

“AIDS IS SOMETHING SCARY”: CANADIAN ABORIGINAL YOUTH AND HIV TESTING¹

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ABSTRACT

The purpose of the current study was to explore the HIV testing behaviours of Canadian Aboriginal youth, who have an increased vulnerability to HIV infection. In our mixed method study, 28 Aboriginal youth participated in an in-depth, semi-structured interview and 413 youth from all ten provinces and one territory completed a cross-sectional, self-administered, survey. Slightly more than half of the surveyed youth (50.8%) and almost all of the interviewed youth (89.2%) reported ever having an HIV test. A significant proportion of the youth believed that they did not need an HIV test because they were at low risk for HIV, had never had sex with an infected person, or felt healthy. Female participants with a history of pregnancy were more likely to have had an HIV test. A significant number of participants

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viewed AIDS as a scary disease associated with a death sentence. These findings are relevant to the planning and implementation of youth HIV testing services, as part of comprehensive HIV and STI prevention programs.

Key words: HIV testing; youth; Canada; HIV prevention; mixed method

In Canada, Aboriginal (First Nation, Métis, and Inuit) persons are infected with HIV at a younger age, and at a higher rate than non-Aboriginal persons (Public Health Agency of Canada [PHAC], 2010). In a recent review of the sexual health of Canadian adolescents, Maticka-Tyndale (2008) reported that Canadian Aboriginal youth experience a higher burden of poor sexual health. Aboriginal youth are more likely to practice inconsistent condom use (Canadian Federation of Sexual Health [CFSH], 2007; Ontario Federation of Indian Friendship Centres [OFIFC], 2002; Calzavara et al., 1998b) and experience high rates of teenage pregnancy, (OFIFC, 2002), sexual abuse (Devries et al., 2009; Mehrabadi et al., 2008b), and sexually transmitted infections (STIs) (CFSH, 2007; Shields et al., 2004). Female Aboriginal youth may be more vulnerable to HIV infection than their male counterparts due to higher rates of sexual abuse and unsafe sex (Mehrabadi, et al, 2008). These factors, in combination with feelings of invulnerability common in youth generally (PHAC, 2007), suggest that Aboriginal youth may have an increased vulnerability to HIV infection.

Several studies have examined why youth access HIV testing and why they do not. In a study of 278 minority American youth, a low perception of risk or not feeling sick (54.1%) and never having been offered a test (62.8%) were common reasons for not accessing HIV testing and services (Peralta et al., 2007). For these youth, the availability of oral, rapid, and free HIV testing services, provided in a confidential environment, were considered motivators to access HIV testing. Similarly, Lapidus and colleagues (2006) reported that almost half of the American Indians and Alaskan Natives in their study underestimated their personal risk of HIV infection, despite reporting high-risk or potentially high-risk behaviours. Moyer et al. (2007) reported that a significant number of American youth engaged in behaviours that placed them at risk of HIV infection; however, they often did not access HIV testing and counseling. Furthermore, Moyer and colleagues reported that 49% of females in their study population and 42% of males did not think that they were engaged in any "high risk" activities.

In a recent Canadian study, Wardman and colleagues (2006) reported that 60.4% of their Aboriginal study participants had undergone HIV test-

ing. Participants were more likely to have received an HIV test if they were: 20–29 years of age; female; lived off reserve; had a sexually transmitted infection (STI); used drugs; were two-spirited; or had higher HIV risk factors (e.g., using cocaine, not using clean needles). Nguyen and colleagues (2000) reported that Aboriginal youth accessed HIV testing as much or more than the general population. Research with a prison population, on the other hand, found that Aboriginal inmates were less likely to have had an HIV test and more likely to state that they did not know where to access an HIV test than non-Aboriginal inmates (Calzavara et al., 1998a). Research exploring the timing of HIV and AIDS diagnosis, and survival rates following a diagnosis with AIDS, suggests that Aboriginal persons may be reticent to access HIV testing. Based on an analysis of AIDS cases, Stokes and colleagues (2006) reported that Aboriginal persons were significantly more likely to have a late diagnosis of their HIV infection. Similarly, Goldstone and colleagues (2000) reported that First Nations individuals with AIDS became ill earlier, had shorter survival times and more hospital admissions than non-First Nations individuals.

