HIV Risk, Systemic Inequities, and Aboriginal Youth

Widening the Circle for HIV Prevention Programming

June Larkin, PhD[1]
Sarah Flicker, PhD[1,2]
Ruth Koleszar-Green[1,3]
Susan Mintz, BA[1,4]
Michelle Dagnino, MA[1,5]
Claudia Mitchell, PhD[6]

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

La traduction du résumé se trouve à la fin de l'article.

1. The Gendering Adolescent AIDS Prevention (GAAP) Project, Women and Gender Studies Institute, University of Toronto, Toronto, ON
2. Faculty of Environmental Studies, York University, Toronto
3. Social Work, Ryerson University, Toronto
4. Urban Studies, University of Toronto
5. Osgoode Law School, York University
6. The Gendering Adolescent AIDS Prevention (GAAP) Project, Faculty of Education, McGill University, Montreal, QC

Correspondence and reprint requests: June Larkin, Undergraduate Coordinator Women and Gender Studies, Women and Gender Studies Institute, New College, 40 Willcocks, University of Toronto, Toronto, ON M5S 1C6, Tel: 416-946-3817, Fax: 416-946-5561, E-mail: Jlarkin@oise.utoronto.ca

Acknowledgements: The authors thank the youth and community partners for their participation and David Flicker for his editorial brilliance. This study was supported by the Social Science and Humanities Research Council (SSHRC) and the Canadian Foundation for AIDS Research (CANFAR).

This paper discusses some of the ways Aboriginal youth understand AIDS and HIV risk[1-3] and the relevance of this information for prevention programming. Aboriginal peoples are both "overrepresented in the HIV epidemic" and "infected at a younger age than non-Aboriginal peoples"(pg. 1).[1] The higher infection rates in Aboriginal communities point to "the complexity of Canada's HIV epidemic"[1] and the need to understand the dynamics of the disease. HIV infection patterns follow the biases of social inequity,[4,5] with youth from marginalized groups most at risk. Aboriginal peoples are disproportionately affected by social, economic and behavioural risk factors (such as poverty, substance abuse, sexually transmitted diseases, limited access to health care services) that can increase vulnerability to HIV infection.[1] Not surprisingly, Aboriginal communities across Canada are experiencing growing rates of HIV infection.[1]

The data reported here are part of a larger study on gender, youth and HIV risk involving Ontario youth participants in focus groups conducted by the Gendering Adolescent AIDS Prevention (GAAP) project. GAAP works with youth in Canada and South Africa on issues related to gender and HIV risk (for further information, see: www.utgaap.info). While the Canadian HIV infection rate is nowhere near the epidemic proportion of South Africa, the vulnerability of youth is a growing concern.[6-8] In this paper, we focus on data collected with urban Aboriginal youth for three reasons: 1) the disproportionate burden of the disease shouldered by this community; 2) a request by Aboriginal community workers for further data to guide their prevention work; and 3) the unique issues and links raised by Aboriginal youth offer important insights for understanding risk and prevention. Our focus on Aboriginal youth in Toronto is a response to concerns about the lack of health research on Aboriginals living in urban settings.[9] Throughout this paper, we use the general term 'Aboriginal' to refer to youth who identify as Aboriginal, Native, Indian, First Nations, Status, non-Status, Métis or Inuit as defined in the Canada Act of 1982.

METHODS

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

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.

TABLE I
Focus Groups Descriptions

General Descriptor		Average Age (Years)	Age Range	Gender Ratio
Small		15.7		40% Male
Town	#	------------	------------	------------
Group A	12	15.5	11-18	64% Male
Group B	15	14.3	13-16	40% Male
Group C	6	17.3	16-18	0% Male
Urban		17.7		42% Male
Youth	#	------------	------------	------------
CHC	15	–	–	33% Male
Alt HS	17	17.6	16-19	30% Male
Public HS(1)	10	17.4	16-18	60% Male
Public HS(2)	16	18.2	14-20	25% Male
Aboriginal Youth	#	20	14-29	61% Male
Group 1	9	16.6	14-21	67% Male
Group 2	12	21.5	16-29	58% Male
Group 3	12	21.5	16-29	58% Male
Group 4	15	19.4	16-23	63% Male

