Canadian cities, only between 30-40% of the charges involved customers, and in three cities approximately 25% or fewer of the charges were laid against customers. Shaver also adds, "...there is evidence that the sentences against prostitutes were more severe than those received by customers" (p. 214), and even when the prior record of the accused was controlled, first-offender prostitutes received more severe sentences than first-offender customers in at least two cities (p. 215). This means that more often than not it is the woman who suffers the greatest consequences related to arrest, especially if part of the sentence includes a curfew that impinges upon the woman's ability to work and thus her economic livelihood.

Numerous studies have also noted that violent crimes against female prostitutes frequently go unsolved, and in some instances

there is a weak, if any, response by the police and other authorities to the assaults and crimes against the women (Maticka-Tyndale and Lewis 1999; Ward et al. 1999; Williamson and Folaron 2001). Williamson and Folaron (2001) note that, "Prosecutors typically do not prosecute cases involving prostitute victims, and in many cases automatically dismiss sexual assault complaints initiated by known prostitutes" (p. 464). Alexander (1997) notes, "Police, prosecutors, and judges all too often believe that a prostitute, by definition, cannot be raped, and refuse to enforce the law when one is. When prostitutes are murdered, police make little effort to find the killer unless or until he kills someone who is not a prostitute" (p. 92). According to the Canadian Federal/Provincial Territorial Working Group on Prostitution (1998), "At the end of 1996, 54% of homicides involving known prostitutes reported between 1991 and 1995 remained unsolved (34 incidents). In comparison, only 20% of all homicide incidents remained unsolved when they involved other than known prostitutes (p. 8). Commenting on her experience with the police, one woman interviewed for a research study on female prostitution in Halifax, Nova Scotia, Canada complained,

'Cause I'm a prostitute so he [client] can go around strangling anybody and get away with it. So buddy got away with it [strangling the woman]. I find that when you call the police, half of the time they don't want to help you 'cause you're a prostitute. There's a lot of prostitutes that got killed and you don't see no police trying to find anybody that did it (Jackson et al. 2000b).

At the same time as there is relatively little interest in addressing the acts of violence committed against female prostitutes, in many centres there is state support for such prostitution- related activities as escort services and body rub parlours (which are often male owned and operated) (Lowman 1997). Typically, escort services and body rub parlours are provided licenses to operate, and municipalities profit from these establishments. Moreover, those involved in managing such activities profit from the women's work of selling sexual services although it is the women who take the greatest risks in terms of violence perpetrated by clients (Alexander 1997; Jackson and Hood 2001). Just as some women working the streets have had, and currently have, 'pimps' who profit from the women's work, prostitutes who work in escort agencies or in body rub parlours are typically required to provide a large percentage of their earnings to the owners of these establishments. Prostitutes working in Atlantic Canada have reported, for example, that escort services most often require half the women's earnings, and in some instances also require that the women clean the spaces where services are provided and/or pay taxi fees for 'out calls' (i.e., services provided at hotels, etc.) (Jackson et al. 2000b).

# HIV-PREVENTION PROGRAMMES AND THE SEX TRADE INDUSTRY: FOCUS ON FEMALE PROSTITUTES

To date, the focus of much HIV prevention work within the sex trade industry in the Canadian context (as well as parts of Europe) has been on the female prostitute. Most prevention programmes have attempted to ensure that female prostitutes have a high level of knowledge of HIV transmission and access to (and utilize) condoms, as well as clean needles and drug paraphernalia if the woman is an injection drug user. There are relatively few published evaluations of such HIV prevention programmes, but the literature that does exist suggests that these programmes have been effective in terms of their objectives of targeting female prostitutes, and that peer education in particular has played an important role in accessing women who might not otherwise have access to HIV education and need social and medical services (Blakey and Frankland 1995; Crosby 1997; Dorfman, Derish and Cohen 1992; Stepping Stone 2000-01). However, the focus on the female prostitute as the "keeper of safer sex" fails to direct attention to the client's role in the potential spread of HIV, and also obscures the class, race and gender inequities that play a fundamental role in women's entrance into prostitution and their vulnerability to HIV (Dalla 2000; Erickson et al. 2000; Working Group on Youth Exploited for the Sex Trade, 1993).2