Views toward health and illness are relevant to the understanding of attitudes toward HIV testing among Aboriginal youth. The belief that a “disease must be felt” before seeking treatment was documented during a research project in northern Alberta (Morse et al., 1991, p. 1362), and more recently in a study of the experience of Aboriginal HIV positive women (Mill, 2000). Also within the context of Aboriginal healing traditions, serious illness was viewed as “a penalty for a prior transgression of the moral order” (Waldram et al., 2006, p. 130) and confession of this transgression was part of the treatment process. A large survey to document the knowledge and attitudes of First Nations individuals toward AIDS found that many participants perceived AIDS as a “white gay-male disease” and a large proportion did not feel that they were at risk for HIV infection (Myers et al., 1993, p. 59). These views and beliefs may result in some Aboriginal people being less likely to request an HIV test, or, if positive, reluctant to initiate treatment, when they otherwise feel healthy.

Aboriginal youth may be particularly vulnerable to HIV. In Canada, the Aboriginal population has experienced a long history of marginalization, racism, colonization, and disenfranchisement (Adelson, 2005; King et al., 2009; Haskell and Randall, 2009; Larkin et al., 2007; Pearce et al., 2008). Pearce and colleagues (2008) argue that risky sexual behaviours, past sexual abuse, and the elevated risk of HIV infection in Canadian Aboriginal youth must be situated within the context of colonization, historical, and inter-

generational trauma. Therefore, it is important to understand the factors that influence Aboriginal youths' decisions to access HIV testing, and subsequently if positive, to access care. HIV testing is a critical component of comprehensive HIV prevention programs for youth. The purpose of the current study was to explore the testing behaviours of Canadian Aboriginal youth, and here we present findings related to the decision to test. Additional findings from the study have been reported elsewhere (Mill et al., 2008b; Worthington et al., 2010).

DESIGN AND METHODS

An exploratory mixed method design, using a cross sectional, self-administered survey and in-depth interviews to collect the data, was used for this study (Mill et al., 2008b). Between January 2004 and February 2005, participants were recruited at nine sites in seven provinces and one territory across Canada. Eleven community-based organizations, including Aboriginal health and friendship centres and AIDS service organizations (ASOs), assisted with participant recruitment. Eligibility criteria for the study included: being Aboriginal; living in an urban or rural community; being between 15 and 30 years of age; and speaking English or French. The term Aboriginal was defined as an individual who self-identified as First Nations, Métis, or Inuit. In Canada, First Nations (FN) refers to persons of Indian origin who were the first occupants of the land (Wotherspoon and Satzewich, 1993). *Status* First Nation peoples are registered with the federal government under the Indian Act; *nonstatus* First Nation peoples are not registered with the federal government.

To achieve our goal of exploring and describing Aboriginal youth experiences of HIV testing and care we used a community-based research (CBR), collaborative approach throughout the study. Fundamental underpinnings of community-based approaches are: recognition of local knowledge systems and multiple perspectives of viewing the world; collaboration with participants and communities involved in the research; and commitment to act on the problems identified by the research (Cornwall and Jewkes, 1995; Fletcher, 2003; Flicker et al., 2008). In addition to adhering to these protocols, we also incorporated community Ownership, Control, Access and Possession (OCAP) principles for research involving Aboriginal communities (Patterson et al., 2006) in the study. Ethical and cultural considerations were addressed through appropriate institutional and governmental approvals at project locations across Canada. Ethics committees at the Universities

of Alberta, Calgary, Toronto, and Health Canada and the Aurora Research Institute in the Northwest Territories approved the research project.

To honour OCAP principles, a community advisory committee (CAC) was formed at the outset of the project to provide the research team with guidance on the research design, data analysis, and the interpretation and dissemination of the findings. The CAC advised recruiting youth up to the age of 30 years based on their collective experiences with HIV in Aboriginal communities, and helped to ensure that the research was congruent with the Canadian Institutes for Health Research (CIHR) *Guidelines for Health Research Involving Aboriginal People* (CIHR, 2007). Following an extensive review of the literature, a self-administered survey was developed to explore HIV testing and care in Aboriginal youth. The survey was pretested by members of the CAC to enhance face and content validity, and translated into French. The survey was further refined following pilot testing with two groups of youth (total $n=19$), one English speaking and one French speaking. A training session was held with representatives from participating organizations to ensure that the survey and interview methods were applied consistently. Convenience and network sampling (Wood and Ross-Kerr, 2006) were used by the organizations to recruit youth to complete a survey or participate in an interview. Two research project coordinators (one for eastern Canada and one for western Canada) ensured free and informed consent from participants. A small token of appreciation was provided to each participant and compensation for staff time was provided to participating organizations.

