

Secrets and lies

Stigma of disclosure a key prevention issue

by Glen Hillson

Disclosure of HIV serostatus has been a difficult issue for most PWAs since the beginning of the epidemic. In Canada and elsewhere in the northern hemisphere, gay men and injection drug users have been the most vulnerable to HIV infection and to the discrimination that goes with it. In the northern hemisphere, at least two-thirds of infections have been in gay men and men who have sex with men. Early in the epidemic, recipients of blood and blood products also accounted for a sizeable number of HIV infections. In the southern hemisphere, sexual transmission among heterosexuals accounts for the largest proportion of infections.

For gay men in North America, the gay rights movement was little more than a decade old when AIDS arrived on the scene. Gays were rapidly acquiring legitimacy as a social identity group. At the same time, they were experiencing sexual freedom and defining that freedom and their sexuality in distinctive ways.

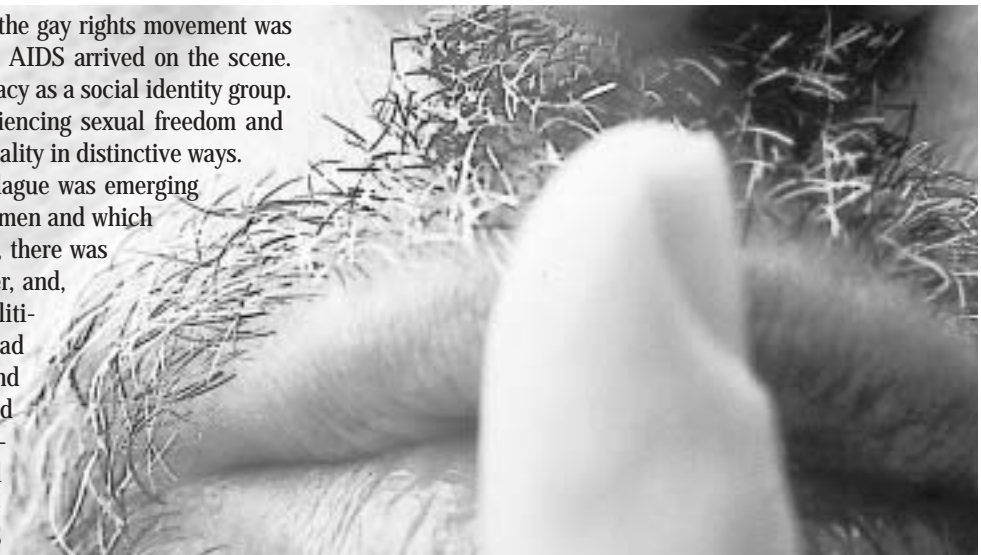
As it became apparent that a plague was emerging that predominately occurred in gay men and which was likely related to sexual activity, there was a great deal of despair, denial, anger, and, of course, fear. In the 1980s, the political pendulum in North America had swung far to the right. Business and religious interests heavily influenced the ideologies of right-wing governments led by BC Premier Bill Vander Zalm, Canadian Prime Minister Brian Mulroney, and US President Ronald Reagan. Many people thought the epidemic was God's punishment. All the civil rights victories of the gay movement were in danger of being swept away by homophobes who would use AIDS as the cudgel to punish those who were already suffering and dying.

Fear of ostracism

Many gay men had adopted a sexual lifestyle that included frequent casual or anonymous sex with multiple partners. We met in parks, bathhouses, and bars, and often we had sex with very little prior conversation or exchange of personal information. Discussion of HIV status seldom occurred for many reasons. It didn't fit with

the excitement of spontaneous sexual encounters with strangers. Disclosure of positive HIV status had its own set of risks. HIV-positive people feared being cast as social pariahs accused of illegal behaviour and feared losing their cherished sexual freedom.

In addition to caring for those afflicted, one of the tasks of those in the community who first took up the challenge of responding to the epidemic was gathering and disseminating what little information was available about HIV transmission. Prevention efforts were well underway, even before the virus that causes AIDS was discovered.



