



Canadian Aboriginal AIDS Network

Brief Overview of the Canadian Aboriginal AIDS Network (CAAN)

The Canadian Aboriginal AIDS Network is a national, not-for-profit organization:

- Established in 1997
- Represents over 400 member organizations and individuals
- Governed by a national thirteen member Board of Directors
- Has a four member Executive Board of Directors
- Provides a national forum for members to express needs and concerns
- Ensures access to HIV/AIDS-related services through advocacy
- Provides relevant, accurate and up-to-date HIV/AIDS information

Mission Statement

As a key national voice of a collection of individuals, organizations and provincial/territorial associations, CAAN provides leadership, support and advocacy for Aboriginal people living with and affected by HIV/AIDS. CAAN faces the challenges created by HIV/AIDS in a spirit of wholeness and healing that promotes empowerment, inclusion, and honours the cultural traditions, uniqueness and diversity of all First Nations, Inuit and Métis people regardless of where they reside.

Acknowledgements

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Editorial Policies: Purpose and Audience

The CJACBR is an annual on-line and paper journal published by CAAN as a service to its members and anyone with an interest in Aboriginal Community-Based Research.

The CJACBR is a peer-reviewed journal which welcomes contributions from any author. Priority however, may be given to an author of Aboriginal ancestry/background, should manuscripts of comparable quality be available. First consideration will be given to innovative articles covering areas identified as HIV/AIDS research-intensive which demonstrates the use of Aboriginal Community-Based Research (ACBR) methods or philosophy.

Articles published in CJACBR are directed toward several audiences. The primary audience is Aboriginal HIV/AIDS service organizations and Aboriginal people living with HIV/AIDS (APHAs). The CJACBR secondary audiences include community leaders, policy and decision-makers, and anyone with an interest in HIV/AIDS, particularly within Aboriginal populations and communities.

Acknowledgements:

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Introduction

The Canadian Journal of Aboriginal Community-based HIV/AIDS Research (CJACBR) began as a project idea in late 2003. It is so exciting to now be publishing our third edition! This volume brings a variety of new perspectives and new authors to the CJACBR. The articles discuss community engagement, explore lessons learned and offer new evidence which continues to inform our response to HIV and AIDS within the Aboriginal community in Canada.

CAAN continues to invest in community-based research with increasing engagement from within our membership and broadly among Aboriginal and allied community stakeholders. More and more we have the opportunity to draw upon our own research for evidence to inform our path forward. With these opportunities we are better able to explore our understanding of HIV and AIDS within ourselves, our families, our communities and our Nations. The creation of the Journal is a medium to support knowledge dissemination and contribute to academic understanding of Aboriginal issues related to HIV and AIDS.

The CJACBR continues to evolve from our initial desire to assist in the dissemination of research findings into a vehicle to promote and encourage Aboriginal community-based HIV and AIDS research. We continue to emphasize the review and development of meaningful policies to guide journal submissions and peer review processes. Authors from across the country have submitted manuscripts and the dedicated Editorial Peer Review Board has once more offered carefully considered feedback for each article.

In addition, the CJACBR will enjoy greater exposure through indexing with the Open J Gate database!

Enjoy this Volume and please help us to continue to grow the CJACBR by submitting articles, thoughts and reflections to share. As researchers, students, academics, and activists we have so much to say!

In solidarity,

Renée Masching

Research and Policy Manager

Canadian Journal of Aboriginal Community-based HIV/AIDS Research

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Suit the Situation: Comparing Urban and On-Reserve Aboriginal youth preferences for Effective HIV Prevention Messaging

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ABSTRACT

The researchers set out to determine whether one's location on a reserve or in an urban setting makes a difference in Aboriginal youth preferences for effective HIV prevention messaging. Locally recruited facilitators used community based participatory research methodology to convene focus groups with a total of 61 participants in 6 communities in central Canada. Three of the communities could be characterized as rural reserves. Three of the communities were large urban settings. Data were analyzed using a modified grounded theory interpretive approach. According to our small sample, having HIV prevention programs designed specifically for particular Aboriginal communities, whether they are on reserve or off reserve, is more likely to increase their effectiveness than a universal message approach. We find agreement across the groups that HIV prevention messaging and strategies must be captivating innovative and flexible to adapt to the diverse and distinct characteristics of each community. Furthermore, first person and peer-based approaches will find greater reception in urban contexts than on reserve while rural strategies should be fun and involve the whole community in some way. All agreed that because Aboriginal communities are diverse and distinctive, HIV prevention should be designed specifically for each separate context. Both groups demonstrated an awareness of, and interest in colonialism and intergenerational impacts.

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INTRODUCTION

In this paper we report on the findings of a project with urban and on-reserve Aboriginal youth designed to explore their understanding of HIV risk and uncover new possibilities for prevention. As a group, young people are experiencing a growth in rates of Human Immunodeficiency Virus (HIV) with half of all new infections worldwide in youth between the ages of 15 to 24 (Flicker, Larkin, Smilie-Adjarkwa, Restoule, Barlow, Dagnino, et al., 2007; UNAIDS, 2004; UNICEF, UNAIDS, & WHO, 2002). Aboriginal youth are particularly vulnerable and are overrepresented in Canadian HIV/AIDS statistics. In 2006, 28% of people with positive HIV tests were First Nations, Inuit or Métis (Public Health Agency of Canada, 2007) even though Aboriginal people represent only 3.8% of Canada's population (Statistics Canada, 2006). We know that the pattern of HIV infection in Aboriginal populations is different. Forty-eight percent of Aboriginal people who test positive are women (Ontario HIV Treatment Network & Ontario Aboriginal HIV/AIDS Strategy, 2008). Further, Aboriginal youth are more likely to have a late diagnosis, more likely to become acutely ill earlier, less likely to receive optimal medical treatment, and have shorter survival rates (Mill, Jackson, Worthington, Archibald, Wong, Myers, et al., 2008). Because of the distinctive nature of HIV infection in the Aboriginal population, the Gendering Adolescent AIDS Prevention Program (GAAP), University of Toronto, specifically organized engagements with Aboriginal participants. The GAAP brings together youth, community based service providers, policy makers, students and researchers on projects that use participatory approaches to working with young people in relation to sexuality, HIV prevention and AIDS awareness.

The GAAP initially sought to analyze gender as a risk factor in youth HIV transmission in South Africa and Canada, using a community based participatory approach (Minkler & Wallerstein, 2003). In the initial GAAP focus groups, Aboriginal participants conveyed markedly different responses from other participants. Intrigued by these findings, and curious whether these responses were commonly held among Aboriginal youth, the GAAP team embarked on a more targeted study.

The new research team was composed of June Larkin and Jean-Paul Restoule from the University of Toronto; Sarah Flicker, York University; Kevin Barlow, Canadian Aboriginal AIDS Network; Claudia Mitchell, McGill University; project coordinators Christine Smilie-Adjarkwa, and Michelle Dagnino; and student researchers Ruth Koleszar-Green and Christina Ricci. The overall goals of the study were:

- 1) To further our work with Aboriginal youth on issues related to HIV risk and to use this data to suggest prevention strategies that may work for Aboriginal populations.
- 2) To compare issues facing Aboriginal youth with regards to HIV in different geographical locations.
- 3) To ensure the voices of Aboriginal youth in various contexts are considered in HIV prevention programming.
- 4) To consider the relevance of our findings for HIV prevention programming for both Aboriginal and non-Aboriginal youth.

We expanded on the research of our recently completed CANFAR project by conducting additional focus groups with Aboriginal youth in urban and on-reserve settings in two Canadian provinces: Ontario and Quebec. The focus group discussion guide developed for this project was revised based on the findings of our previous study and the issues identified by Aboriginal youth themselves (See Figure 1).

The team held focus groups with Aboriginal youth seeking their views on effective HIV prevention. Half of the 61 participants were residing on reserves and the other half in urban areas (Larkin, Flicker, Restoule,

Barlow, Mitchell, & Smillie-Adjarkwa, 2007). The Aboriginal participants in these focus groups suggested that HIV prevention strategies should be designed specifically to address urban or on-reserve populations, as well as specific cultural groups. The research team examined the data to better reveal differences and similarities between urban and rural youth preferences.

METHODS

GAAP adopts a community-based participatory research approach (Minkler & Wallerstein, 2003). This means that we understand youth to be vital partners in the HIV response. We recognize that youth and the community organizations that serve them have important assets, talents, skills and ways of seeing and understanding their world that need to be leveraged for an effective response. Drawing on feminist, critical and post-modern theory to blur the distinctions between objectivity and subjectivity (Gaventa, 1993; Wallerstein & Duran, 2003), participatory approaches acknowledge that communities often already have local knowledge that is crucial to understanding and addressing their own social problems. As such, GAAP partners with local communities in all aspects of knowledge creation and social change (Cornwall & Jewkes, 1995; Hall, 1993; Maguire, 1987), and attempts to break down the rigid distinctions between the researcher and the researched (Gaventa, 1993). Using a CBPR approach has been highlighted as particularly effective for health research with young people. (Grossman, Agarwal, Biggs, & Brennenman, 2004; Smyth, 2001; Society for Adolescent Medicine, 2003).