For the quantitative data analysis, SPSS 11.5 statistical software program (Chicago, IL) was used. Bivariate analyses involving categorical variables were performed using Chi-square and Fisher's Exact tests. Variables with $p<0.1$ in bivariate analysis were entered into the multivariate logistic regression model to control for confounders. An association was considered statistically significant when the 2-sided p value was <0.05 .

An inductive process was used to carry out a thematic analysis of the qualitative data (Miles and Huberman, 1994) to develop a coding framework. Three members of the research team, including the principal investigator, one of the co-investigators, and the project coordinator, all with extensive experience in qualitative analysis, developed the coding framework. The framework was based on the reading and discussion of three interviews to develop consensus on the emerging themes. The team members agreed on descriptive labels for particular segments of data and then all subsequent interviews were analyzed and coded according to these themes. The quali-

tative analysis was assisted by the use of the qualitative software program QSR*[®]N6 to label, revise, and retrieve codes.

FINDINGS

Youth residing in all ten provinces and one territory contributed to the data set of 28 Aboriginal youth, who participated in an in-depth, semistructured interview, and 413 youth, who completed the survey. Participants were recruited from nine sites across Canada, with sites purposively selected to ensure an overrepresentation of Inuit youth² (see Table 1). Approximately half (50.8%) of the survey participants and almost all (89.2%) of the interview participants had received an HIV test. All interview quotations presented have been assigned pseudonyms.

Table 1: Characteristics of Participants

<i>Variable</i>	<i>Survey</i>	<i>Interview</i>
Sample size	413	28
Age in years(Mean)		
Survey respondents range 15–30 years	21.5	
Interview participants range 16–30 years		24.4
Residence		
Urban (over 10,000 population)	64.4	
Rural (less than 10,000 population)	35.6	
Characteristics reported in	%	%
Gender		
Male	47.0	42.9
Female	52.8	57.1
Transgender	0.2	0.0
Aboriginal background		
First Nations Status	56.2	89.2
First Nations Non Status	6.8	0.0
Métis	20.8	<1.0
Inuit	10.7	<1.0
Inuvait	2.2	0.0
Other	1.7	0.0
Not reported	1.6	0.0
HIV testing		
Ever tested for HIV	50.8	89.3
Tested positive (among those tested)	12.4	36.0

CHARACTERISTICS OF HIV TESTERS AND NONTESTERS

In bivariate analysis, a number of sociodemographic and behavioural factors were associated with a history of HIV testing (Table 2). After controlling for potential confounders in multivariate analysis, Aboriginal youth were *more likely* to have been tested for HIV if they were older (adj. OR 5.0, 95% CI=2.5-10.0), First Nations (adj. OR 2.8, 95% CI=1.4-5.4), living outside of

2. The proportion of Aboriginal peoples who identify as Inuit is only 4% (Statistics Canada, 2006 Census) and therefore it was necessary to oversample Inuit youth.

an Aboriginal community (adj. OR 2.5, 95% CI=1.3-5.0), receiving financial support from welfare (adj. OR 3.6, 95% CI=1.7-7.6), having a history of STIs (adj. OR 3.4, 95% CI=1.7-6.8), and, in the case of females, a history of pregnancy (adj. OR 7.5, 95% CI=3.7-15.2) (Table 3).

