Living with HIV

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L'auteure vit avec le virus du sida depuis 12 ans et nous fait part de ses discussions au sujet du virus et les femmes dans une perspective canadienne, partageant ce qu'elle a vu et appris.

As a woman who has lived with HIV for over 12 years, and as someone who has worked with women with HIV in Canada, I would like to share with you some of what I have seen and learned.

There is a common belief today that we in Canada have the HIV epidemic under control. There is a belief that infection rates are down, that HIV is no longer a killer, that people therefore need not worry about becoming infected; that treatments have made this a chronic, manageable disease and that treatments are available to all Canadians who want them.

These beliefs are simply not true and I would argue that women are perhaps the group—or rather the groups, since women are not one single monolithic group—that dispel these mistaken beliefs most starkly. Why is that? Well, in 2002, women accounted for nearly one third of the new infections in this country. More startling is that, in the age group between 15 to 29, women made up nearly half of all new infections (Health Canada). What a devastating situation for these young women whose lives have barely begun, and for those who love them. I remember only too well the feeling of complete shock and total hopelessness I felt when I was given my diagnosis over the phone by my family doctor.

So, is this tragedy an inevitable result of the perceived infallibility of youth? Or have we as a society failed these young women? I would argue that we must bear a portion of the blame for these infections. Why do I say this? Well, we know that women are biologically, economically, socially, and culturally more vulnerable to HIV infection than men. But what does this mean in a practical context? It means that women who are in violent relationships, or who fear violence cannot negotiate safer sex practices with their partners. It means that women who are raped are more likely to be infected due to physical trauma opening wounds for HIV to enter. It means that women who are dependent on their sexual partners for food and shelter for themselves and their children cannot demand condom use.

We have failed as a society to provide women with sufficient social safety nets to leave unsafe relationships or the tools to protect themselves where social safety nets cannot practically do so. And how could we do more to support these women? We need education and awareness programs targeted to women and their partners (when I was diagnosed I had no idea women could even contract HIV), more shelters for women to escape the nightmare of violent relationships, adequate social assistance programs to give them financial independence, and more drug rehabilitation programs to ensure they can participate fully in supporting themselves and their families.

We also need more money for research on microbicides, a completely user-controlled form of HIV protection. And we desperately need to tackle the stigma and discrimination that has made so many of us ashamed to declare our medical status publicly.

One of the most heartbreaking moments I can remember is a phone call I received to tell me that my wonderful, bright, funny girlfriend Candace had jumped to her death from the fifteenth floor of her apartment building, even as her care worker made her bed in the other room. Her body had not yet succumbed to this disease but the depression, fear , and shame she felt about her HIV status drove her to end her own life.

There is clearly much work to be done to recognize the vulnerability of women generally to HIV. But it is also clear that all women are not equally vulnerable either. Some groups of Canadian women have additional risk factors that increase their vulnerability to HIV.

Aboriginal women are certainly in this situation. Research, and commonsense, tell us that social factors including racism and sexism piled on top of stigma, discrimination, and poverty have more to do with vulnerability to HIV than does individual behaviour.

The history of our, to say the least, unfortunate relationship with our First Nations people is well documented. It has led to a range of pressing social problems, each one a contributor to HIV infection, including alcoholism, substance use, high suicide rates, violence against women, and family violence. Shockingly, Aboriginal women make up half of all new infections among Aboriginal people. Nearly half of these women are between the ages of 15 and 29 years. Aboriginal women are also twice as likely to be infected by injection drug use as by sex (Health Canada).

In one health care district in Regina, Saskatchewan, eight women tested positive in a 12-month period last year, five of whom were Aboriginal, six with addiction issues. All presented in late stage pregnancy and none had been connected to any health or community services before this time. What a disaster for generations of mothers and daughters and families. We need new and dedicated resources to reach these women and their partners. We need: better harm reduction strategies; more affordable housing; more resources for women to leave violent relationships; and more child care for single mothers.

Our society must create the necessary social environment to support self-determination. Otherwise we will merely perpetuate the terrible situation in which this generation of women finds itself into the future. Imagine the layers and layers of discrimination a woman feels because of her sex, because she is Aboriginal, because she is an intravenous drug user and because she is poor and probably homeless or underhoused and unemployed. This is the situation in which many intravenous drug using women find themselves in Canada. Nowhere is this social recipe for HIV more apparent than in the downtown eastside of Vancouver. I can well recall doctors working in this area warning the world of this looming disaster at the World AIDS Conference in Vancouver in 1996. And yet, we are shocked when the full scope of this catastrophe was subsequently felt, as bodies piled up in back alleys. And, who are these lost, and often forgotten men and women?

Studies in Vancouver have shown that the incidence of HIV among female drug users is 40 per cent higher than male drug users. These women are more likely to be Aboriginal, younger, to have had non-consensual sex, to have an intravenous using male partner, to inject heroin and cocaine, to smoke crack, and to need assistance in injecting. I have watched the impact of drug addiction and HIV on women first hand. Last year, a dear HIV+ friend and colleague at Voices of Positive Women died. Betty was an injection drug user on and off for many years and had fought her addictions for years. When she wasn't using she was one of the most reliable and hard-working people I knew. She had a dignity I truly admired and she never appeared to feel sorry for herself. She just couldn't beat her addictions. Finally, her liver failed due to a combination of the disease and drug toxicities. I still wonder what we could have done differently to support this extraordinary woman. Once again, the inescapable and only logical conclusion is that resources for gender and population specific programs are urgently needed including needle exchange, safe injection sites, and street nurses.

