

HIV Testing and Access to Care: The Experience of Canadian Aboriginal Youth



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Background

HIV is a serious concern for the Canadian Aboriginal population since they are over-represented in Canada's HIV epidemic

Aboriginal peoples represent 3.3% of the Canadian population and yet comprised approximately 200 to 400 (9%) of the estimated total of 2,300 to 4,500 new HIV infections in Canada in 2005. Therefore, the overall infection rate among Aboriginal persons in 2005 was about 2.8 times higher than among non-Aboriginal persons. In addition, the proportion of new HIV infections in 2005 due to injecting drug use (IDU) among Aboriginal Canadians (53%) was much higher than among all Canadians (14%), highlighting the unique aspects of the epidemic in this group. HIV infection has the potential to have a profound impact on Aboriginal youth. Approximately two-thirds of the Canadian Aboriginal population is under the age of 30 and younger people often perceive that they are less vulnerable to HIV infection.

In Canada, Aboriginal persons appear to be infected with HIV at a younger age than non-Aboriginal persons: 21.7% of new positive HIV test reports among Aboriginal persons were in people under the age of 30 years compared with 16% among non-Aboriginal persons. Little is known about the access of Canadian Aboriginal people to HIV testing and care, but many Aboriginal people face significant barriers due to the remoteness of communities, confidentiality concerns, and feelings of discomfort accessing mainstream health services.

Objectives and Methods

In a sample of Aboriginal youth in Canada:

- Describe testing behaviour
- Explore self-reported stage of disease at the time of HIV diagnosis
- Evaluate access to care

An exploratory, community-based research design was used for this study involving a self-administered questionnaire with a purposive sample of 413 youth and an in-depth, open-ended interview with 28 youth (a few youth participated in both). Youth were defined in this study as persons between 15 and 30 years of age. Participants were recruited with assistance provided by 10 agencies from across Canada that provide services to Aboriginal persons living off reserve, including Aboriginal and non-Aboriginal AIDS service organizations, health centres, community organizations and friendship centres. Organizations were selected so that the sample would include both Aboriginal youth who had tested and had not tested for HIV as well as both HIV-positive and HIV-negative youth.

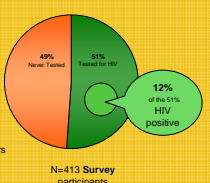
Although the resulting sample was not representative of the Aboriginal youth population in Canada, important information about HIV testing and access to care among Aboriginal youth was obtained due to the diversity of participants. Respondents and recruitment agencies were provided with reimbursement to cover expenses related to study participation. All questionnaire responses were coded and entered into SPSS®; interview data were audio recorded, transcribed, entered into QSR®N6® and then coded to identify major themes. This study had significant community involvement and support, and was guided by the principles of Ownership, Control, Access and Possession (OCAP) of research information by Aboriginal communities themselves.

Results

Testing associations and stage of disease at time of diagnosis

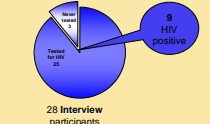
Of the 413 youth completing questionnaires, 210 (51%) had ever been tested for HIV and 26 of these youth (12.4%) reported being HIV-positive. It should be noted that neither of these percentages is representative of Aboriginal youth in general and both are likely too high since many of the recruiting agencies provided HIV testing services and/or services for HIV-positive persons.

The youth who had been tested for HIV were more likely to report risk factors for HIV infection. For example, compared to those not tested for HIV, testers were more likely to report a previous diagnosis of a sexually transmitted infection (47% vs 12%) or a history of injecting drug use (21% vs 5%).



Of the 26 youth who reported being HIV-positive, eight (31%) had symptoms related to HIV/AIDS at the time of HIV diagnosis, including six (23%) who had AIDS.

Of the 28 youth who participated in open-ended interviews, 25 had tested for HIV and 9 reported that they were HIV-positive. Two participants had symptoms of HIV at diagnosis.



Some dominant themes emerged from the interviews that may account for why some Aboriginal youth decide to test while others do not, and of those who do test, why some test late in the course of disease.

A number of interview participants reported that some youth think that it can't happen to me despite knowledge of HIV and despite participation in high risk behaviours such as unsafe sex and sex. Other youth reported that fear of the unknown contributed to their delay in testing for HIV while still others reported that knowing their HIV status was not a priority in their lives when compared to the considerable social, economic, and emotional challenges they face on a day-to-day basis.

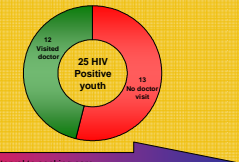
But at the same time, you're like "Oh, you know...he seems like an okay guy or an okay girl...Doesn't seem to take drugs...Basically, I think it's like mental blocks, where people say, "no, no, it can't happen to me." (First Nations, female, 20 years old)

If you're not familiar with something, you're going to be afraid of it, right? You're going to be scared of doing something like that. That's why I procrastinated on getting HIV testing done, I had to get me pregnant in order to get my HIV test done. (First Nations, female, 26 years old)

I guess I was pretty sure that I had it...because I used needles and a lot of times I just didn't care. I would use a used needle and I just didn't care...Another thing too was I was having night sweats...and I knew that was a symptom of having HIV. (First Nations, male, 30 years old)

Accessing care

Of the 26 youth in our survey sample who reported being HIV-positive, further information on access to care was available for 25 youth. Of these, 12 (48%) had visited a doctor after HIV diagnosis and of the 10 who provided information on when they saw a doctor, 8 (80%) had done so within one year of diagnosis.



