**HIV Risk, Systemic Inequities, and Aboriginal Youth**

**Widening the Circle for HIV Prevention Programming**

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**ABSTRACT**

**Background:** In Canada, Aboriginal people are overrepresented in the HIV epidemic and infected at a younger age than non-Aboriginal people. This paper discusses some of the ways Aboriginal youth in Toronto understand HIV/AIDS risk and the relevance of their comments for HIV prevention education. This research is part of a larger study conducted with Ontario youth through the Gendering Adolescent AIDS Prevention (GAAP) project.

**Methods:** We conducted 11 GAAP focus groups with Ontario youth. This paper focuses primarily on the four groups of Aboriginal youth. A modified grounded theory approach guided analyses. Data were coded using Nud*ist qualitative data management software.

**Findings:** Aboriginal youth were more aware of HIV/AIDS and the structural inequities that contribute to risk than their non-Aboriginal counterparts. In addition, they were the only group to talk about colonialism in the context of HIV in their community. Aboriginal youth were, however, more likely to hold a fatalistic view of their future and to blame their own community for high infection rates.

**Interpretation:** We argue for incorporating structural factors of risk, including the legacy of colonialism, in HIV prevention programs for all youth. This may help to eradicate the stigma and self-blame that negatively impact on Aboriginal youth while allowing other youth populations to distance themselves from the disease.

**MeSH terms:** Aboriginal; adolescent; HIV; risk; prevention; colonialism

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**Methods**

We conducted 11 GAAP focus groups with Ontario youth: 4 with students from

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Toronto high schools (including one alternative school); 1 with youth of colour recruited from a Toronto Community Health Centre; 3 with Caucasian youth from towns in southern Ontario; and 4 with Aboriginal youth who are the focus of this paper. The University of Toronto ethical review board approved the project (Reference #11383). Our research process is outlined below.

Youth facilitator
Aboriginal youth facilitators with strong community connections and experience in AIDS prevention education were hired and trained. The facilitators contacted key community agencies that work with Aboriginal youth and invited them to participate. The agencies helped to recruit focus group participants. One of the facilitators continued with the project as a member of the data analysis team. This aligned with a key goal of GAAP – to develop youth capacity for HIV/AIDS research and education from the communities in which we work.

Youth participants
Forty-eight Aboriginal youth (ages 14-29; average age 20) recruited from Aboriginal youth-serving agencies in downtown Toronto participated. Males constituted 62% of the participants, females 38% (Table I). The gender and age distribution was reflective of the agencies’ youth demographics. As in all GAAP focus groups, participants received an honorarium, as well as pizza and travel tokens.

Procedure
Informed consent was sought from all participants and guardian consent for those under the age of 18. Youth also filled out a brief demographic survey. Focus groups lasted between 2 and 3 hours. Discussions were audio-taped and transcribed.

Focus group discussion guides
To begin, youth filled out an agree/disagree activity sheet designed to get participants thinking about the biological and socio-cultural determinants of AIDS. Responses were debriefed in the larger group and followed up with a facilitated discussion of questions designed to explore knowledge and perceptions of HIV risk. Focus groups were semi-structured, and facilitators were encouraged to follow up on comments made to generate more localized and nuanced discussions.

Data analysis
A modified grounded theory interpretive approach guided analyses. As transcripts and field notes were read (and re-read), the coding scheme iteratively developed through an adaptation of the constant comparisons methods used in grounded theory.10-14 The main modification in taking a participatory approach.15,16 The coding framework and subsequent analyses were conducted collaboratively by the team of authors which included students, the Aboriginal youth facilitator, and the principal investigator. This methodology also helped to improve trustworthiness as multiple viewpoints were incorporated. Trustworthiness was also enhanced through triangulation17-19 and keeping a clear “audit trail”.17,19,20 Transcripts were coded separately by at least two team members who then met to discuss their coding. Once they reached consensus, the codes were entered into Nud*ist qualitative data analysis software. Coded data were returned to the larger team, who discussed themes, gaps and issues in weekly meetings. Data from the Aboriginal focus groups were compared and contrasted with those from other focus groups.

RESULTS

This section discusses our analysis of the Aboriginal focus groups data in the context of GAAP focus groups conducted in Ontario at large. While the issues that youth raised were similar in many respects (e.g., the persistence of the slut/stud dichotomy, the inadequate state of sex education, the widespread support for the importance of condoms), the experience of Aboriginal youth was distinct, particularly in perception of vulnerability to HIV infection. These distinctions are the focus of this paper (for other results, see Larkin et al.21).

Most non-Aboriginal youth saw HIV as a disease of ‘the other’.2,21 Whether talking about “people in Africa,” “poor people,” “city” or “urban” dwellers, young people often perceive HIV to be something that happens to people ‘elsewhere.’22,23

When you think of AIDS you think of someone who… sleeps around… you just think of a ‘ho,’ right? And… when I think of poverty, I think of an African person…. (non-Aboriginal female)

In contrast, Aboriginal youth worried more about HIV/AIDS, which they recognized as a real and persistent problem in their community. Given the disproportionately high rates of HIV in Aboriginal populations, Aboriginal youth may be more aware of HIV/AIDS than other youth. For those who had personal experience with HIV, this awareness created a heightened anxiety:

My uncle has AIDS, so that’s why maybe I know a little bit too, and why I’m so paranoid and I get tested all the time. (Aboriginal male)

Aboriginal youth were more likely than other groups to view being HIV positive as a ‘death sentence’: I don’t want to get AIDS from having sex and like die in a couple years.
Aboriginal youth were also more likely than non-Aboriginal youth to recognize poverty as a systemic risk factor for HIV/AIDS both within and beyond their own communities. Several made the links through material deprivation.