However, opportunities for youth to participate can be hampered by stigmatizing attitudes and social discouragement from their communities and peers (Vailaitis, 2002; Watt, Higgins, & Kendrick, 2000). Young people's skills and talents are regularly underestimated by both the mainstream public and the academic research community (Checkoway, Richards-Schuster et al., 2003). Often youth internalize "adultist" notions that they have nothing to offer (Checkoway & Richards-Schuster, 2001). Only a small fraction of youth are aware of research as a form of participation and fewer still have the resources to take action of this type (Checkoway, Dobbie, & Richards-Schuster, 2003).

Involving youth in research is often complicated by greater barriers to participation such as having to navigate parental consent (Flicker & Guta, 2008), and the fact that young people are often seen as "problematic" research subjects because of their alleged "unreliability" and "lack of cognitive, emotional or intellectual maturity." Time constraints often due to school and/or work, lack of drivers licenses, unsafe public transit systems, and living in suburban and rural communities may also be a barrier for meeting attendance during regular work hours (McCormack-Brown et al., 2001). Marginalized young people who may be homeless, gay or lesbian, inject drugs, and/or living with HIV are even less likely to be invited to the table (Flicker et al., 2005).

Nevertheless, this commitment to investing in and building the capacities of young people to become active research partners is a cornerstone value of our approach. Active community participation in research often renders results more accessible, accountable and relevant to people's lives (Israel et al., 1998), with the added value of an increased likelihood of program and/or policy change (Flicker et al., 2007). Finally, given the historical human right violations that have happened in the name of "research on Indigenous communities" we believed it to be vitally important to do research "with" Aboriginal youth that was respectful of the diversity and talents of young people (Smith, 1999).

In 2007, sixty-one Aboriginal youth, from six communities, participated in three-hour facilitated discussions on issues relating to their own communities with regard to HIV/AIDS. Consistent with our commitment to community based participatory research, the project put out a call for youth facilitators to convene the focus groups that were to be held in their community. Training youth in local communities builds the capacities of young people to engage in research and promotes dialogue about HIV prevention, with multiple benefits: the youth acquire confidence and skills that can lead to long-term opportunities (Flicker, 2006; Jarrett, Sullivan, & Watkins, 2005) and the communal social capital is strengthened by keeping knowledge and resources in the community after the project is completed (Hawe, Noort, King, & Jordens, 1997). Youth facilitators gain valuable job experience and the project benefits because young people engage more freely with a known facilitator.

Youth facilitators who had a strong connection with a school and/or community group were selected. Facilitators were at least 16 years of age and had some experience working with youth and facilitating small group discussions. Generally, facilitators were responsible for recruiting youth participants in their community, finding an appropriate space, facilitating the group and subsequent follow-up. The youth facilitator and participants of each focus group were paid an honorarium for their time. The focus groups began by discussing an agree/disagree exercise on issues related to HIV. The discussion was recorded and transcribed. The facilitator offered input when participants had questions about the study or requested further information on matters related to HIV/AIDS. In each focus group location, a contact person (e.g., teacher, community worker) acted as a liaison between the youth facilitator, the focus group participants and project coordinator. The liaison person advertised the project, collected consent forms, distributed the ad for the facilitator position, and carried out other minor administrative tasks associated with the project.

Youth participated in three-hour guided discussions on issues relating to their own communities with regard to HIV/AIDS. The goals of the focus groups were to further explore the links between systemic and individual risk. Youth facilitators worked with the research coordinator to co-facilitate focus groups in their own communities. Youth were provided with an honorarium for their time (\$20) and a meal. Informed consent was sought from all participants. Parental consent was sought for those youth under the age of 18. At the beginning of each session, a consent form was read aloud and there was time for questions from group participants. All forms were collected prior to the beginning of the focus group. Youth were then asked to fill out a short quiz that helped them reflect on how they understood HIV risk. The questions were designed as a warm-up to provide a starting point for discussion (see Figure 1 below). After the participants completed the exercise individually, the facilitator took up the responses and probed for further understandings of the issues raised through a semi-structured facilitation process. The conversations were focused on unpacking notions of HIV vulnerability and uncovering new possibilities for culturally appropriate HIV responses. The discussions generated through this process were rich and nuanced. All discussions were audio-taped and professionally transcribed verbatim.

Figure 1: Modified Agree/Disagree Exercise for GAAP Focus Group Discussion

Question	Agree/Disagree?	
Men's biological make-up makes their chances of HIV infection higher than women.	Agree	Disagree
When someone has an STD, they are more at risk for HIV infection.	Agree	Disagree
Globally, women and girls are more at risk of HIV infection than men and boys.	Agree	Disagree
Being poor puts people more at risk for HIV infection.	Agree	Disagree
HIV is a gay disease.	Agree	Disagree
Condom use is now a regular practice in the sexual activities of gay and straight youth	Agree	Disagree
Young women and young men are equally willing to use condoms.	Agree	Disagree
Getting an HIV test is a common practice for sexually active youth.	Agree	Disagree
Young people worry about contracting HIV/AIDS.	Agree	Disagree
Some youth are more at risk for contracting HIV than others.	Agree	Disagree
There are still many myths and stereotypes about HIV/AIDS.	Agree	Disagree
I had a good sex education that included information about HIV/AIDS.	Agree	Disagree
I know people who have been affected by HIV/AIDS.	Agree	Disagree
HIV/AIDS is a problem for people in my community.	Agree	Disagree

*This activity is used as a spring board for discussion. Once the youth participants had completed the form individually, the facilitator takes up their responses in the larger group.

Participants were aware that meeting in a group setting provided limits to the degree of anonymity or confidentiality that researchers could meaningfully promise. The duty to report suspicions of abuse was communicated but there was no disclosure of this sort in the circles. Accounts of high-risk behaviour and infection were second-hand. The youth facilitator had been trained in HIV prevention and used the discussion guide as a tool for providing accurate information, and provided further resources for individuals to access after the focus group. While confidentiality could not be completely controlled by the research team, pseudonyms were used for participants and no personally identifying names or characteristics, other than gender and urban/rural status, have been reported in subsequent publications.

A data analysis team of the principal investigator, two co-investigators, the research coordinator, one graduate student and an undergraduate youth facilitator developed the coding framework and subsequent analysis. Three of the data analysis team members (50%) were Aboriginal. An inductive approach guided analysis. A sub-sample of transcripts was offered to the data analysis team for preliminary analysis. Based on emerging themes, commonalities and major differences, a preliminary coding framework was developed. Each transcript was coded separately by two team members. The coding scheme was revised to accommodate new themes as they emerged. The codes were then entered into Nud*ist qualitative data management software. Coded data were returned to the larger team for analysis. Weekly meetings were held to go over the coded data and discuss main themes, relevance and implications for each code and compare and contrast findings. Collectively, the team’s notes were discussed and summary documents were constructed to capture the most common themes, gaps and issues. This method of collaborative analysis created an environment of mutual learning where the skills and knowledge of various team members were exchanged and built upon. Including youth facilitators on the data analysis team also ensured that contextual factors that may not have surfaced in transcripts were attended to in analyses. Furthermore, this method of transparent sharing and discussion assisted with nuanced analyses that are in line with the principles of OCAP that are central to research in partnership with Aboriginal peoples.

Contacts were made through Aboriginal members of the research team who had connections to various Aboriginal communities. Individuals were contacted who work with Aboriginal youth in schools, friendship centres, youth councils and other locations. One of the goals of the project was to have a balance of urban and rural focus groups. Ultimately, we were able to conduct three focus groups in urban locations and three groups in rural reserve communities.

Table 1 shows the composition of the six focus groups.

Table 1: Focus Group Demographics

General Descriptor	Average Age	Age Range	Gender Ratio Female	Gender Ratio Male
Urban Youth #	20 yrs	14-27	50% Female	50% Male
Ontario 1 8	16 yrs	15 – 17	60%	40%
Quebec 1 14	21 yrs	14 – 25	50%	50%
Quebec 2 6	23 yrs	20 - 27	30%	70%
On-Reserve Youth #	16 yrs	14-24	76% Female	24% Male
Ontario 2 9	18 yrs	17 – 20	70%	30%
Ontario 3 10	17 yrs	16 – 20	86%	14%
Quebec 3 14	16 yrs	14 - 24		

Table 2 shows the number of female and male youth participants in urban and on-reserve locations.

Table 2: Focus Group Gender Distribution

Focus Group Location	# of Female Participants	# of Male Participants
Urban Youth		
Ontario 1	5	3
Quebec 1	7	7
Quebec 2	2	4
On-Reserve Youth		
Ontario 2	6	3
Ontario 3	7	3
Quebec 3	12	2

RESULTS

The results from this comparison of rural and urban focus groups are preliminary. While the overall suggestions made in urban and rural groups intersected, there were some ideas more strongly represented in each group.

Both rural and urban groups spoke more about prevention with regard to safer sex, and better sex education, than safer injecting practices, although injection drug use is the most common route of transmission for Aboriginal people in Canada (Public Health Agency of Canada, 2004). There was agreement that sex education was inadequate.