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 triangulation[17-19] 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'.[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 male). For some, this sense of fatalism was part of a general feeling of despair present in Aboriginal communities:

You don't care. It's just like, "Oh, we've got to live, but I'm already doing this… so, hey, what's left? If I catch AIDS it will be over sooner." (Aboriginal male)

When discussing the higher HIV rates in their community, some youth referred to widespread substance abuse and sexual abuse, both on reserve and in the city. These comments were largely stripped of the history of colonialism, residential schooling and ongoing poverty and marginalization that have created conditions that heightened HIV vulnerability. When one young man was challenged for suggesting that abnormal hemoglobin was a factor in the higher Aboriginal HIV rates, he admitted to struggling with his own internalized racism, a point he made by referring to himself as an apple (white on the inside, red on the outside):

And I know with Native Peoples, the hemoglobin, there's something wrong with the hemoglobin too. (Aboriginal male)

Yes. Well, it's not wrong with it, it's our hemoglobin different. (Aboriginal female)

Exactly! That's bad cultural talk, okay. Our blood is fine… thank you very much. (Aboriginal female)

Yes, at one time I was an apple. I'm learning though, I'm learning. (Aboriginal male)

Some Aboriginal youth, however, strongly linked experiences of colonialism and HIV. Given the history of Aboriginal peoples' experiences with European infectious diseases, perhaps these youth are attuned to the complex ways in which colonialism operates to spread illness. One youth was keenly aware of the impact of colonialism on his community.

I've got my family who I love, right? And to see them like drinking, getting murdered, killing themselves, living on the streets, and knowing that... we weren't on the streets and drinking like that doing drugs before contact happened, right?… That makes me angry…. (Aboriginal male)

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,[24] 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,[25] 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.[26] 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,[27] 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 (pg. 12).[27]

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:[28]

As a result of colonization and the residential school system, violence, poverty and racism are commonplace in the lives of many Aboriginal youth… [C]ommon coping mechanisms… are migration to urban centres, street involvement and injection drug use. All of these are associated with high risk behaviours such as trading sex for food, shelter or drugs; alcohol and substance abuse; inconsistent condom use; sex with more than one partner; and sharing needles or other drug use equipment (pg. 3).[1]

Here individual behaviour/risk is interpreted in a historical and socio-political context.[29] In linking the health challenges Aboriginal people face today to the culture-decimating legacy of colonialism, Hackett argues for the inclusion of history in public health research, something we see as also relevant to HIV prevention work.[21,30] Incorporating history into awareness programs may help to disrupt racist stereotypes associated with AIDS. Such efforts may diminish the stigma, fatalism and self-blame that negatively impact 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)."[1] 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.[25] Understanding the unique situations of youth is essential to developing programs that work for diverse populations.