Studies have noted that economic factors are key influences

on many women's entrance into the sex trade industry, and that such economic need is related to gender and racial inequities (Davidson 1998; McCleod 1982; Scambler et al. 1990). As Scambler et al. (1990) note, "...many sex workers (especially on the streets) belong to an oppressed minority of women, driven or recruited to sex work for want of alternative means to subsist and to provide as single parents" (p. 269). In some instances, women who work in prostitution have experienced a history of child abuse - physical, sexual and/or emotional that has led them to leave home at an early age, forfeiting educational opportunities that might otherwise be available to them (Youth Services 1991). Attempts to continue their education often prove extremely difficult given the economic costs of education and the cost of living. Many seek social assistance, especially if they have children and little if any financial support from a partner or family, that often proves to be insufficient to cover general living expenses. In this context, the sex trade industry is an option that allows women to augment their income, and provides work opportunities for those who do not possess the education and skills to otherwise obtain a decent wage. As McCleod (1982) notes, "Women with limited education and training are especially disadvantaged ... and it is from the vast ranks of women in these circumstances that prostitutes are mainly drawn" (p. 29).

Research has found that many women who work as prostitutes within the North American context are relatively consistent users of condoms. However, research also indicates that when condoms are not utilized during the prostitute-client relationship, it is frequently because the client resists (Dalla 2000; McKeganey and Barnard 1992; Wong et al.1994; Jackson et al. 2000a). Client resistance to condom use can take many different forms, from subtle coercion to more overt forms of violence, but regardless of the form, it represents a risk of HIV transmission. Commenting on a male client's resistance to condom use, one female prostitute in Halifax, Nova Scotia, reported, "Oh yeah, this one fellow he punched me in my head and roughed me up a bit cause he didn't want me to use a condom, but I got away from him without being seriously hurt" (Jackson et al. 2000a). Other female prostitutes have noted that some clients offer financial incentives for the non-use of condoms (McLeod 1982; Jackson et al. 2000b) – incentives that some women find difficult to resist because of their desperate economic need (Jackson et al. 1992, 2001; Wojcicki and Malala 2001). Economic need may be related to multiple issues including the need to provide support for one's family/children and/or drug or alcohol addiction.

The emphasis on the female prostitute as the "keeper of safer sex" not only detracts attention from the contexts that make it difficult for the women to practice safer sex - including the economic forces that have shaped many women's entrance into prostitution and that make economic incentives for non-condom use attractive - but also reinforces the idea that the women, and not the men, are to blame if one or more parties becomes HIV infected. It is widely believed that HIV-infected female prostitutes should not be working, but calls to have HIV-positive men who frequent prostitutes barred from visiting prostitutes are not heard. Just as women have traditionally been responsible for birth control and the unintended pregnancies resulting from birth control failures, female prostitutes are typically viewed as responsible for keeping the trade safe from STDs, including HIV. In many instances, women take on this role because of the importance of maintaining their health, and so they can continue to care for and financially support their families (Jackson et al. 2000b). However, the focus on women is problematic, especially given that in at least some instances noncondom use is situated within specific contexts over which the women have little, if any, control.

## Addictions and Safer Sex

Alcohol and/or drug addictions can also influence women's susceptibility to client demands for sexual services without the use of condoms, and to economic incentives not to use a condom. Indeed, the need to support an addiction can overshadow concerns about HIV infection and possible future health problems (Crosby 1997; Jackson 1992). Although there are not extensive data on the extent to which women with addictions who work in the sex trade industry succumb to clients' demands not to use a condom, or do not use condoms for other reasons, one study in Winnipeg, Manitoba (Canada) found that 71% of female injection drug users (IDU) reported that they had been paid for sex, and 25% indicated inconsistent condom use with their sex trade clients (Bureau of HIV/AIDS/STDs and TB 2002).

Among female prostitutes who are injection drug users there are also risks of HIV if needles and drug paraphernalia are shared. Needle exchanges exist in a number of major metropolitan centres in Canada, and the Bureau of HIV/AIDS/STDs and TB reports that, "most international studies report substantial declines in needle sharing" among IDUs who use needle-exchange programmes (2002). Still, problems of access to needles during particular times of the day and night have been reported, and access remains an issue in some contexts (Jackson et al. in press). In addition, research from the United States suggests that sex workers are reluctant to carry large numbers of syringes for fear of harassment by police (Paone et al. 1999). It is unknown if this is also the case in Canada, but it may be a factor for some prostitutes, and may affect risks of HIV.

At present, within Canada, there are some treatment programmes to assist women – prostitute and non-prostitute women alike – who want to receive help with their addictions. However, there are numerous obstacles to accessing the programmes. These obstacles include long waiting times, a lack of economic and social support for their children when they are in treatment, and the poor attitudes of some counselors who are not sensitive to the women's situations (Whynot 1998). For many sex trade workers who want to access addictions programmes, as well as other social and health services, there are also additional obstacles including fears related to revealing their work status. As Williamson and Folaron (2001) note, "Having often been threatened with incarceration or the removal of their children, sex workers remain distant from public institutions" (p. 474). Weiner (1996) reports that for female prostitutes with children, one of their greatest fears is that of being investigated by social service agencies and having their children taken away from them.