You learn basics... very basics, what STDs are...and the boys go in the other room (Female, on-reserve).

They taught me about sex in grade 8 or 9 and I was like, “You guys are kind of late because most people have had sex already. Good time to tell us!” (Male, urban).

Prentice (2004) argues that Aboriginal youth under the age of 15, and injection drug users, are the people most in need of HIV prevention. While our participants rarely discussed injection drug use, there were some comments on the risky behaviours associated with using drugs generally. When asked about risk factors, one participant noted that “there are many drugs in my community,” while another participant shared: “Sometimes youth are high on my reserve, they have like orgy parties [Laughter]...yeh, and they’re so drunk they don’t care who they’re with, some youth don’t care about their future. Yeh, there’s nothing else to do so they just do what feels good all the time.” (Male, on-reserve). Harm reduction has been used in Canada as a way of addressing the risks of injection drug use in urban contexts. The Canadian Aboriginal AIDS Network (2004) and others such as Landau (1996) criticize abstinence based programs and suggest the use of harm reduction programs for Aboriginal people. Australian and New Zealand scholars in response to Landau’s article raise challenges to this approach arguing that a harm reduction approach can be culturally unsuitable, where many Aboriginal community members hold a view that alcohol and drugs are alien to Aboriginal cultures, and as such promote the use of both abstinence and harm reduction programs (Kahn & Fua, 1997; Sellman & Huriwai, 1997).

Rural and urban youth agreed that HIV prevention needs to be captivating, using pop culture such as television and comic books that entertain and emotionally engage.

TV shows like *Degrassi High*, if we had an Aboriginal version that tackles issues Aboriginal youth face then maybe that would get the youths interested (Male, urban).

We grow up watching media, they can put messages through the media (Female, on reserve).

I think it needs to be put out there more and it needs to grab the people and really educate them because the information that we get now is so bland (Male, urban).

On-reserve youth suggested that fear would engage their interest. They believed their peers could be motivated by fear to make better decisions.

We learn in a different way than mainstream kids, we need to be scared of what could happen, need graphic details, pictures, people talking about it (Female, on-reserve).

(We) need pictures of people all disfigured or something, or their internal organs and how they are affected compared to a normal person, or a picture of the number of medications they have to take (Female, on-reserve).

Rural youth on reserve had confidence that young people would attend HIV prevention which was paired with fun activities, and that generally young people in their communities are eager to show up and see what's going on.

There was a program called "Try Hugs Not Drugs" and when they first started it, the lady who co-ordinates it honestly thought that there would only be 2 or 3 kids who would show up. But when it started there was a lot more people who showed up because they provided a lot of fun things to do. If you do something like that about AIDS and have different stations where you can go and do something fun with lots of activities about AIDS, then a lot of people would come (Female, on-reserve).

In a recent workshop organized as part of an extension of this current study, our community coordinator from the reserve believed that the reason for the high turnout of youth to the workshop was that 'it gave them something to do.' For on-reserve youth, HIV prevention workshops could be popular because they provide a place to go and an activity to be involved in.

Urban youth highlighted how fun also needed to be "cool," to know about sex is "cool."

Female: In the street art festival they made a game out of it. There was a spinning wheel, I remember that. It was like snakes and ladders and you had to answer questions.

Male: They made it into a game, asking sex questions to see how much you know about sex.

Female: You felt pretty cool if you won.

Male: It means you know a lot.

Female: If you didn't win you were so surprised (Urban).

Both on-reserve youth and urban youth felt like they were considered "others" by mainstream society. The urban youth were more likely to name racism as a problem while on-reserve youth showed concern with being or feeling isolated and its consequences. The following quotes illustrate issues connected with assimilation. It seems from the comments by the youth participants that urban youth deal more with racism and on-reserve youth deal with issues of isolation and its consequences.

There are so many misconceptions, because nobody understands, nobody knows. So people think "Oh you are Indian," well maybe you don't pay taxes, or this, that, or I thought Indians are gone. (Male urban)

I get that people refuse to believe that I'm Aboriginal. It's either that or it's oh God, she's Aboriginal. They always go do you drink a lot? One of my names growing up was Pocahontas because the movie had just come out and they're like "hey Native girl." And they're like "Oh, it's her, it's Pocahontas". (Female urban)

On-reserve youth felt that they were considered “the others” by mainstream society and had strong feelings about how things needed to change to bridge the relationship between Aboriginal peoples and the rest of Canada. These quotes show how isolation on reserves can make Aboriginal youth feel disconnected from the rest of society.

We need Canadians to understand our issues, they are ignorant about our problems and our issues and they think we have it so good. (Female on-reserve)

What about our land rights, and what they are doing to mother earth, they don't care. (Female on – reserve)

The connection between HIV vulnerability and intergenerational trauma has been well documented (Pearce, Christian, Patterson, Norris, Moniruzzaman, Craib, et al., 2008) and the young people in our study demonstrated awareness of this association. Both groups suggested HIV prevention in Aboriginal communities should explicitly recognize the role of colonialism and its intergenerational impacts. As Chansonneuve (2002) noted, the heightened need for HIV prevention in Aboriginal communities may be usefully situated within the disproportionate representation of Aboriginal people with HIV as well as other preventable social, economic and legal problems in Canada. This seemed very important to both groups.

We need Canadians to understand our issues, they are ignorant about our problems and our issues and they think we have it so good (Female on-reserve).

From my understanding, from seeing my mother's generation and being taken away from her mother and with her having children and not knowing how to be a mother, then raising children is hard, because she didn't know how to be a mother. They didn't know the teachings and the things about culture. They were taken away from them. I think the whole residential schools had a huge effect on self-esteem. Safe sex has a lot to do with self-esteem. Like saying the way you want to respect yourself and it has to do with social problems (Female, urban).

Aboriginal youth are from diverse and distinctive cultural groups. HIV prevention must be designed for specific cultural contexts. While both groups were interested in first person accounts and peer-based approaches, the urban groups stressed these approaches to greater degrees and also emphasized the importance of messaging that specifically targeted people from similar cultural and geographical contexts.

The hardcore reality is effective. Somebody who is living in a city is not going to really relate to someone who lives in the country. You need to suit the situation (Female, urban).

The heightened stigma associated with positive HIV status in on-reserve communities may render first person and peer based approaches less pragmatic. In Mill et al., (2008) some Aboriginal youth commented on the lack of openness about HIV and AIDS on reserves:

It's just a different way of life. I mean we look at it as a Southerner, as someone who's been used to a different culture, one where in school, I was taught about AIDS and HIV and not having sex before a certain age, and not getting pregnant, and stuff like that. Then I came up here and pretty much everyone I met - like young, old, whatever ... I mean everything seems to be different here. Just the way children are raised and what they're taught, it's kind of like they're left to fend for themselves. (Female, urban).

If it is important for young people to learn from people who intimately understand their community, and if it is unsafe for a young person to disclose a positive HIV/AIDS status, it would be unreasonable to suggest a first person approach. On-reserve youth were less likely to suggest peer-based approaches than their urban counterparts, and more likely to suggest approaches that involved their whole community, particularly Elders. They were more interested in their communities connecting with other communities, and learning from each other.

I think video conferencing would be good. Then you could connect all the communities together and everyone would be getting the same information and then the Elders and other people could watch and find out the truth and stop banishing people with HIV/AIDS (Male, on reserve).

CONCLUSION

While more research is needed, important findings have emerged from this study. To increase the success of HIV prevention programs, messages must be targeted to their specific audience. Having HIV prevention programs designed specifically for particular Aboriginal communities – on reserve and off reserve – is likely to increase their effectiveness. That is, as one young person in the research stated, efforts to message HIV prevention must “suit the situation.” In rural reserve contexts, this means engaging the whole community, not just the youth; including activities that are fun; and using messages that provoke using fear or scare tactics. To a greater degree than rural youth, the urban youth suggested that peer-based approaches and first person accounts would be an effective means for HIV prevention education. Involving young people as collaborators in designing the HIV prevention they require may be a very successful strategy. As well, the youth stated that the messages should be distinct for First Nations, Métis and Inuit Nations and should represent each group individually and in a culturally relevant manner. These comments are an important reminder that Aboriginal youth are not a homogenous group; providing messages that have a pan-Aboriginal approach will not work. First Nations, Métis and Inuit youth all come from diverse, distinct cultures and each culture’s values and beliefs need to be addressed and respected.

New, culturally appropriate, participatory approaches that engage youth, peers, parents, and Elders in HIV prevention are necessary to create holistic approaches to prevention. Our partnership is currently developing proposals for this work. We hope to work directly with Aboriginal youth to identify contextual community based approaches using the strengths, talents, and assets of young people. Arts-based methods (photography, video, dance, mural-making) will explore the links between individual and systemic risk and create culturally meaningful prevention media (by youth for youth) addressing a range of prevention needs.