Therefore, in this limited sample, only 38% (80% of 48%) of Aboriginal youth who had a positive HIV test were assessed for care by a doctor within one year of their diagnosis.

Of the 9 participants in the open-ended interviews who had tested positive, the length of time between initial diagnosis and seeking care for their HIV varied dramatically. While some sought care within a few months of diagnosis, others waited up to 7 years.

One participant who tested positive in prison was offered medical care immediately, while another participant who was pregnant at the time of diagnosis was given little information and had to actively seek medical attention for herself and her baby.

Other participants took longer to access care and only after they had symptoms of HIV illness. One participant reported that he first received medical attention when he was admitted to hospital with pneumonia approximately 1 year following his HIV diagnosis:

When I was diagnosed, the doctor where I'm from just said, "Ok, you're positive"...and that's all there is. I had to tell him that I'm pregnant, that I should be on meds. I was the one who told him that my baby needs meds to reduce the risks. It's like, "You should phone [provincial AIDS organization] or somebody and talk to them." He did, and they got hold of an infectious disease clinic and that's where they sent me to go get my meds. But it took about 3 weeks before I could get over there after I found out I was diagnosed. Three weeks to a month. (First Nations, female, 24 years old)

How I got my meds was I was in the hospital with pneumonia. I was also...I was junkie right? I was a heroin addict. One of the doctors...comes in, and he's a methadone doctor, and he got me on methadone. For me, going to the clinic to get my methadone script...they [also] helped me out with my HIV. It was about a year after my diagnosis. (First Nations, male, 30 years old)

When I finally did test positive, it was really hard for me...I was in a daze for quite a while. I started drinking more. I didn't want to be sober because I didn't want to think about my disease, and I didn't want to think about dying and the whole AIDS thing. (First Nations, female, 24 years old)

Of those who delayed care seeking, reasons provided included being scared, not wanting to know their stage of disease, being preoccupied with drugs or alcohol and not wanting to live.

[After my diagnosis] I was on a down low...I wasn't seeing doctors and stuff like that. I was really in a bad situation. I was doing lots of drugs and stuff like that. I didn't know anything about care. (First Nations, female, 30 years old)

I didn't really want to go see [a doctor] because I didn't want to know my results or my counts or none of those things. Because when you get your counts and your viral load, it lets you know where you stand. So I was sort of hesitant and scared at the beginning that I didn't want to go get them. (First Nations, male, 27 years old)

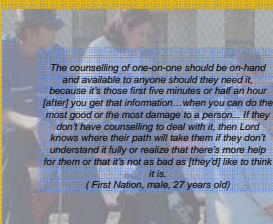
I can't really say I [sought care for my HIV] on my own...I told my sister I was pregnant and she was just excited...Then she told me that I had to quit my drinking and drugging and that if she ever caught me drinking or anything that she would take my baby away on me...So that's what I did, I quit drinking and drugging and they sent me to a specialist. (First Nations, female, 24 years old)

After talking to a lot of my friends who are HIV positive and had been through this, they said, "It's not only for your good, it's just for...it's a peace of mind that you know where you stand on the scale of HIV"...So after enough friends coaxed me into it...one friend said, "I'll come with you to the doctor's for the first visit if that's what you'd like." [So] he came with me [and we] handled it. (First Nations, male, 27 years old)

For several participants, the support they received from family and friends was an important element in making the decision to seek care.

Recommendations from youth participants*

When asked what recommendations they had to improve access to and use of HIV testing and care services, participants spoke of street outreach and non-judgmental post-test counselling as an effective means to accomplish this goal.



The counselling of one-on-one should be on-hand and available to anyone should they need it, because it's those first five minutes or half an hour [after] you get that information...when you can do the most good or the most damage to a person...If they don't have counselling to deal with it, then Lord knows where their path will take them if they don't understand it fully or realize that there's more help for them or that it's not as bad as [they'd] like to think it is. (First Nation, male, 27 years old)

Another thing about...drug addicts, they will neglect their health right? They could be really, really sick and they won't care. So it's really about the people who are either the nurses or the clinics around here going out to people. It's not about them waiting for people to come, they have to actually go get these people. (First Nations, male, 27 years old)

Conclusions

This exploratory study suggests that a considerable proportion of HIV diagnoses among Aboriginal youth are made late in the course of disease. In addition, once diagnosed, only about one-third are assessed for medical care within the following year. To address these issues and take better advantage of HIV prevention counselling and new treatment options, HIV testing and care services need to be made more relevant and available for Aboriginal youth.

Recommendations made by participants (such as increasing outreach) should be considered as a way to improve access to and use of these services and to help address the serious issue of HIV/AIDS among Aboriginal youth in Canada.



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* Photos representative only, not actual participants. Used with permission from a Canadian First Nation youth council.