# HIV PREVENTION PROGRAMMES AND FEMALE PROSTITUTES' PRIVATE LIVES

The focus of prevention programmes on prostitutes' working lives has not been matched by prevention efforts related to their private lives. Indeed, relatively little attention has been given to female prostitutes' private sexual lives and their risks of HIV infection within this sphere. The difficulties of targeting prostitutes' private sexual lives are numerous and include women's fears about the potential repercussions of revealing information about their private lives, as well as their resistance to using condoms within the private sphere (Jackson et al. 1992; Crosby 1997).

For many prostitutes, condoms are associated with work and, as a result, there is some resistance to using condoms when having sexual relations with someone other than a client. Some women have noted that a condom interferes with the closeness of a private relationship because of the use of condoms with clients. The non-use of condoms in the private sphere symbolizes the closeness of the relationship and the non-commercial character of the sexual activity (Jackson et al. 1992; Jesson et al. 1994; McKeganey and Barnard 1992; Ward et al. 1993).

Nevertheless, policies and programmes that encourage condom use at work while remaining relatively silent on sexual relations at home may actually be encouraging condom use in a sphere where condoms are an accepted part of the culture, while ignoring a sphere that may represent more of a risk in terms of the transmission of HIV (Jackson and Hood 2001; Scambler et al. 1990; Ward et al. 1993).

The relatively low use of condoms within female prostitutes' private or home lives represents relatively low levels of condom use in heterosexual relationships generally (Crosby 1997), but still requires greater attention in terms of HIV prevention. In some instances, female prostitutes' greatest risk of HIV may be when having sexual relations with a private partner (e.g., a spouse or a boyfriend) (Ward et al. 1993; Ward, Day and Weber

1999), especially when a private partner is at particularly high risk as in the case of injection drug users who are sharing needles and drug paraphernalia (Day 1988).

Although many female prostitutes have reported that there is a fundamental dislike of the use of condoms within the private sphere, there are instances when they feel they would like to use condoms with a boyfriend or spouse because they believe that they are at high risk of HIV or other STDs. However, they are often fearful of even broaching the topic for fear of negative repercussions. Some women have reported that their male partner would be offended if the issue of condom use was raised because it would represent the client-prostitute relationship rather than an intimate relationship. In some cases women suffer the consequences of the man's anger related to condom use (Jackson et al. 2000b; Sterk 1999). This points to the fact that safer sex is not safe if it has the potential to challenge a relationship with a significant partner who might become violent. As Maman et al. (2000) have noted,

Condom promotion and other HIV prevention programs will have limited impact unless they take into account the role of violence in women's lives. Women who are victims of violence or threats of violence by intimate partners often do not have the means of HIV protection within their personal control (p. 476).

#### DISCUSSION

Since the 1980s, many HIV-focused programmes have been developed based on a concern for prostitutes' health and wellbeing. Numerous and varied educational programmes now exist in many centres, and prostitutes are frequently provided free condoms, and clean needles, 'bad trick sheets' to warn against violent clients, as well as access to counseling and other social and medical services. Such programmes appear to have been very effective in providing women who might not otherwise have these services with needed supports. As such, these programmes appear to have played an important role in helping to keep female prostitutes safe, and improving their health and well-being. Still, many female prostitutes continue to be at risk of HIV infection in contexts where they do not, or are unable to use condoms. Moreover, for a large number of women who work in the sex trade industry, their vulnerability to HIV is rooted in the fact that they are economically disadvantaged and their poverty is directly related to gender, racial and other inequalities. In order to adequately address the health, safety and well-being of female prostitutes – including risks of HIV – it is imperative that programmes and policies address both the immediate health and safety issues faced by these women, as well as the underlying inequities that lead women to enter the sex trade, keep them tied to this industry, and make it difficult for those who choose to leave to find alternative sources of employment/income.

At present, a number of harm reduction strategies are in place in many centres. However, in some instances access remains a problem, particularly access to clean needles and drug and alcohol programmes (e.g., methadone programmes). There is a need to make these programmes more accessible. There is also a need to conduct research to determine how and why female prostitutes may not be able to access these programmes, including the specific barriers to access faced by women from varied backgrounds and regions of the country.