Building community capacity in the areas of research and HIV prevention is just one way we ensure the sustainability of our work. The youth who participated in the focus groups had many interesting ideas for prevention messages and programs. The comment that came up the most often is that programs should be interactive and fun. Most youth agreed that face to face and peer programming may be effective, as well as initiatives that have a connection with real people such as HIV/AIDS workers and people with HIV. Participants also pointed out that youth would be interested in media as a form of communication, such as video conferencing which could also be utilized by other members of the community such as Elders, parents and smaller children.

Other youth have suggested a youth conference and an intergenerational connection where Elders and youth can learn together and then work together to fight this problem in their communities. Perhaps the current generation of Aboriginal youth can break the cycle of shame and stigma around sexual practices and HIV/AIDS in Aboriginal communities by talking openly about sexual education and risky behaviours. Aboriginal youth have many creative and relevant suggestions with regards to preventing HIV/AIDS in their communities. Putting the power and resources in the hands of Aboriginal youth and community members is an important first step in stopping the epidemic of HIV/AIDS in Aboriginal communities.

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Strengthening Community-Based Approaches to HIV/AIDS & STI Screening, Treatment & Prevention among Atlantic First Nations People

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ABSTRACT

Sexually transmitted infections (STIs) like the Human Immunodeficiency Virus (HIV), Chlamydia and Gonorrhea among others, pose serious health concerns to many Aboriginal populations in Canada. Despite consistently high STI rates and known risk factors (e.g. poverty, discrimination, colonialism, limited healthcare access, addictions and so forth), few efforts have been made to improve screening, treatment and prevention of HIV/AIDS and other STIs among Aboriginal people throughout Canada. Through a partnership with Healing Our Nations, Health Canada First Nations and Inuit Health (Atlantic Division) and Dalhousie University School of Nursing and following the OCAP principles (Ownership, Control, Access, Possession) we developed a sexual health workshop that would unite Aboriginal community members and community organizations, academics, researchers, clinicians and other organizations to collectively develop a strategic plan that would help Aboriginal communities in the Maritimes prioritize their sexual health needs and be better prepared to improve screening, treatment and prevention of HIV/AIDS and other STIs. The results of our workshop have since been used to develop a comprehensive sexual health report and a community-based sexual health needs assessment tool that will be made available to the general public in the near future.

BACKGROUND

For many Aboriginal people living in Canada (e.g. Inuit, First Nations, Métis), issues around HIV/AIDS and sexually transmitted infections (STIs) remain poorly understood (Barlow 2009). There is a common perception that HIV is not a prominent health concern in Canada, especially in rural and northern regions where many

Aboriginal communities are situated. HIV is however, a serious threat. The Public Health Agency of Canada (PHAC) reports over 67,442 cases of HIV/AIDS in Canada (PHAC 2008 HIV/AIDS Surveillance Report); it is alarming to note that among certain Aboriginal populations, new infections have increased from 18.8% in 1998 to 29.4% in 2008 (PHAC, 2008). These figures significantly understate the magnitude of the HIV epidemic among Aboriginal populations due to low screening rates and lack of ethnocentric data in some provinces.

It is well documented that Aboriginal people living in both rural communities and urban areas are not adequately captured in existing national HIV surveillance data and as such, Aboriginal people may not fully understand the impact HIV may have on their communities (CAAN, 2006). Simply put, it is not clear whether current surveillance data accurately reflect the actual rates of HIV infection and other STIs among Aboriginal peoples in Canada.

Aboriginal peoples in Canada continue to experience disproportionate rates of STIs compared to non-Aboriginal people (Ricci et al 2009). Historical legacies of marginalization and Western assimilation have resulted in isolated communities with high levels of poverty and other social and environmental determinants that have placed Aboriginal people at higher risk for HIV and STI acquisition and transmission than other Canadians. The Canadian Aboriginal AIDS Network (CAAN) reports an even more disconcerting trend; Aboriginal peoples are becoming infected at younger ages than the overall population. It is estimated that one in four youth (under 30) who tests positive for HIV in Canada is Aboriginal (CAAN, 2006).

In recent years, organizations such as the National Aboriginal Health Organization (NAHO) and CAAN have repeatedly called attention to the linkages between current high rates of HIV infections in Aboriginal communities and the residual effects of colonial practices (such as residential schooling) resulting in permanent loss of language, traditions, severed connections to family and community, as well as collective and personal experiences of trauma (Barlow 2003). As a result of past experiences with disease and culturally inappropriate western health frameworks, HIV/AIDS in Aboriginal communities was, and often continues to be, met with shame due to stigma and discrimination toward individuals who are infected. Against this backdrop, it is essential that Aboriginal communities/organizations, researchers, clinicians, policy makers and key stakeholders work together to identify the gaps that currently exist in HIV and STI screening, treatment and prevention. We must approach the issue of HIV/AIDS in Aboriginal communities with cultural sensitivity and most importantly, attempt to ensure that the OCAP principles are in place, ensuring that Aboriginal communities are centrally involved in the design and implementation of research, surveillance, and intervention efforts (Dixon 2003, Marsdon 2002, Smith 1999, Wilson, 2008).

This paper presents the results from a workshop held in Dartmouth Nova Scotia, April 2009. This workshop was designed to generate input from the above mentioned stakeholders in order to develop a culturally relevant, sexual health needs assessment tool that would be reflective of issues surrounding access to sexual health services in Atlantic Mi'kmaq and Maliseet communities and adaptable to other Aboriginal contexts across Canada.

PROJECT OBJECTIVES

Through a collaborative partnership between Healing our Nations (an Aboriginal-based organization that delivers sexual health education to Aboriginal communities in Atlantic Canada), Health Canada, First Nations and Inuit Health (Atlantic Division) and Dalhousie University, School of Nursing, a working group was established in the winter of 2008. Our preliminary objective was to organize a one-day sexual health workshop that would bring together Aboriginal community members (from several regions in Nova Scotia and neighbouring New Brunswick), academics, sexual health researchers, clinicians and decision makers to brainstorm ideas around sexual health issues, priorities and healthcare service delivery in Aboriginal communities; b) develop a community-driven strategic plan that can help address sexual health issues in Aboriginal communities, and c) develop a culturally sensitive, community-based sexual health needs assessment tool. Recognizing that each Aboriginal community has unique sexual health needs and priorities, the research team (comprised of two Aboriginal and two non-Aboriginal members) worked in collaboration with a workshop facilitator to design a

suitable workshop format and focus group questions (Appendix A). The goal of the workshop was to engage participants in discussions that would inform the eventual development of a needs assessment tool that would: a) be adaptable to a diversity of both individual and community needs; b) be inclusive of and capture the uniqueness of individuals (LGBT, males and females) and, c) recognize the difference in sexual health needs across age groups (youth, adults and Elders).

SEXUAL HEALTH WORKSHOP

A one-day sexual health workshop (funded through Health Canada/Atlantic Division) was held on April 6th, 2009 at the Dartmouth (NS) Holiday Inn. Funding covered the event and costs of travel and accommodation for all Aboriginal community members and out-of-town participants attending the event as well as a banquet that was held later that same evening. Healing Our Nations (HON) acted as a project liaison by identifying Mi'kmaq and Maliseet communities in Nova Scotia and New Brunswick that would be interested in participating in both the project and workshop. Face to face meetings were then scheduled with the health directors, interested community health nurses and project staff to build partnerships with the communities and to help maintain interest and commitment to the project. Health directors were also invited to collaborate with the research team, participate in the sexual health workshop and, contribute to the development and piloting of the community-based sexual health needs assessment tool after the workshop was completed. The principle investigator and project coordinator were accompanied by a HON representative for all face-to-face meetings that were held at the participating communities. In addition, each health center Director or Community Health Representative were asked to nominate 5 or more members from their community who had an interest in Aboriginal sexual health and an interest in attending the workshop. An effort was made to include an equal number of Elders, youth and adults as well as an equal number of males and females from the community.

The Aboriginal communities involved in the project included: Millbrook First Nation, Bear River First Nation, Elsipogtog First Nation, Eskasoni First Nation and the Forgotten People of Weymouth. Other participants included: Pauktuutit Inuit Women of Canada, Nova Scotia Advisory Commission on AIDS, Confederacy of Mainland Mi'kmaq, Healing Our Nations, Dalhousie University, University of Moncton, St. Francis Xavier University, First Nations University of Saskatchewan, Canadian Aboriginal AIDS Network, Health Promotion and Protection, Health Canada and the Public Health Agency of Canada.

The workshop was divided in to two sessions; the morning session concentrated on general sexual health services that were offered at the community level (Appendixes A & B), while the afternoon session focused on issues pertaining directly to youth, Elders and adults and sexual health education and prevention (Appendixes A,C-E). The focus groups were asked, in each case to identify a) what the relevant services available to each group (i.e.: general population and then youth and elders, specifically); b) what the priorities for each group are and c) ways to improve upon those services for each group (see Appendix A for a list of questions asked of each focus group). Participants were informed that a written report of the workshop findings would be prepared and made available to each community health centre and to interested participants. Once developed and piloted, the sexual health needs assessment tool would also be made available to each community and hopefully, made available online through the Health Canada Website. All participants were invited to provide contact information if they wished to continue participating in the project at a later date (i.e.: participate in the piloting of the needs assessment) and if they wished to receive the report once the information from the workshop was synthesized.