Table 2. Characteristics* of Aboriginal Youth without vs. with a History of HIV Testing – Bivariate analysis

Characteristics	Never had HIV Test (n=203) Frequency (%)	Ever had HIV test (n=210) Frequency (%)	P-value	OR	(95% CI)
Age 15-19 years**	117/201 (58.2)	40/208 (19.2)	<0.001	5.9	(3.7-9.4)
French as first spoken language	7/203 (3.4)	25/210 (11.9)	0.001	0.3	(0.1-0.7)
Male	115/203 (56.7)	79/210 (37.6)	<0.001	2.2	(1.4-3.3)
Heterosexual	188/201 (93.5)	162/209 (77.5)	<0.001	4.2	(2.1-8.5)
Single	160/201 (79.0)	126/207 (60.9)	<0.001	2.5	(1.6-0)
Student currently	108/202 (53.5)	64/209 (30.0)	<0.001	2.6	(1.7-4.0)
Follow traditional Aboriginal practices	73/200 (36.5)	98/204 (48.0)	0.02	0.6	(0.4-0.9)
First Nations***	110/202 (54.5)	153/205 (74.6)	<0.001	0.4	(0.3-0.6)
Living in First Nations, Métis or Inuit community	75/201 (37.3)	47/208 (22.6)	0.001	2.0	(1.3-3.2)
Living in a city with more than 10,000 people	109/200 (54.5)	157/207 (75.8)	<0.001	0.4	(0.2-0.6)
Living at home of parent(s)	94/200 (47.0)	34/209 (16.3)	<0.001	4.6	(2.8-7.4)
Income from job	89/203 (43.8)	65/209 (31.1)	0.008	1.7	(1.1-2.6)
Income from welfare	34/203 (16.7)	88/209 (42.1)	<0.001	0.3	(0.2-0.5)
Financial support by parents	26/203 (12.8)	9/209 (4.3)	0.002	3.3	(1.4-7.7)
Income from street	18/203 (8.9)	36/209 (17.2)	0.01	0.5	(0.2-0.9)
Ever had an STI other than HIV	25/201 (12.4)	99/208 (47.6)	<0.001	0.2	(0.1-0.3)
Oral sex in past 6 months	117/198 (59.1)	145/207 (70.0)	0.02	0.6	(0.4-1.0)
Anal sex in past 6 months	29/198 (14.6)	52/206 (25.2)	0.008	0.5	(0.3-0.9)
Always using condoms with anal sex in past 6 months	13/29 (44.8)	10/50 (20)	0.02	3.3	(1.1-10.1)
Injection drug use (IDU) in past 6 months	10/199 (5.0)	44/208 (21.2)	<0.001	0.2	(0.1-0.4)
Ever been pregnant (females)	31/86 (36.0)	103/130 (79.2)	<0.001	0.2	(0.1-0.3)

*OR = Odds Ratio, Only characteristics that are statistically different at $p < 0.05$ are shown

** Comparison of younger youth (age 15-9 years) vs. older youth (age 20-30 years)

*** Compared to other Aboriginal groups (Métis, Inuit, and other)

Table 3. Predictors of Past HIV Testing in Aboriginal Youth: Multivariate Analysis*

Characteristics	Adjusted OR	95% Confidence Interval
Age 15 to 19 years	0.2	0.1-0.4
Age 20 to 30 years	ref	
First Nations	2.8	1.4-5.4
Métis/Inuit/Other Aboriginal youth	ref	
Living in First Nations, Métis or Inuit community	0.4	0.2-0.8
Living outside of these communities	ref	
Income from welfare	3.6	1.7-7.6
Income from other sources	ref	
Ever had STI other than HIV	3.4	1.7-6.8
Never had STI other than HIV	ref	
Ever been pregnant (female)	7.5	3.7-15.2
Never been pregnant	ref	

* Controlling for gender, mother tongue, Aboriginal practices, marital status, living arrangements, sexual practices, recent injection drug use

FACTORS INFLUENCING HIV TESTING DECISIONS

Surveyed youth were asked about factors that would influence their taking an HIV test (see Table 4). Approximately one quarter of the youth (25.3%) would be deterred from taking an HIV test if the health worker arranging for the HIV test was from the same home community. Most participants (53%) agreed that a doctor or a nurse (46.8%) would favourably influence their acceptance of an HIV test. The most common reasons for HIV testing given by those surveyed included: having sex without a condom (43.6%); being pregnant or thinking they were (35.4%); being part of regular screening (28.9%); feeling at high risk for HIV infection (27.5%); being in a new relationship (23.7%); and as part of screening for STDs (20.9%).