REFERENCES

1. HC. HIV/AIDS among Aboriginal people in Canada: A continuing concern. *HIV AIDS Epi Update*. Health Canada, 2004.
2. CDCP. HIV/AIDS Epi Update: HIV and AIDS Among Youth in Canada. Ottawa, ON: Centre for Disease Prevention and Control, Health Canada, 2003.
3. UNAIDS. Canada. Epidemiological Facts Sheets on HIV/AIDS and Sexually Transmitted Infections. Switzerland: UNAIDS/WHO Working Group on Global HIV/AIDS, 2004.
4. Albertyn C. Contesting democracy: HIV/AIDS and the achievement of gender equality in South Africa. *Feminist Studies* 2003;29(3):595-615.
5. Farmer P. *Infections and Inequalities: The Modern Plagues*. Berkeley, CA: University of California Press, 1999.
6. Flicker S, Skinner H, Read S, Veinot T, McClelland A, Saulnier P, Goldberg E. Falling through the cracks of the big cities: Who is meeting the needs of HIV-positive youth? *Can J Public Health* 2005;96(4):308-12.
7. Flicker S, Goldberg E, Read S, Veinot T, McClelland A, Saulnier P, et al. HIV-positive youth's perspectives on the internet and e-health. *J Med Internet Res* 2004;6(3):e32.
8. Veinot T, Flicker S, Skinner H, McClelland A, Saulnier P, Read S, Goldberg E. "Supposed to make you better but it doesn't really": HIV-positive youths' perceptions of HIV treatment. *J Adolesc Health* 2006;38(3):261-67.
9. Young TK. Review of research on aboriginal populations in Canada: Relevance to their health needs. *Br Med J* 2003;327:419-22.
10. Strauss A, Corbin J. Grounded theory methodology: An overview. In: Lincoln YS, Denzin NK (Eds.), *Handbook of Qualitative Research*. Thousand Oaks, CA: Sage Publications, 1994.
11. Strauss A, Corbin J. *Basics of Qualitative Research: Grounded Theory Procedures and Techniques*. Newbury Park, CA: Sage Publications, 1990.
12. Taylor SJ, Bogdan R. *Introduction to Qualitative Research Methods: A Guidebook and Resource,* 3rd ed. New York, NY: John Wiley & Sons, Inc., 1998.
13. Charmaz K. Grounded theory: Objectivist and constructivist methods. In: Denzin NK, Lincoln YS (Eds.), *Handbook of Qualitative Research*, 2nd ed. Thousand Oaks: Sage Publications, Ltd, 2000;509-36.
14. Glaser BG, Strauss AL. *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Chicago, IL: Aldine, 1967.
15. Flicker S. "Ask me no secrets, I'll tell you no lies": What happens when a respondent's story makes no sense. *The Qualitative Report* 2004;9(3):528-37.
16. Israel BA, Eng E, Schulz AJ, Parker EA. *Methods in Community-Based Participatory Research for Health*. San Francisco, CA: Jossey Bass, 2005.
17. Lincoln YS, Guba E. *Naturalistic Inquiry*. Beverly Hills, CA: Sage, 1985.
18. Cresswell J. *Qualitative Inquiry and Research Design: Choosing Among Five Traditions*. Thousand Oaks: Sage Publications, 1998.
19. Miles MB, Huberman AM. *Qualitative Data Analysis: A Sourcebook of New Methods*. Beverly Hills: Sage, 1984.
20. Devers KJ. How will we know "good" qualitative research when we see it? Beginning the dialogue in health services research. *Health Serv Res* 1999;34(5):1153-88.
21. Larkin J, Mitchell C, Flicker S, Dagnino M, Koleszar-Green R, Mintz S. HIV risk, prevention education, and youth. Toronto, ON: Report to the Canadian Foundation for AIDS Research (CANFAR), 2004.
22. Patton C. *Globalizing AIDS*. Minneapolis, MN: University of Minnesota Press, 2002.
23. Patton C. Inventing 'African AIDS'. In: Parker R, Aggleton P (Eds.), *Culture, Society and Sexuality*. London, UK: UCL, 1999;387-404.
24. AHS. Access and Utilization of Health Care Services and HIV Testing among British Columbia's First Nation. Vancouver, BC: Aboriginal HIV/AIDS Society, Healing Our Spirit, 2004.
25. CAAN. HIV Prevention Messages for Canadian Aboriginal Youth. Ottawa: Canadian Aboriginal AIDS Association (CAAN). 2004.
26. An Ethnographic/community based research investigation into why First Nation youth take risks: Recommendations for health care providers, youth and elders on HCV prevention. (poster). Canadian Association for HIV Research Conference (CAHR), Vancouver, BC, 2005.
27. HC. Research on HIV/AIDS in Aboriginal people: A Background Paper. Winnipeg, MB: Health Canada & University of Manitoba, 1998.
28. Matiation S. *Canadian HIV/AIDS Policy & Law Newsletter* 1999;4(2/3).
29. CAAN. Strengthening Ties - Strengthening Communities. An Aboriginal Strategy on HIV/AIDS in Canada for First Nations, Inuit and Métis People. Ottawa: Canadian Aboriginal AIDS Network (CAAN), 2003.
30. Hackett P. From past to present: Understanding First Nations health patterns in a historical context. *Can J Public Health* 2005;96(Suppl. 1):S17-S21.

Received: July 25, 2005
Revisions requested: November 17, 2005
Revised ms: October 6, 2006
Accepted: November 6, 2006

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 au VIH et au sida, ainsi qu'aux inégalités structurelles qui font augmenter le risque de contracter le virus. 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 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.