WORKSHOP RESULTS

Approximately 50 people representing various interest groups and Aboriginal communities attended this day-long workshop. After a brief re-introduction of the project working group, workshop and project objectives, participants were divided into 8 separate groups; each group assigned a facilitator to guide their discussion, a note taker to record information generated by the group and a reporter to share discussion highlights with all participants. A transcriptionist from the First Nations and Inuit Health Branch (FNIHB), Atlantic Region was

also available to record the group discussion as it unfolded throughout the day. After the workshop, all written information from the group sessions was entered into a Word document; one document per group and workshop session. This information was later synthesized and organized according to various themes.

Screening, treatment and contact tracing for STIs and HIV/AIDS were identified by participants as essential services for Aboriginal communities. HIV screening was seen as especially problematic by most participants particularly with regards to confidentiality, anonymity and access; some communities reported that STI/HIV screening is not offered in their communities at all. The lack of male screening was also identified as a barrier as men in general, access community health centres with much less frequency than women. The top priorities around sexual healthcare services included: accessibility, communication, cultural appropriateness, awareness, collaboration, normalization, confidentiality, support and prevention. The main results of the workshop are detailed below.

Accessibility

Health services in general need to be more available to rural communities, especially in light of barriers such as transportation and confidentiality. Services offered to youth in particular, should be more immediate and on a drop-in basis; it was felt that youth would access sexual health services if these accommodations were made.

Communication

Strategies need to be explored to create better, more informed, open and forthright/candid conversations about sexual health between parents and their children and among community members as a whole. Better communication channels could be created in order to move toward a more open sexual health environment that would ultimately help normalize sexual health discussions at individual, family and community levels.

Culturally Appropriate Services

Services offered to Aboriginal communities need to be more holistic in nature, encompassing all aspects of health, healing and well being, including ceremony and community cohesiveness. A level of cooperation between doctors and traditional healers needs to be established; one can refer the services of the other to their clients when the occasion arises, for example. Issues of racism must also be acknowledged and addressed.

Collaboration

Aboriginal communities should be encouraged to work collaboratively on addressing sexual health issues. This effort could potentially cut down on work load and expenses for communities involved and reduce the isolation often felt by community health workers. Also, a more united front may earn more attention from funding bodies, government and other relevant institutions. Youth should also be approached for collaboration with sexual health projects concerning them.

Normalization

Healthy attitudes towards sexuality and sexual health were part of traditional teachings for most, if not all Aboriginal cultures. Better attitudes around sexual health help to reduce the stigma surrounding STIs, sexual health and HIV/AIDS. Candid discussions about sexual health between youth and Elders for example, may help to build comfort when discussing sexual health. Making an effort to make information about sexual health and birth control easily accessible to those in need is also a priority.

Confidentiality

Community members who access sexual health services need to feel safe and secure when accessing these services. An enormous effort must be put into trust-building in order for clients to begin to feel safe going to community health centres.

Support

Better supports should be offered to community members. People should be encouraged to seek emotional support from Elders who are comfortable and willing to discuss sensitive issues in times of need, for example; it is important to note that some Elders have personal issues or past experiences (e.g. residential school, sexual abuse) that may not make them suitable to act as community counselors and would subsequently require support themselves. The lack of counselling services available to community members to help them through their test results was also recognized. Young males also need to be empowered to engage in healthy sexual practices and be responsible for family planning issues and STI screening.

Prevention

An emphasis should be placed on STI/HIV prevention measures. Safer sex practices should be promoted in all age groups; condoms should be available to everyone; harm-reduction workshops should be promoted (in communities that are ready and willing), delivered and employed. The introduction of age-appropriate, culturally relevant sexual health education to children was also discussed; it was felt that children should be exposed to this material at younger ages than they are at present.

Ceremony

To make healthcare services more appropriate for Aboriginal peoples, ceremony and traditional culture must be incorporated into all initiatives. Some examples of ceremony that could be integrated in to health care services include, but are not limited to: storytelling, Aboriginal ceremonies, Medicine Wheel, Powwows, Coming of Age ceremonies, traditional crafts, family, Elders and discussion.

NEEDS ASSESSMENT TOOL

After the information gathered at the workshop was compiled and synthesized, a needs assessment tool was developed by the project team – PI, project coordinator, Healing Our Nations and FNIHB. Once the first draft was completed, it was sent to an expert panel for their feedback and comments. The expert panel was comprised of several workshop participants; community members as well as health care directors and academics. The comments and necessary revisions from this process were then incorporated into the final needs assessment tool.

Once the needs assessment tool was complete, the health directors from the participating communities were asked to help recruit members of their respective communities to participate in the piloting of the questionnaire. This process was instrumental to ensure that the language of the survey was appropriate for the community, asked questions that held relevance to community members and reflected the situation in each community. The feedback from the piloting stage of the questionnaire is currently being compiled and a final draft of the questionnaire drafted. Once this process is complete, the questionnaire will be made available to participating health centers and other health centers in the Atlantic region.

DISCUSSION

Sexual healthcare services are a priority for many Aboriginal communities. With a history of high STI rates, inaccessible, ineffective and/or culturally inappropriate sexual health programs, limited education and prevention strategies among others, it is essential that Aboriginal communities be given the opportunity to collaborate on health service development/delivery and, on needs assessment and prioritization. This is further compounded by issues surrounding confidentiality, anonymity, stigma and racism.

Aboriginal communities/organizations, researchers, clinicians, policy makers and key stakeholders must work together to identify the gaps that currently exist in HIV and STI screening, treatment and prevention so that we may collectively approach the issue of HIV/AIDS in Aboriginal communities with sensitivity and caution, and to ensure that Aboriginal communities are centrally involved in the design and implementation of research, surveillance, and intervention efforts. Without input from Aboriginal communities, efforts will remain largely ineffectual.

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APPENDIX A

Focus Group Questions (morning & afternoon sessions)

A. Sexual Health Services (morning session)

1. What sexual health care services (e.g. Family planning, STI screening, treatment & contact tracing, HIV testing etc) are available in the communities represented at your table. Which of these services work well and which do not?
2. List the top 3 priorities for dealing with sexual health in Aboriginal communities
3. What aspects of Aboriginal culture can be applied to sexual health? Examples may include: coming of age ceremonies, storytelling, songs, and pictures

B. Youth Sexual Health (Afternoon session)

1. Please list the sexual health care services (e.g. Family planning, STI screening, treatment & contact tracing, HIV testing) specific to the youth population at the various communities around the table and identify which work well and which do not.
2. As a group, list the top 3 priorities that are essential for youth sexual health. These priorities should take into consideration the following: age, sex (male or female) and the sexual orientation (heterosexual, homosexual (two spirited), and transgendered).
3. Please give us two examples of how we can make sexual healthcare services like STI screening, HIV testing, family planning etc more normal or acceptable to Aboriginal youth.

C. Adult/Elder Sexual Health (Afternoon session)

1. List the sexual health care services (e.g. Family planning, STI screening, treatment & contact tracing, HIV testing) that are specific to the adults/Elders at the various communities around the table and identify which work well and which do not.
2. As a group, list the top 3 priorities that are essential for adult/ Elder sexual health. These priorities should take into consideration the following: age, sex (male or female) and the sexual orientation (heterosexual, homosexual), and transgendered) of adult/Elder clients.
3. How can we improve sexual health Aboriginal adults/Elders?

D. Sexual Health Education/Promotion/Prevention (Afternoon session)

1. Please list how sexual health education and prevention programs are delivered at the various communities around the table; identify which work well and which do not.
2. Give two examples of how we can improve upon the programs and services listed above so that they better achieve their goals?
3. Give two examples of how we can make sexual health education and prevention more culturally appropriate.