Table 4. Health Worker Influence on Getting HIV Testing

Characteristic: "I would have an HIV test if..."	Strongly Agree/ Agree	Neutral	Strongly Disagree/ Disagree
	Frequency (%)*		
I knew the health worker (n=400)	152 (38.0)	199 (49.8)	49 (12.2)
The health worker was from the same cultural background (n=399)	130 (32.6)	230 (57.6)	39 (9.8)
The health worker was a doctor (n=400)	212 (53.0)	173 (43.3)	15 (3.8)
The health worker was a nurse (n=400)	187 (46.8)	187 (46.8)	26 (6.5)
The health worker was of the same sex (n=394)	140 (35.5)	214 (54.3)	40 (10.2)
The health worker was from my home community (n=400)	76 (19.0)	223 (55.8)	101 (25.3)
The health worker was close to my age (n=397)	81 (20.4)	262 (66.0)	54 (13.6)

*Excludes missing values

SEXUAL ATTITUDES AND BEHAVIOUR

Aboriginal youths' attitudes to sexuality, including feeling invulnerable to HIV and AIDS appeared to influence their decision to test. Among surveyed youth who had not been tested for HIV (49.2%), the most common reasons were: feeling at low risk for HIV/AIDS (45.3%); never having sex with an infected person (34.5%); always having safe sex (33.3%); never sharing needles (26.1%); doctor or nurse didn't recommend (26.1%); and feeling healthy (25.6%).

Similarly, interview participants mentioned that youth, and in particular Aboriginal youth, often had a feeling of invulnerability in relation to HIV risk:

Aboriginals have a feeling that they can walk on water without getting hurt, you know, play with fire without getting hurt. So to change the AIDS thing, would have to change the mentality, that's what I think. (Carl, FN, Male)

A few of the youth interviewed recalled feeling invulnerable in relation to their own risk of HIV:

Yeah, because, I don't know, it just didn't seem like it could happen to me, you know. But I guess it can happen to anybody. (Zinn, FN, Female)

Well, I mean, you learn it in school, right, so — well, the schools that I went to, anyway. You learn it there, plus the drop-ins that I would go to, you learn it from there, too; like, the counselors there, too. So I knew it was risky, but at the time, I didn't care; I was just young and stupid. (Beth, FN, Female)

The feeling of invulnerability to HIV also may influence youths' decisions to use condoms. When asked about their sexual experiences, most survey participants did not consistently use a condom (see Table 5). Interview participants commented on their view and use of condoms. For example, Oliver recalled receiving advice from his father to use condoms; however, he had only used them on a few occasions:

He told me to wrap up. [laughs] That's all he told me about it.... I've done it twice. I've only wore condoms twice. I don't know why. I just [pause] I don't know why. [laughs] Can't explain to you why. I'm not sure. (Oliver, FN, Male)

Melanie had found that some men did not like using condoms; however, she insisted that they use one with her:

Plus you might have some people, like some guys really, they're, like, "Oh, I don't like wearing condoms." They don't like the feel.... (Melanie, FN, Female)

A few of the participants believed that different types of sexual identity (e.g. gay, lesbian, two-spirited) were not well tolerated on-reserves. Rachel had found it easier to live in a larger city as a two-spirited woman:

I suppose the other reason why, too, I like the city is because it's [being two-spirited] more accepted out here, as opposed to a small city or a small rez. That's some of the reason why I, too, am scared to go back home and visit with my family.... (Rachel, FN, Female)

Similarly, Sam had left his reserve at the age of 19 because he was tired of "living a lie" in relation to his sexual orientation:

I came when I was 19. I left [eastern Canadian city] and the reservation up north. Tried [eastern Canadian city #2] for a year and that didn't work out too well. Got tired of living a lie and two different lives all the time to my family on the phone and to what actually who I was and what I was going through.... (Sam, FN, Male)

Table 5. Frequency of non use of condoms (did you use a condom for....)