From the mid-80s to the mid-90s, prevention campaigns were developed by community-based organizations working in partnership with government, public health officials, and other funders. Prevention work largely consisted of public awareness campaigns and condom distribution. These were augmented by support groups and discussion groups and by AIDS educators speaking to various audiences wherever opportunities arose.

With virtually no exception, the messages were directed at HIV-negative people. They sought to inform, support, and encourage the uninfected to practice safer sex and safer injecting habits to avoid contracting HIV. The critical role of HIV-positive people in prevent-

ing the spread of the virus was all but ignored. It is somewhat difficult to understand why this happened. After all, every time someone is infected, an HIV-positive person is one-half of the equation.

In that case, why were there no prevention messages that spoke to HIV-positive people, messages that provided information and support that would empower PWAs to make healthy choices for themselves and others in their community? One theory is that drawing attention to the roles and responsibilities of PWAs would fuel the fires of vigilantism in a political climate that was unfriendly to those who already lived on the fringes of society.

Civil liberties in jeopardy

In 1986, the BC provincial government passed legislation allowing for the quarantine of people with HIV/AIDS. (That legislation is still on the books.) The community was cautious about giving unnecessary exposure to the reality that the actions and behaviours of HIV-positive people were equally as important as those of HIV-negative people in the spread of the disease. For gay people, recently won civil liberties and other freedoms might have been in jeopardy if the large

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er society saw gays as the vectors of catastrophic illness. For injection drugs users (IDUs), there were similar dangers of being exposed for criminal conduct or being mistakenly labelled as homosexual.

There were other shortcomings of the prevention strategies of the time. Despite growing recognition that the messages of prevention campaigns needed to move away from a "one size fits all" model, little effort was made to respond accordingly.

HIV/AIDS typically affects people who, for very different sets of reasons, are the most vulnerable. For gay men, two of the main contributors to vulnerability are homophobia and drug use. For

IDUs, society's persistent failure to recognize addiction as a health issue bolsters the stigmatization of drug use. For aboriginal Canadians and people of colour, racism creates vulnerability to HIV. Women are economically and socially disadvantaged throughout most of the world. Gender inequality leading to sexual and other forms of assault makes sexism the primary source of vulnerability. And so on.

Prevention campaigns on the wane

One might think that by the mid to late 1990s that increased knowledge about the spread of HIV would have led to improved prevention campaigns and greater success in quelling the spread of the epidemic. Instead, even the marginally effective messages from earlier times seemed to disappear.

Except for the recent "Arouse" campaign in Vancouver, there have been precious few visible messages about stopping the spread of HIV. The "Arouse" campaign was a reasonable start to getting the ball rolling again but was very limited in scope. The message was that HIV is still a serious matter and that HIV drugs are no picnic. Last year, a Toronto group launched the unfortunate "Condom Country—Ride Safely" campaign. With its outdated cowboy aesthetic, it appeared to be designed by and for the over-forty set.

We still have a very long way to go to develop evidence-based strategies sensitive to the needs and realities of different populations at risk. When people encounter a prevention message and think, "that's for someone else," it simply will not have any impact.

We have learned a lot about the spread of HIV/AIDS in the past twenty years. We need to continue to build on that evidence and hold our governments and community organizations accountable for getting prevention efforts back on track. It is only a matter of time before the volume is turned up on discussions about disclosure of HIV status. Now is the time to start preparing for those discussions to ensure people hear the valuable experience and knowledge of PWAs. ⊕



Glen Hillson is the chair of the BCPWA Society.

Upcoming BCPWA Society Board Meetings

Date	Time	Location	Reports to be presented
October 30, 2002	3:00pm	Training Room	Executive Committee / Written Executive Director Report
November 13, 2002	3:00pm	Training Room	Standing Committee / Written Departmental Reports
November 27, 2002	3:00pm	Training Room	Director of MVR / Written Executive Director Report
December 11, 2002	3:00pm	Training Room	Executive Committee / Written Department Director Report

The BC Persons With AIDS Society is located at 1107 Seymour St., Vancouver.

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