APPENDIX B

Sexual Healthcare Services in the Community (Priorities)	
Priorities	Comments
<p>Accessibility:</p> <ol style="list-style-type: none"> 1. Accessibility 2. Communication 3. Cultural appropriate services 4. Awareness 5. Collaboration 6. Normalization 7. Confidentiality 8. Support 9. Prevention 	<ol style="list-style-type: none"> 1. Immediacy of services especially for youth; more access to care/knowledge/approachable; access to services in rural communities 2. Parent/youth; better communication channels; data sharing, even if common with common tools for a fair process; breaking taboos; FNs leading the discussions; language 3. More holistic; Doctor referrals to traditional health and healing; need traditional medicine; addressing determinants of health 4. Self awareness; inheriting residential school abuses; more male involvement; lack of knowledge on disparities of health 5. With communities/Aboriginal youth; pairing programs for sexual health and substance abuse; resource infusion 6. Reduce stigma; awareness to sexual health and rights to it 7. Testing and access; safe place; trust; confidentiality, racism 8. Seek more emotional help from spiritual Elders; support programs/counselling to deal with test results 9. Promote safer sex; condoms; peer to peer; protect yourself- more risk reduction (needle exchange)- limit STIs and teen pregnancies
<p>Education</p>	<ol style="list-style-type: none"> 1. Inclusion of target population in program development & delivery 2. Lack of information; youth education at a younger age 3. Teaching about sexual health; peer educators 4. Education guiding youth- culturally competent education- adding sexual curriculum to high school

APPENDIX C

Youth specific priorities	
Priorities	Comments
<p>Accessibility:</p> <ol style="list-style-type: none"> 1. Availability 2. Normalization 3. Frontline support workers 4. Gatherings 5. Confidentiality 6. Young men 7. Counselling 8. Sexual orientation/gender 9. Youth clinics 	<ol style="list-style-type: none"> 1. Youth friendly, more youth centers, access to professionals, 1-800 numbers, better locations 2. Make sexual health easy to talk about- empower youth 3. Look at staff composition 4. More youth gatherings at HC and schools 5. Provide comfortable support/confidentiality & trust 6. Empower young men, enforce annual STI testing, more access and involve men in sexual health 7. Somewhere to talk about sexuality 8. Workshops on sexual orientation/family planning, two-spirited, trans-gender 9. Youth wellness centers with condom distribution
<p>Education:</p> <ol style="list-style-type: none"> 1. Material 2. Prevention 	<ol style="list-style-type: none"> 1. On sexual orientation, prevention education for age 10, have nurse go to schools, workshops on safer sex presented by youth, more cultural awareness, gender specific story telling, pairing sex education with substance abuse 2. Prevention strategies for HIV, creative prevention programs

APPENDIX D

Adult & Elder specific priorities	
Priorities	Comments
<ol style="list-style-type: none"> 1. Accessibility 2. Communication 3. Cultural appropriate services 4. Awareness 5. Community champion 6. Health services 7. Confidentiality 8. Gender 	<ol style="list-style-type: none"> 1. Needs improvement to accommodate different needs 2. Better emphasized in line with age, experience, status in community 3. More holistic 4. Better information, more context and roles 5. Having individuals that are trusted in the community 6. Not very catered to adult/Elder needs- need a more broader look on sexuality through the ages- also more emphasis on two-spirited and transgendered 7. More on confidentiality and anonymity 8. Poor male involvement- women treated for STIs but not the men which leads to re-infection
Education:	<ol style="list-style-type: none"> 1. Providing Elders with education so that they can support the youth in a sensitive manner (residential schools)

APPENDIX E

How to make improve sexual health education and prevention	
Example	Comments
Media	<ol style="list-style-type: none"> 1. Contests, comics, videos, plays and posters 2. TV ads, web-sites for youth (Face book or MySpace) 3. Culturally appropriate materials- posters/written material 4. Seek out images that relate to the target populations
Collaboration	<ol style="list-style-type: none"> 1. Elder/community/youth all working together 2. Partner with Aboriginal organizations 3. Invite First Nations people to present 4. Utilize First Nations people for consulting, printing, designing
Normalization	<ol style="list-style-type: none"> 1. Normalize sex 2. Talk more about how you can prevent HIV/AIDS 3. Open doors to communication 4. Teach FN at a younger age 5. Talk openly as an everyday thing
Cultural	<ol style="list-style-type: none"> 1. Talking circles 2. Develop terminology on sexual health in language and dialects 3. Speaking with Elders/ grandparents 4. Coming of age ceremonies
Education	<ol style="list-style-type: none"> 1. Of healthcare providers 2. Of academics 3. Programs delivered by Aboriginal men and women 4. Area specific-cultural teachings

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Watching the Tide come in: An Aboriginal participant reflects on participating in the HIV Research field and the University Without Walls Program

Doris O'Brien-Teengs

Doris O'Brien-Teengs is of Mushkego Cree and second generation Irish Canadian heritage. She grew up in Moosonee, Ontario. She has worked for the Ontario Aboriginal HIV/AIDS Strategy in Toronto for the last eleven years as a Regional Outreach Worker and has been involved in community based research for the past nine years.

We are all situated. Who we are, how we grew up, what we do with our time, all make a difference in how well we engage and are treated in the world. I am a pale Cree girl of mixed heritage, who speaks some of her language, but not fluently. I grew up in an Aboriginal community, but not a reserve, which still had a lot of my relatives in it. Both of my parents worked through my entire childhood until their retirement. I am post-secondary educated and my writing has been published. I've had the same job for eleven years – which to some constitutes a career. I have a mortgage on a nice house, am married and have two children now in school. I am short, but not tiny. I have moments of absolute candour and deep quiet – both of which may happen at the right or wrong times, leading to interesting and challenging consequences. Most of these things add up to privilege in Canadian society and some of it contributes to privilege in my Native identity. The fundamentals of who I am I did not ask for and it is the same for everyone. No one can make these choices. Through all of this, I live in a Canadian society that is based on trying to eliminate the Aboriginal 'problem'. The problem being there are Aboriginal peoples on resource-rich lands. The calculated and continuing attempt at assimilation of Aboriginal peoples, it can be argued, has led to the current state of our low status in Canadian society, which includes various negative psychological and health outcomes – the one I am most concerned about is high incidence of HIV and AIDS.

I am involved in HIV Research and learned from the ground up with a great bunch of people who sat on a Community Advisory Board. This year, I participated in the University Without Walls program funded by REACH from January to June of 2010. Almost every other Monday we would participate in three hour webinars, which consisted of tutorials and group planning meetings through the internet and phone. We were assigned to debate a topic at a World Café event in Winnipeg during our one week Learning Institute, as well as prepare a presentation on a given topic. Our tutorials were given by guest speakers on Ethics, Community Based Research (CBR), HIV statistics, CIHR funding protocols, Aboriginal and "Other" non-white and culturally relevant perspectives, etc. It was a well rounded outline. Most of the Fellows were either Master's or PhD students, and so I am assuming that a lot of the 'academic lessons' were a refresher for them. As for me, I enjoyed learning as much as I could about the ins and outs of applying for research funding, the processes involved before, during and after the research takes place.

I was also fascinated by the ethics discussions. We learned of the horrific events that lead to the establishment of ethics boards which would control experiments that are both physical and psychological on human subjects. As long as they are funded, the research has to be approved by at least one Research Ethics Board (REB). On principle, no subject is supposed to be harmed in any way during the research process – whether physically, emotionally or psychologically. It made me think about research that is done on Aboriginal peoples. We have come a long way in terms of how research is done for and on us, but I still think we need to be cautious. Aboriginal peoples continue to be hurt by research, both by the processes and the absence of integrated outcomes. I tried to make an impression upon my co-Fellows, stating that Aboriginal people are not to be studied and objectified, but to be wooed and engaged, leading to a lifelong relationship and commitment.

In the last few years, I have noticed that one of the reoccurring themes in the HIV research field is the engagement in Aboriginal research which has to include Aboriginal people. So, what is community based research when it is not initiated by us? Academic, public health, or institutionalized idealism? Researchers call us with the OCAP

principles in hand, as if that were enough. These principles were not born out of our philosophies, but out of necessity, a means of expressing our engagement in any research process which includes us. These are words that the colonizer has used as an expression of what he understands to be important in the research process; words this Western world promotes as normal ways of doing things. If we have to Own, Control, have Access to and Possess these things to be partners for our community, we *will* do it. But we would rather just do things ourselves in our own ways.

Sometimes we do. But when we are being romanced by funders to get involved so that community based research with non-Aboriginals about Aboriginals can get done, the lines get blurred along the way. It does not help when the funding mandates are encouraging everyone to do research on Aboriginal people, but they won't fund a lot of Aboriginal initiated research. Sometimes we need and want to know the results of research for the benefit of our people. Many Aboriginal academics and thinkers have stressed that in order for it to be meaningful, any research that is done on or for us must be analyzed by a team that includes us.

It is important to be critical of who we talk to, the language that we use, and on whose terms that conversation takes place. Any discussion of community based research that is initiated outside of the defined community is questionable. Why would anyone outside of the community want to know our health outcomes? For whose benefits? The greater public health? What about our own public health? And what about our own ideologies and methodologies? Why is the Canadian Research movement so interested in Aboriginal people, but is reluctant to let these Aboriginal ideologies and methodologies evolve in their organic way? I leave the answer to your intellect and imagination.

Would I participate in this kind of cross cultural learning exchange again and would I suggest this program for other Aboriginal people involved in the HIV research field? Absolutely! It is essential to make the contacts and have a strong sense of who is out there. We do have very strong allies! It is equally important to know who *not* to work with. Most of all, it is important to make contacts with new researchers who are still pliable to cooperative ways of thinking and working. I think that the success in this program will happen because we are new researchers and excited to engage in dialogue with one another.

Author's note:

The University Without Walls (UWW) is funded by the Canadian Institutes of Health Research's (CIHR) Strategic Training Initiative in Health Research (STIHR). It is linked to the CIHR Centre for REACH (Research Evidence into Action for Community Health).

UWW is a National Interdisciplinary Learning Network connecting academics, community members and policy makers. For more information on the UWW program, including student recruitment or teaching opportunities, please contact Francisco Ibanez-Carrasco: fbanezcarrasco@ohtn.on.ca.