<i>Past six months had</i>	<i>Frequency (%)</i>		<i>Did not consistently use a condom*</i>	
Vaginal sex	320/406	78.8%	218/305	71.5%
Oral sex	262/405	64.7%	215/245	87.8%
Anal sex	81/404	20.0%	56/79	70.9%
Used injection drugs	54/407	13.3%	45/50	90.0%
Had an STI	124/409	30.3%	-	-

*Defined as never, rarely, or sometimes

IMPACT OF SEXUAL ABUSE

Two of the young women related their current sexual behaviour to the sexual abuse that they had endured as a young girl. Zelda believed that youth were becoming sexually active at an earlier age and related her early sexual initiation to the sexual abuse she had experienced:

I started sex at an early age; I started at 11 years old living with my common-law.... Then by 13, I was a prostitute in the street. So kids aren't usually 15 when they have sex; they're starting to have sex at a younger age. It's for the bars and that. For me, I went through sex and stuff, like, through sexual abuse, you know, and it just made me more curious and wanting to fit in with other people, so that's why I chose to do that. (Zelda, FN, Female)

Similarly, Kayla related her current sexual behaviour to her abuse as a young child:

I had depression, and I was trying to recall [memories of] being sexually abused, 'cause my sexual history now and hers is pretty similar to mine, but she is very high risk behaviour.... If you don't care about yourself, you're going to sleep around without condoms. You will. I try really hard when I have a new partner to use condoms, but when I'm drunk, [sighs] I'll sleep with him, and then I'll black out, and then I won't remember. (Kayla, Inuit, Female)

Kayla went on to relate the sexual abuse and other social problems that Aboriginal individuals and communities were experiencing to residential schools. She believed that the social problems resulting from residential schools were affecting the choices that youth make:

How residential school has fd [us]up in the head.... My mom, for being abused by her mom. It's hard. We've got more problems than white people, and we're not coping and dealing with things. We've only maybe [had] the last hundred years to get used to everything that's happened, and we're still — we're losing our language and our culture, our self-respect, our —. So we're [all] lost.... They [youth] don't feel like anyone cares or loves them, because they're seeing abuse — drug, alcohol abuse at home, verbal abuse. (Kayla, Inuit, Female)

Sexual abuse has been associated with behaviours that place Aboriginal women at higher risk of transmission of diseases such as HIV (Mill, 1997; Mehrabadi et. al., 2008b).

AIDS IS A “SCARY” DISEASE: AVOIDING AN HIV TEST

The interviewed youth provided insights about why youth might not test for HIV. AIDS was still seen as a “death sentence” for some while many participants still found AIDS to be a “scary” disease. About 25 % of the interview participants mentioned that they still associated HIV and AIDS with a death sentence. For example, when asked about the differences between HIV and hepatitis C, Sara shared her thoughts:

There's a very big difference there. Hep C, I make the decision as to whether I let the disease kill me or not ... once it (HIV) changes into the actual virus, you catch a cold, and you die. I mean, that sucks. I don't even have that great of an immune system, as it is.... Doesn't matter what anybody tells me, that's still a horrible disease. Seventy-five percent of the people who get it die from it. Doesn't matter what anybody says, that's a scary thought. (Sara, Métis, Female)

Zinn had been for an HIV test and was negative but she believed that receiving the results of a positive HIV test was the worst thing that could happen to someone:

Oh, God, it's probably the worst thing you could ever hear — depending on if you care or not.... If it was someone who is really careful and stuff and made a mistake and they got it, I'm sure it would be like the end of the world, like a wall would come crashing down. (Zinn, FN, Female)

Many of the participants stated that they still found AIDS to be a “scary” disease:

I think people should just go regularly, just go and get it as part of the check-up, because it is a dangerous disease, and it is scary.... (Beth, FN, Female)

Me, I'm scared, and I'm going to — soon, I'm planning on going and testing myself, making another test, because AIDS is something scary, and that ruins a lot of lives. (Hazel, FN, Female)

Irene also believed that Aboriginal health and healing beliefs influenced the decision to test:

I clearly think that it's a transition between their [pause] I'll call it their natural life, their natural-born life, their Aboriginal culture here, their Inuvialuit culture, into what it is that the 'Whities,' as they call it, have come in and shown them.... I

think they're kind of caught in the middle of just really not knowing what to be at, to be perfectly honest. (Irene, FN, Female)

Several of the surveyed youth also described *emotional* factors that had influenced their decision not to test. Participants “worried about being discriminated against” (13.3%), and were “afraid that someone would find out” (10.8%). Eleven (10.8%) percent of youth responded that “if I tested positive, nothing can be done.”