Like if you have your last ten bucks in your pocket, it’s between buying condoms and buying food, you know… what are you going to choose? (Aboriginal female)

A finding unique to Aboriginal youth was the positive way they spoke about available support systems. Despite diverse ethnic and tribal affiliations, Aboriginal youth participants talked about being a part of a unique and supportive community. Given the lack of culturally appropriate health services for Aboriginal youth, this strong community identification is an important risk prevention factor.

LIMITATIONS

The Toronto agencies that expressed most interest in participating in the study were those that served higher-risk Aboriginal youth. This may reflect concerns that these youth are a heightened risk group within an already vulnerable population. While this specificity limits the generalization of the findings, to some extent the experience of colonialism, poverty and fatalism reported here are shared across Aboriginal youth groups. Future research should focus on the particular social determinants of HIV risk of Aboriginal youth in diverse situations, including on-reserve youth and youth who migrate between cities and reserves.

DISCUSSION

Our study provided insight into systemic issues relevant to HIV risk in urban Aboriginal youth. While some were able to identify poverty, colonialism and other structural inequities as precipitating factors of risk, Aboriginal youth were the only group to hold their own community responsible for high infection rates. The discourses of self-blame that informed their comments may be a reflection of their internalization of negative portrayals of Aboriginal people in mainstream society. In the study of HIV/AIDS, a contributing factor to such portrayals may be the overemphasis on seroprevalence research to the exclusion of studies on the social determinants of risk. Although tracking the epidemic is important, Health Canada has warned that focusing solely on increasing infection rates in Aboriginal communities can reinforce negative stereotypes and discrimination against Aboriginal people both within and beyond their own community.

A response to the HIV/AIDS epidemic in Aboriginal communities must begin with an understanding of the unique social, cultural and economic issues facing Aboriginal people.

As a result of colonization and the residential school system, violence, poverty and racism are commonplace in the lives of many Aboriginal youth... (Aboriginal female)

Individuals are more likely to distance themselves from the disease. For these reasons, an understanding of the devasting impact of colonialism on Aboriginal youth while allowing other youth populations to distance themselves from the disease. For these reasons, an examination of the impact of colonialism on Aboriginal populations should be mainstreamed into prevention programming for both Aboriginal and non-Aboriginal youth. This approach could be extended to include an understanding of the devastation of AIDS in high prevalence countries, particularly those in the developing world.

Health Canada warns that "the HIV epidemic in the Aboriginal community shows..."
no sign of abating (pg. 9). Working with youth to halt the spread of the epidemic has proven to be one of the most effective ways to confront rising infection rates. Understanding the unique situations of youth is essential to developing programs that work for diverse populations.

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RéSUMÉ

Contexte : Au Canada, les Autochtones sont surreprésentés dans l’épidémie de VIH, et ils sont infectés à un âge moins avancé que les non-Autochtones. Dans cet article, il est question de la perception du risque de contracter le VIH chez les jeunes Autochtones de Toronto et de la pertinence des commentaires de ces jeunes pour les programmes d’éducation visant à prévenir le VIH. Cette étude s’inscrit dans une étude de plus grande envergure menée auprès des jeunes Ontariens dans le cadre du projet GAAP (Gendering Adolescent AIDS Prevention).

Méthode : Nous avons organisé 11 groupes de discussion GAAP avec des jeunes Ontariens. Dans cet article, nous nous intéressons principalement aux quatre groupes composés de jeunes Autochtones. Nos analyses se sont inspirées d’une approche théorique à base empirique modifiée. Les données ont été codées à l’aide du logiciel de gestion de données qualitatives Nud*ist.

Résultats : Les jeunes Autochtones étaient plus conscientisés que leurs concitoyens non-Autochtones du risque de contracter le VIH et avaient une plus grande expérience sexuelle. De plus, ils ont été les seuls à parler du colonialisme dans le contexte du VIH dans leur communauté. Les jeunes Autochtones étaient cependant plus susceptibles d’envisager de moins en moins de lutter contre la maladie et de moins se montrer optimistes à l’avenir avec fatalisme et de blâmer leur propre communauté pour les taux d’infection élevés qui y prévalent.

Interprétation : Nous préconisons l’intégration de facteurs de risque structurels, y compris l’héritage du colonialisme, dans les programmes de prévention du VIH, et ce, pour tous les jeunes. Cette mesure pourrait contribuer à éradiquer la stigmatisation et l’auto-accusation dont souffrent les jeunes Autochtones tout en permettant aux autres groupes de jeunes de prendre leurs distances par rapport à la maladie.