For those of us who have been able to obtain treatments and to benefit from them, they have been nothing short of life saving. There is a rather widely held belief that everyone in Canada who needs treatment can access it. This is simply not correct.

Other women who have been sadly overlooked and underestimated regarding their risk for HIV infection are those from countries where HIV is endemic: Africa and the Caribbean. When a report from the Toronto Hospital for Sick Children found that 70 per cent of the maternal-infant transmission of HIV at that hospital in 1996 had occurred among people from HIV-endemic countries, the magnitude of the problem could no longer be ignored.

In-depth research involving these men and women began in Ontario. It shows that HIV+ women from endemic countries represent a startling one-third of AIDS-related deaths in 1996 in that province. It is estimated that 30 to 40 per cent of these women were infected after the establishment of residence in Canada, contrary to the popular belief that the virus is brought to Canada by immigrants.

For women in these cultures, unique and deeply rooted socio-cultural and structural factors intersect with gender, race, class, political and economic conditions to make them vulnerable to HIV infection. In these societies, where the well being of the family and the community supercedes the well being of the individual, strategies must target whole communities in order to modify cultural values, beliefs, norms and practices that increase the risk of HIV infection faced by women in these communities.

Women in prisons also face high infection rates for HIV as well as Hepatitis C. Some enter prison with HIV but many are infected in prison due to injection drug use and tattooing. These infections are easily prevented by implementing policies that ensure clean needles and safe injection practices. Clearly, we are really dealing with an epidemic among women that is fuelled by complex factors that are social, economic, cultural, and racial. For this reason, discreet strategies are required to reach these groups of women effectively and to reduce their risk for HIV. This will require new resources and strategies developed by the communities themselves.

Not only is there much to be done for each group on the prevention front but also Canada has much to do to ensure that treatments are reaching all of these populations. Treatment and prevention are inextricably linked. For those of us who have been able to obtain treatments and to benefit from them, they have been nothing short of life saving. There is a rather widely held belief that everyone in Canada who needs treatment can access it. This is simply not correct.

While most provinces have some program to provide some medications to certain of its citizens, these plans are not universal, comprehensive, or easily accessible. Studies have shown that women in many of these groups do not access medications. One study indicates that a shocking one-third of people who died in Vancouver between 1995 and 2001 had been taking no antiretroviral treatment in a province where medication is free. The worst off were Aboriginal women living in poverty.

Inability to access and/or navigate the system due to money, culture, language and power barriers can have fatal consequences for Aboriginal women, intravenous drug using women, women in prisons and women from countries where HIV is endemic.

In some cases, the system simply is too costly with co-payments or deductibles that many simply cannot afford. Or it requires an ability to understand bureaucratic forms and procedures that are too complex for most people. Or it requires a level of tenacity that a person who is marginalized may well not have the confidence to display.

Gender exacerbates each of these barriers.

I trust that in years to come it will not be so. Canada made a wonderful start to turning this situation around when it introduced the Canadian Strategy on HIV/AIDS in the early 1990s with funding dedicated to strategic initiatives to address the epidemic. Sadly, this strategy is now woefully underfunded to meet the particular challenges faced by women among others. Provincial governments need more funding for their HIV+ citizens.

Canada wisely endorsed the United Nations Declaration of Commitment on HIV/AIDS in June 2001. Full implementation of the priorities set out in this Declaration will go a long way to combatting HIV in Canada, thereby easing the plight of HIV+ women, among others.

I believe that HIV is much more than a virus. It has socio-economic, political, and ethical dimensions the likes of which humanity has never before encountered. It has brought out the worst in some of us, but I believe that it has also brought out the best and will continue to do so. For inspiration I often reread the words of the late Jonathan Mann in a 1996 speech (XI International AIDS Conference, Vancouver, BC) on global solidarity and the HIV movement:

> Why did so many of us feel in joining the work against AIDS at any level, in any place, within any discipline or organization—that we belonged—perhaps for the first time as adults—to something larger than a nation, an ethnic group, or a profession. We shared a feeling of participating in something universal. Deeply held values and beliefs were engaged about the sanctity of life, and the basic equality and fundamental dignity of people. And these individual feelings, spoken or unspoken, were shared, so that we knew that somehow, together, we would, and could prevail even where others had failed.

I invite you to share with me in that belief.

I dedicate these remarks to my dear friends Jacqui P. and Evan Ruderman who I know are watching from somewhere.

Article adapted from a speech given at a Department of Foreign Affairs and International Trade (DFAIT)-sponsored event on the theme of "Women and HIV" held on International Women's Day, March 8, 2004.

Louise Binder is an HIV/AIDS advocate who has worked in this area for over twelve years.

References

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