HIV TESTING AND PREGNANCY

The findings from the current study suggest a relationship between HIV testing and pregnancy. Over two-thirds of all respondents (68.1%) felt that HIV testing during pregnancy was a good idea, with another quarter (24.9%) undecided. Fewer females (16.2%) than males (34.6%) were undecided. Among female youth surveyed, 61.5% had been pregnant at least once. Of those, only 60.4% had received HIV testing during pregnancy and 6.0% did not know if they were tested during pregnancy. Among youth with a history of pregnancy, 83.5% thought that it is a good idea to have an HIV test during pregnancy and 83.6% would want an HIV test if they were pregnant in the future.

Several of the interview participants also felt that it was very important to have an HIV test before becoming pregnant and felt quite strongly that if a woman was HIV positive she should not have children. A few of the participants believed that an HIV positive mother would always pass the virus to her child and believed HIV positive women should not have children:

Plus, let's say the person wants to have a kid, that would be a really good reason to go out yourself and do the exam, not wait to be pregnant and they do the test for you because they have to. It's better if you go and do it, because I think having a kid with AIDS, it's almost killing a kid. That should be illegal. (Hazel, FN, Female)

No. I wouldn't have children if I have AIDS. I wouldn't. I'd probably kill myself, to be honest with you. That's not something that I'm willing to live with.... (Sara, Métis, Female)

Two young women, on the other hand, had given birth to children who were negative since becoming HIV positive themselves. Yvonne had been HIV positive for 6 years and was very proud to have given birth to four beautiful children after she had received her diagnosis:

But now, I totally regret the choices that I made, because I'm — I can't really say that I totally regret, because since I became HIV positive, there's been a lot of good

things in my life, one being — well, mostly being my children. Because I've got four beautiful children that are HIV negative, and they're happy. (Yvonne, FN, Female)

Edward was very pleased that he had fathered a healthy baby six months before receiving his HIV positive diagnosis. He believed that if he died, he would leave part of himself in his son:

So I like every time I say, 'Thank you, God,' because you give a beautiful gift. I got a son. Six months before I [became] HIV [positive], I make a son.... And me, if I'm going to die, I've got a part of my body there. That's why I'm every time happy. (Edward, FN, Male)

DISCUSSION

Due to the paucity of research on the experiences of Canadian Aboriginal youth and HIV testing, the findings from the current study have been considered in the context of youth in general and the Aboriginal population more broadly. The finding that a significant proportion of the youth believed that they did not need to be tested because they were at low risk for HIV, had never had sex with an infected person, felt “healthy” or could “walk on water without getting hurt” is of concern. The perception that HIV testing is not necessary for individuals without symptoms of AIDS has been reported among South African (MacPhail et al., 2008) and American (Peralta et al. 2007) youth. Research to assess the influence of risk perception on HIV testing is inconsistent. Among rural Aboriginal Canadians, participants who were at risk for HIV were more likely to be tested for HIV (Wardman et al., 2006). The authors suggest that this may reflect the impact of targeted, culturally sensitive HIV prevention. Moyer and colleagues (2007), on the other hand, reported that American youth with the highest level of unsafe behaviours were less likely to have had an HIV test due to concern about receiving a positive result.

In the current study, a history of pregnancy was associated with being more likely to have had an HIV test. The relationship between HIV testing and pregnancy has been reported previously. A cross-sectional study of American detained youth (Voisin et al., 2004) reported that HIV testing was more prevalent among participants who had ever been pregnant or caused a pregnancy. Similarly, a study of HIV testing in adult American women (Bond et al., 2005) reported that women who had given birth recently were five times more likely to have had an HIV test than women who had not.

It is interesting that despite the availability and effectiveness of highly active antiretroviral treatment (HAART) for HIV infection, a significant num-

ber of participants still viewed AIDS as a scary disease, associated AIDS with a “death sentence,” or believed that if they tested positive, nothing could be done. These factors may operate in combination with feelings of invulnerability as barriers to HIV testing in youth. The association of AIDS with death and the fear of AIDS as a disease has been previously reported in both Aboriginal (Mill et al., 2008a) and non-Aboriginal populations (MacPhail et al., 2008).