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Addressing HIV/AIDS among Aboriginal People using a Health Status, Health Determinants and Health Care Framework: A Literature Review and Conceptual Analysis

Earl Nowgesic, RN, BScN, MHSc

Earl Nowgesic is Ojibwa from the Gull Bay First Nation, and has more than 20 years of experience working in the health sector. He has worked in Aboriginal health research and evaluation, Aboriginal health policy and practice, and health education. Earl has held many national leadership positions in Canada in the area of Aboriginal health research.

ABSTRACT

Objectives: (1) To describe the Human Immunodeficiency Virus (HIV) infection among Aboriginal populations using a mixed methods approach (i.e. quantitative and qualitative methods); (2) to examine the individual-level and community-level relationships between HIV/AIDS, health determinants, and health care (e.g. diagnosis, access to treatment and health services planning); and (3) to explore innovative solutions to address HIV/AIDS among Aboriginal populations based upon research and infrastructure (e.g. partnerships, data sources and management, health indicators and culture) and policy (i.e. self-determination of Aboriginal Peoples).

Methods: Literature review and conceptual analysis using a health status, health determinants and health care framework.

Results: In comparison to non-Aboriginal persons, HIV infection is higher among Aboriginal persons, is more directly attributable to unique risk factors and socio-demographic characteristics, and yields more adverse health outcomes. Culture, poverty and self-determination are determinants of health for Aboriginal populations. Aboriginal people have inadequate primary care and, in particular, specialist care. It is necessary to include traditional Aboriginal approaches and culture when addressing Aboriginal health while understanding competing paradigms between modern medicine and Aboriginal traditions.

Conclusion: There is a need for self-determination of Aboriginal Peoples in order to improve the health of Aboriginal communities and those living with HIV/AIDS. Research and policy affecting Aboriginal people should be of the highest quality and based upon Aboriginal community relevance and involvement.

INTRODUCTION

In 2006, 3.8% of the 31,241,030 people living in Canada identified as having Aboriginal ancestry (Statistics Canada, 2008). For the period 1996 to 2006, the growth rate for the Aboriginal identity population was 44.9% in comparison to the non-Aboriginal population at 8.4% (Statistics Canada, 2008). This growth rate is particularly noteworthy when taken into account with other factors such as poverty. “Long considered to be the most disadvantaged group in an otherwise affluent society, Aboriginal people today paradoxically experience the kinds of health problems most closely associated with poverty, problems linked to their historical position within the Canadian social system” (Waldram, Herring, & Young, 2007, p. 3).

The Aboriginal people of Canada consist of three distinct groups: First Nations, Métis and Inuit (Department of Justice Canada, 1982). According to the 2006 Canadian census, First Nations comprise the largest portion of the Aboriginal population at 59.5% followed by the Métis at 33.2% (Statistics Canada, 2008). “‘Status’ or ‘registered’ Indians are those individuals legally recognized by the federal government to be ‘Indians’ for purposes of the Indian Act....The Inuit are separate from the registered Indians, and there is no legislation comparable to the Indian Act defining them. The federal government has nevertheless assumed primary responsibility for these people and provides or delegates many services to them as if they were registered

Indians. The Métis and non-status Indians have a legal status that is, in many ways no different from that of other Canadians, the Constitution notwithstanding” (Waldram, Herring, & Young, 2007, p. 11). According to the Canadian Constitution, Aboriginal Peoples of Canada have existing Aboriginal and treaty rights which are recognized and affirmed (Department of Justice Canada, 1982).

Aboriginal people in Canada are a ‘young’ population. In comparison to the non-Aboriginal population, the median age of the Aboriginal populations is younger at 26.5 years (Statistics Canada, 2008) versus 39.5 years (Statistics Canada, 2007). These demographics will have an impact on the distribution of the Aboriginal population over time (i.e. the aged 65 and over dependency ratio, and the child dependency ratio). Given the growth rate, the health problems associated with poverty and the historical position of Aboriginal people within the Canadian social system, it is important to be aware of Aboriginal health in Canada and the implications of this situation for future health research and policy.

A literature review of Aboriginal health issues was conducted by Young (2003) covering the period 1992 to 2001. Exclusion criteria included articles which did not have an abstract and did not focus on Aboriginal people, health or Canada. This review measured exposure and outcome variables and it yielded 254 published research articles categorized into three main topics: health determinants, health status and health care. The literature review revealed that off-reserve and urban Aboriginal people were underrepresented, as were the Métis. The Inuit were overrepresented. Sixty percent of the articles targeted First Nations. Further, over half of the articles did not utilize a comparison group. Moreover, 28% of the 174 health determinants-categorized articles only made reference to the social environment and of the 173 health status-categorized articles, very few of them made reference to the Human Immunodeficiency Virus (HIV) (4.6%) and mental health (4%) issues. Although this literature review was restricted to published articles using a Western scientific paradigm, it provided an excellent framework to set health research and policy priorities focusing on Aboriginal populations.

In order to complement the Young (2003) literature review and address the limited information on HIV and mental health issues, Nowgesic (2010) conducted a separate literature review and developed an annotated bibliography which will inform the rest of this paper. This paper will also use the health status, health determinants and health care framework developed by Young (2003) in order to address HIV among Aboriginal people mainly from a social epidemiological perspective.

It is evident that health disparities exist in Canada between Aboriginal people and non-Aboriginal people. Of particular importance to population health and public health is the rate of HIV infection among Aboriginal people. HIV is higher among Aboriginal people in comparison to non-Aboriginal people (Craib et al., 2003; Heath et al., 1999). Furthermore, the time between diagnosis and access to care among Aboriginal HIV-infected persons is longer compared to non-Aboriginal persons (Plitt et al., 2009). Given such health inequities, this paper will address the relationship between HIV, health determinants and health care within the overall context of future directions in Aboriginal health research and policy. The objectives of this paper are: (1) to describe HIV among Aboriginal populations using a mixed methods approach (i.e. quantitative and qualitative methods); (2) to examine the individual-level and community-level relationships between HIV, health determinants (e.g. colonialism, poverty, mental health, culture, Aboriginal self-determination), and health care (e.g. diagnosis, access to treatment and health services planning); and (3) to explore innovative solutions to address HIV among Aboriginal populations based upon research and infrastructure (e.g. partnerships, data sources and management, health indicators and culture), and policy (i.e. self-determination of Aboriginal people). Each objective discussed in this paper will be supported by evidence and a body of knowledge.

OVERALL CONTEXT AND IMPORTANCE OF HIV AMONG THE ABORIGINAL POPULATION IN CANADA

In 2005, it was estimated that 58,000 people were living with HIV in Canada, and Aboriginal people accounted for approximately 7.5% of all prevalent infections (Public Health Agency of Canada, 2007). Also in 2005,

among all Canadians, new HIV infections were estimated at a range of 2,300 to 4,500, and Aboriginal persons accounted for 9% of all new HIV infections (Public Health Agency of Canada, 2007). “Therefore, the overall infection rate among Aboriginal persons is 2.8 times higher than among non-Aboriginal persons”, (Public Health Agency of Canada, 2007, p. 4). City of Vancouver estimates had even higher rates (Wood et al., 2008). According to the Wood et al. (2008) study of injection drug users (IDUs) living in Vancouver, the HIV prevalence rates among Aboriginal persons was much higher than among non-Aboriginal persons (25.1% vs. 16%); $p < .001$) as was the cumulative HIV incidence, estimated at 48 months (18.5% vs. 9.5%; $p < .001$).

Of the 21,435 positive HIV tests reported to the Public Health Agency of Canada from 1998 to 2006, a total of 6,253 (29.2%) contained information on ethnicity (Public Health Agency of Canada, 2007). Of these, 1,458 (23.3%) were accounted for by Aboriginal persons. In comparison to non-Aboriginal people, positive HIV test reports among Aboriginal people were mostly attributable to injection drug use (IDU) at 24.8% and 58.8% respectively. Positive HIV test reports were higher among Aboriginal women than non-Aboriginal women at 48.1% and 20.7% respectively. Also, positive HIV tests were mostly reported from Aboriginal persons younger than 30 years (32.4%) in comparison to non-Aboriginal persons (21.0%) of the same age category.

In addition to HIV surveillance, the monitoring of Acquired Immunodeficiency Syndrome (AIDS) is also useful in describing the HIV/AIDS epidemic. In comparing the Aboriginal groups, there is a difference between exposure categories and gender and age for reported AIDS cases between 1979 and 2006 (Public Health Agency of Canada, 2007). AIDS cases among First Nations were mostly IDU (45.2%) and aged 30-39 years (45.7%) for both sexes combined. The main characteristics of Inuit AIDS cases were IDU (31.8%), heterosexual (31.8%), and aged 30-39 years (54.5%) for both sexes combined. The Métis AIDS cases were mainly men who have sex with men (MSM) at 48.8% and aged 30-39 years (45.5%) for both sexes combined. And finally, among unspecified Aboriginal AIDS cases, the main characteristics were MSM (37.9%) and those aged 30-39 years (49.5%) for both sexes combined.

The overall context and importance of HIV among Aboriginal populations is unquestioned. This paper adopts a social epidemiological perspective in addressing HIV among Aboriginal people and looks at a health status, health determinants, and health care framework in order to guide health research priority-setting and policy development.

