

A positive prevention primer

BCPWA prevention campaign will target people with HIV

by Carl Bognar

Prevention efforts in BC and Canada are failing, and globally they're in a shambles. A glaring lack of leadership and co-ordination characterizes attempts to curb increases in new infections. HIV-positive people haven't been included in prevention strategies, yet they have much to contribute to this struggle. The BCPWA Society is working to correct this exclusion.

What does the word "prevention" mean to people who already have HIV? Traditionally, prevention can be categorized roughly into three types: primary prevention, secondary prevention, and tertiary prevention.

Three types of prevention

Primary prevention programs usually involve raising awareness and providing education about a particular disease for people who don't yet have that disease. These types of programs are usually aimed at large groups of people—gay men or all high school students, for example. Clearly, primary prevention—at least as we currently think about it—isn't the primary mandate of the BCPWA Society, whose members already have HIV.

Secondary prevention means taking action to prevent or minimize the harm caused by a disease. Examples include harm reduction programs, such as needle exchange and methadone maintenance. Early detection of HIV infection through HIV tests is also a form of secondary pre-



vention because it allows people who are infected to get access to care and treatment at the earliest possible stage. This strategy minimizes damage and prevents the disease from getting out of control. In the US, the government is launching programs to increase early identification of HIV infection. It is estimated that up to one-third of Canadians who have HIV infection are not aware of it.

Early identification of HIV infection could also provide knowledge that will enable positive people to make informed and responsible decisions about their sexual activities. However, the idea that early identification programs will help to reduce transmission of HIV remains controversial because it seems to contradict other ideas

about prevention, in particular, that everybody should be taking precautions to limit the possibility of their exposure to HIV.

Tertiary prevention is focused on treating a health problem to lessen its effects, to maximize quality of life, and to prevent further deterioration. This type of prevention includes a wide range of services already provided by the BCPWA Society to its members, such as treatment information and counselling, access to nutrition, information about food and water safety, and income advocacy. Examples include medical treatments to prevent opportunistic infections, such as the use of Bactrim or Septra to prevent pneumocystis carinii pneumonia (PCP), or acyclovir to prevent outbreaks of herpes.

PWAs and primary prevention

What would an increased focus on prevention at the BCPWA Society look like? People working on primary prevention programs are starting to think about the role HIV-positive people might play in primary prevention. Where are positive people in primary prevention messages? Almost all primary prevention programs thus far have been aimed at people who are negative. Early prevention planners were reluctant to include HIV-positive people in prevention messages, at least partly out of concern about further increasing the stigma against people who are positive. But, of course, new infections come from people who are already positive. As increasing numbers of

positive people live healthier lives, it is time to consider what makes prevention difficult from that perspective.

So far, prevention hasn't considered the needs of HIV-positive people. Nearly every positive person has wished that HIV transmission stopped with ourselves, but there has been no support for doing that, especially in the context of intimate and sexual lives. We are still entitled to intimacy and sex, even if we are positive.

A recent survey of gay men conducted by the Community-Based Research Centre found that almost all HIV-positive gay men felt that the gay community is divided by HIV-status, while few negative men felt that way. Other research shows that positive and negative men have quite different beliefs and expectations about whether their sexual partners will disclose HIV status in sexual encounters.

Uncovering the social and medical issues

Positive men are left with a host of social issues they need to deal with. When is the best time to disclose to a partner? How do you handle rejection if you disclose? Who is entitled to know what facts about your life? How do you deal with the isolation from the larger community if you're open about your HIV status? How much of the burden of protection ought to fall on people living with HIV, and how much on people who are (or believe themselves to be) HIV-negative?

Medical issues, too, must be considered. If your viral load is under control, does that mean you are less infectious? (Probably yes, but you are still infectious.) Will barebacking expose you to strains of the virus that are different from the ones you are already carrying around? Does being exposed to different strains increase the likelihood of disease progression? Does it decrease the effectiveness of your treatments? Is it important to care about these issues—to sacrifice intimacy and some types of sexual activity—in the face of a life that will, in all probability, be shortened because of HIV anyway? How do all of these issues interact

to contribute to your decisions about sexual safety? Similar questions no doubt apply to injection drug users.

If HIV-positive people are going to be included in primary prevention, we need to have a clearer picture of what the issues are, how they are interrelated, and what we might do about them. We would also benefit from having the opportunity to talk with each other about these issues. Here the distinctions between primary and tertiary prevention get blurred. This type of approach

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has the potential to reduce the spread of HIV and at the same time improve quality of life by giving us the support and strength and knowledge to deal with these issues openly and with confidence.

Ownership through peer-driven programs

One lesson we have clearly learned from other types of HIV prevention programs is that the most effective programs are the ones that have been designed by peers based on knowledge derived from specific communities, such as younger gay men, injection drug users, and serodivergent couples. Effective prevention isn't something that is done to a community; it should be done with community. This means ownership. Prevention programs for positive people should be designed by positive people.

These types of peer-driven action programs are starting to emerge in a few cities. In San Francisco, a consortium of AIDS service organizations and consumer organizations has launched a prevention campaign targeted primarily at positive people. The campaign includes a range of activities, such as workshops on living with HIV, safer sex cruising, staying healthy, and disclosure. Check out their website at www.hivstopswithme.com. The goals of the campaign include devel-

oping HIV-positive role models and moving HIV-positive people into the forefront of HIV prevention. The George House Trust in Manchester, England, is also developing programs especially targeted to positive people.

There are good reasons to include PWAs in prevention planning. One of the major lessons in HIV prevention has been the need to develop local responses to the epidemic: what works in one place and with one subpopulation won't neces-

sarily work in other places, or even in the same place with different subpopulations. Even more, we have learned that the involvement of community in itself can be a powerful tool in prevention, a type of community development that may be more effective than media campaigns.

Since including HIV-positive people in prevention planning is a new idea, no foundation exists to build upon. We need to find ways to bring PWAs together to discuss these issues and to figure out appropriate courses of action, starting from the ground up. So far, there are very few models.

More HIV-positive people are alive than ever before. Rates of new HIV infection appear to be rising. All levels of government seem interested in tackling this problem. Now is the time that HIV-positive people should be looking for support to be included in prevention planning, for our own benefit and the benefit of all those who are not yet infected. ⊕



Carl Bogner is a freelance researcher interested in HIV and community-based research.