In the current study, 25% of the surveyed youth stated that they would be deterred from HIV testing if the health worker was from their home community. This may be related to concerns about a breach in the confidentiality of their test results. About half of the participants mentioned that they could be encouraged to have an HIV test by a doctor or a nurse. Several authors have examined the barriers and facilitators to HIV testing generally (Bond et al., 2005; Worthington and Myers, 2002; 2003) and for youth specifically (Peralta et al., 2007). The importance of the relationship with the health care provider as a facilitator of testing for HIV (Worthington and Myers, 2002; 2003) and STI (Goldenberg et al., 2008) has been documented previously. In a recent study (Goldenberg et al., 2008) Canadian youth cited negative interactions with service providers as a barrier to STI testing. Worthington and Myers (2002; 2003) explored HIV test recipients’ perspectives of testing services and reported that the demeanor of the test provider and the sense of power (or lack of it) between the test provider and the test recipient were factors that contributed to feelings of anxiety in the HIV test experience. Key aspects in demeanor of the test provider that contributed to a positive test experience were personal warmth and a non-judgmental, respectful approach toward the test recipient (Worthington and Myers, 2002).

In the current study, Métis and Inuit youth were less likely than First Nations youth to have been tested for HIV. This finding must be interpreted cautiously. The sample size does not allow many meaningful comparisons between the different Aboriginal subgroups. Inuit youth were oversampled to compensate for their small proportion in the overall Canadian Aboriginal population. HIV testing history and experiences were self-reported retrospectively by participants and therefore recall bias might have influenced the findings. Finally, our sample was primarily urban and the views of youth on reserve or in rural settings are not represented. Based on these limitations, the findings may not be representative of the actual testing rates of Aboriginal youth in the community, nor of the differences between Métis,

Inuit and First Nations youth. Further, HIV testing services are provincially and regionally administered. As a result variations in testing procedures and practices may influence the responses and attitudes of Aboriginal youth to testing.

Ideally, HIV testing services for youth must address the barriers that deter youth from accessing HIV testing (Moyer et al., 2007) and must be part of a comprehensive HIV prevention program. Programs must be tailored to ensure that they are accessible and acceptable for this population (Peralta et al., 2007). Several authors (Huba and Melchior, 1998; Mehrabadi et. al, 2008a) have stressed the importance of involving youth in all phases of the design, planning, and implementation of HIV and AIDS services. A synthesis of peer-led interventions to reduce HIV risk in youth in low and middle income countries (Maticka-Tyndale and Barnett, 2010) reported that peer-led programs were generally successful at changing community norms, connecting youth to resources, distributing HIV prevention resources, and increasing knowledge and the use of condoms. A recent American study with HIV-positive youth (Naar-King et al., 2006) found that motivational enhancement therapy was effective in reducing risk behaviours. In a recent literature review, Yankah and Aggleton (2008) reported that life skills programs for youth are effective in influencing knowledge, attitudes, intentions, skills, and abilities related to AIDS prevention, however are rarely effective in changing sexual behaviour. Despite knowledge that HIV testing services must be accessible and acceptable for youth, a recent Canadian study (Shoveller et al., 2009) found that “youth-friendly” STI testing services are rare.

HIV prevention programs for Aboriginal youth must be grounded in the beliefs, attitudes and behavioural norms of the culture (Miller et al., 2006; Wardman et al., 2006). Newman and colleagues (2007) highlighted the importance of integrating the values of social participation, family, and collectivity into HIV prevention and treatment services for Aboriginal persons in Australia. HIV prevention programs for Canadian Aboriginal youth must acknowledge the legacy of colonialism and incorporate the structural determinants of risk (Larkin et al., 2007). “Cultural safety” is an example of an approach to health care services that acknowledges the link between the legacy of colonialism and the current health conditions in Aboriginal communities (Brascoupe and Waters, 2009).

HIV infection in the Canadian Aboriginal population, and particularly in youth, is a serious public health concern. Higher rates of teenage pregnancy and sexually transmitted infections provide evidence that Aboriginal

youth are engaged in activities that place them at risk for HIV infection. This reality, in combination with the historical trauma experienced by Canadian Aboriginal communities from colonization, results in an increased vulnerability of Aboriginal youth to HIV infection. The findings in the current study provide important insights into potential barriers to HIV testing in Aboriginal youth and characteristics of Aboriginal youth who are less likely to have been tested for HIV. These insights are relevant to the planning and implementation of HIV testing services, as part of comprehensive HIV and STI prevention programs, for this population.

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