There is also a need to provide appropriate training to individuals – professional and non-professional alike – working and interacting with female prostitutes to ensure that female prostitutes are treated in a non-discriminatory fashion. Female prostitutes should not have to fear that they will lose custody of their children if they seek treatment or other types of assistance. Women who work in the sex trade industry require the same level of protection as all women, and should not have to endure emotional abuse by being labeled as 'deviant', 'immoral', or 'unfit mothers'. These labels and the stigma associated with them only make women feel inferior, and fearful of obtaining needed services that might reduce their vulnerability to HIV.

There have been calls to extend the current harm reduction strategies of providing condoms, clean needles, 'bad trick sheets'

etc., to include the designation of safe places where sex trade workers can take clients (Barnard 1993) and safe drug use settings (Erickson et al. 2000). There is also an increasing interest in targeting clients for HIV education (Campbell 1991; Wong et al. 1994). As Waldby, Kippax and Crawford (1993) have noted, the "pragmatic reason" for making women responsible for safer sex has been "the perception that men will not co-operate with demands for sexually responsible behaviour" (p. 247). However, programmes targeting men – clients and non-clients alike – are needed to shape their interest and concern with HIV and to provide them with appropriate supports (e.g., counseling and anger management) that can reduce the risks that many women face when seeking to use condoms with clients as well as private partners (Crosby 1997; Pyett and Warr 1997; Wong et al. 1994).

Ward, Day and Weber (1999) argue that female prostitutes "face high rates of violent assault in their personal and their professional lives not just because they are prostitutes, but also because they are women, and may be drug users, homeless, young and poor" (p. 342). Turning our attention to the perpetrators of these assaults, and to keeping women safe from violent clients and partners, is essential to maintaining the health and well-being of female prostitutes. As such, police and professionals within the legal profession need to be educated about the realities of these women's lives. Policies need to be developed to ensure that violence against female prostitutes - regardless of who the perpetrator might be – is quickly addressed. Specifically, there is a need to create non-discriminatory policies that ensure women are protected and taken seriously when they experience violence or assaults either at work or at home. Such policies would need to be evaluated on an ongoing basis by sex trade workers and community agencies working with sex trade workers to ensure that they are truly effective.

There is also a need to tackle the underlying issues that are often precursors to women entering the sex trade industry, and that keep them tied to this work even when it is dangerous and risky to their health. As Dalla (2000) notes, "multi-pronged" interventions are needed that address the complex, intertwined issues of poverty, addictions, abuse, underemployment, poor housing, and lack of access to affordable and quality childcare. The socio-economic conditions that make women vulnerable to HIV – lack of power within male-female relationships, economic dependency, drug and alcohol addictions – need to be addressed. Women require access to educational and work opportunities, and this access needs to recognize that many have had very little education as well as little introduction to the structures of educational systems. One-on-one education and training may be necessary in some instances to support women who require help in developing the confidence to pursue education and training in a specific field. In addition, affordable housing and quality childcare are needed for all women irrespective of whether or not they remain in the sex trade.

In the development of policies and programmes, it is important that women who work or have worked in the sex trade industry are a key part of the process. Providing women with a voice in the planning of programmes and development of policies will help to ensure the implementation of social changes that will directly benefit these women. At the same time, integrating current and/or former prostitutes into the process will help to empower the women, most of whom have lived much of their lives outside the realm of programme development and policy decision making. Historically, many policies and programmes have been developed without integrating the voices of the targeted populations, and this has led to inappropriate or poorly conceptualized programmes.

In the area of HIV specifically, there has been an attempt to integrate users, or those for whom the programmes and policies are intended, into the process and even to have them lead or have ownership of the process. The underlying premise of peer education and peer outreach is that members of the target population are best placed to provide the supports and services (Stepping Stone 2000-01; Jackson et al. 1992). Extending this philosophy to the development of broad-based policies would mean that current and former sex trade workers would be key policy-makers tackling issues that directly affect their lives, and that have an important impact on their health and well-being.

#### References

- 1. There is much discussion about what term to use when talking about women who exchange sex for money or in kind compensation (e.g., drugs). We have chosen to use the term "prostitutes" and we are referring specifically to women who exchange sex for money or drugs. We are not including women in the sex trade industry who (exclusively) provide other services such as phone sex.
- 2. Some activists and sex trade workers have argued that becoming a prostitute is a choice that at least some women freely make. Jill Nagle (1997), for example, argues that like some other women, her racial and economic privilege has afforded her "the opportunity to choose participation in the sex industry from among many other options" (p. 2). She further adds, "This is not true for perhaps the vast majority of sex workers worldwide, especially those who exchange sex to survive on the streets, who support an addiction, or who are forced into it by others. Yet most public discussions about sex work fail to distinguish between voluntary and coerced sexual exchange, a distinction every bit as salient (and problematic) as that between consensual sex and rape" (p. 2).

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