THE HIV EPIDEMIOLOGY AMONG ABORIGINAL PEOPLE

As described above using surveillance data, HIV infection is a major health problem affecting Aboriginal people today. Targeted studies are able to provide additional information describing the epidemiology of HIV among Aboriginal people. In comparison to non-Aboriginal persons, the incidence of HIV infection is higher among Aboriginal people (Craib et al., 2003), it is more directly attributable to unique risk factors and socio-demographic characteristics (Heath et al., 1999), and it yields more adverse health outcomes (For the Cedar Project Partnership et al., 2008).

A prospective cohort study conducted by Craib et al. (2003) examined risk factors for increased HIV incidence among Vancouver Aboriginals for the period May 1996 to December 2000. The study involved 230 Aboriginal persons and 711 non-Aboriginal persons all of whom were HIV seronegative upon entering the study. The Aboriginal participants included First Nations (42%), Métis (14%), and other Aboriginals (42%). At 42 months, the HIV incidence among the Aboriginal group was two times higher than the non-Aboriginal group (21% vs. 11%). There was increased risk for both Aboriginal men and women, although due to an insufficient sample size, the risk for Aboriginal women was not statistically significant. Independent predictors of HIV infection were different between Aboriginal males (i.e. frequent cocaine injection and frequent speedball - combined cocaine and heroin - injection) and Aboriginal females (i.e. going on IDU binges, frequent speedball injection, and using condoms with regular sexual partners). The strength of the study is that it is based upon a study of which 24% of the 941 research participants (male and female) were of Aboriginal ancestry, which was thought to be representative of the study population located in the Downtown Eastside community of Vancouver.

Another prospective cohort study, involving MSM living in Canada, examined socio-demographic characteristics and risk factors associated with HIV infection incidence from May 1995 to May 1998 (Heath et al., 1999). The study involved 57 Aboriginal (First Nations, Métis and Inuit) and 624 non-Aboriginal persons aged 18 to 30 years who were HIV seronegative upon enrollment into the study. In comparison to non-Aboriginal MSM, Aboriginal MSM were more likely to have lower socioeconomic status ($p < .01$) and experience depression ($p < .01$). In comparison to non-Aboriginal MSM, a larger proportion of Aboriginal MSM had at least one occurrence of non-consensual sex (50% vs. 33%) which was statistically significant. This non-consensual sex experience involved a relative as the perpetrator in 50% and 25% of cases for Aboriginal MSM and non-Aboriginal MSM respectively. A larger proportion of Aboriginal MSM, upon their first occurrence of non-consensual sex, were 12 years of age and under ($p = .04$). At baseline, newly diagnosed HIV infection was higher among Aboriginal MSM in comparison to non-Aboriginal MSM (4% vs. 1%) although this was not statistically significant.

A cross-sectional study conducted by For the Cedar Project Partnership et al. (2008) examined the association between HIV infection and sexual abuse among Aboriginal people (i.e. Métis, Inuit and First Nations – status and non-status) who lived in Vancouver or Prince George, British Columbia. The study was conducted from October 2003 to April 2005 and used a post-colonial perspective (i.e. historical and intergenerational trauma). Eligibility criteria included the use of drugs within the month prior to enrolment in the study. Drug use was confirmed by saliva screening. Forty-eight percent of participants had experienced sexual abuse with 85% of them occurring before age 13 (the median age was 6 years). This study clearly showed that sexually abused participants were more likely to have been diagnosed with a mental illness, have suicidal ideology, have ever self harmed, have attempted suicide, have lifetime sexual partners > 20 , and have tested HIV positive. Participants who were sexually abused had HIV prevalence rates that were almost four times higher (15% vs. 4%) than those who were never sexually abused.

As revealed in numerous studies, the health status among Aboriginal people is poorer than non-Aboriginal people. Particularly, HIV infection is a critical health disparity mainly affecting Aboriginal populations. It is important to question what determines the higher HIV rate among Aboriginal persons. The three studies noted here have attempted to describe and analyze the occurrence, pattern and distribution of HIV infection among Aboriginal populations (Craib et al., 2003; Heath et al., 1999; For the Cedar Project Partnership et al., 2008). Others have argued for future studies “to move research beyond the division which now exists between epidemiological and cultural studies” (Wilson & Rosenburg, 2002). However to do so, it is important to consider the role health determinants play in the overall health of Aboriginal people.

DETERMINANTS OF HEALTH FOR ABORIGINAL PEOPLE

A study commissioned by the Canadian Aboriginal AIDS Network (Hawkins, Loppie-Reading, & Barlow, 2009) “describes the pathways through which experiences of childhood abuse can lead to future violence in the lives of Aboriginal women with HIV/AIDS and how multifaceted and interwoven these two areas are” (p. 6). It is studies like these that help to further explain why and how health events take place. Additionally, these types of qualitative studies may also assist with generating hypotheses which can then be tested by epidemiological studies. It is the ‘causes of the causes’ or determinants of health (e.g. socio-economic conditions, lifestyle and personal behaviours) which can help to explain the proximal causes, and various causal models in relation to health status. For example, the Indian Act (i.e. structure) may be viewed as a determinant of health for First Nations living in Canada. “First passed in 1876, the Indian Act was designed to facilitate the administration of programs to Indians, as well as to facilitate their assimilation into mainstream Canadian society” (Waldrum, Herring, & Young, 2007, p. 11). Similar health determinants have been studied by others (DeGagne, 2007; Larkin et al., 2007; Chandler & Lalonde, 1998) on both a ‘macro’ (i.e. pattern) and “micro” (i.e. individual health problems) level.

“In 1991, a royal commission was established to investigate a variety of Aboriginal issues in Canada, and one of its priorities was to learn the truth about residential schools. The Royal Commission on Aboriginal Peoples (RCAP)...concluded that nothing short of a complete restructuring of Aboriginal/non-Aboriginal relations in

Canada was required” (Waldram, Herring, & Young, 2007, p. 19). One of the main outcomes of the RCAP was the establishment of the Aboriginal Healing Foundation (AHF).

The AHF and its community initiatives -- a \$390 million investment which took place from 1998 to 2007 -- were evaluated and reported for the time period 1998 to 2005 by DeGagne (2007). The community initiatives addressed the intergenerational legacy of abuse from the Aboriginal residential school system. “The church-run residential schools clearly did serious damage to the lives and cultures of Aboriginal people...[M]any of these changes are now seen to have a direct impact on the mental and physical health and well-being of Aboriginal people today” (Waldram, Herring, & Young, 2007, p. 15). Results of the AHF evaluation indicated that a total of 1246 contribution agreements were supported, valued at \$377,745,857 and involving 725 organizations and communities (DeGagne, 2007). AHF-supported projects reported to be most effective included use of Elders, traditional ceremonies, individual counseling, and western healing strategies used in conjunction with Aboriginal cultural practices. The outcome of the evaluation indicated that “culture is good medicine” and that community healing supports individual healing. In essence, it can be said that culture is an important health determinant of Aboriginal populations.

Consistent with the DeGagne (2007) evaluation, a qualitative study was conducted by Larkin et al. (2007) in order to support HIV prevention education. Larkin et al. (2007) studied the understanding of both structure and the essence of Aboriginal youth’s (males and females aged 14 to 29 years) lived experience. The study used a participatory paradigm and a grounded theory methodology. The study indicated that some youth understood HIV to be associated with the effects of colonialism. Aboriginal youth were concerned about the effects of HIV on their communities within the context of structural inequities (e.g. poverty). The study by Larkin et al. (2007) highlights the fact that colonialism and structural inequities are determinants of health for Aboriginal populations.

Community control may also be considered a health determinant. “The 1980s saw the federal government develop many joint ventures with First Nations, and many took delegated control of areas such as social services, education, and health under ‘transfer’ programs” (Waldram, Herring, & Young, 2007, p. 19). Here community control may be viewed as a means of attaining Aboriginal self-determination and ultimately Aboriginal self-government. “In 1986...the formation of the ‘Program Transfer and Development Directorate’ [was] to direct the new ‘Indian Health Policy’ ...[so] that First Nations could develop slowly, through stages, to the point where they ultimately obtained control over the delivery of health services” (Waldram, Herring, & Young, 2007, p. 267). The assumption of this policy is that ‘health transfer’ (i.e. the transfer of health services administration to First Nations) will lead to the improved health of First Nations.

Following the introduction of the federal Program Transfer and Development Directorate, Chandler and Lalonde (1998) investigated protective factors against suicide among First Nations communities (i.e. 29 tribal councils) from 1987 to 1992. Protective factors in the study were based upon tribal councils’ ability to maintain and retain the continuity of their respective culture. Cultural continuity was measured using six community-level variables: land claims, self-government, education services, police and fire services, health services and cultural facilities. Corresponding scores (from 1 to 6) were then provided to each of the 29 tribal councils based upon an accumulation of the six variables. For example, a score of 6 denoted the highest level of cultural continuity. Results of the study indicated that those tribal councils with higher scores had lower suicide rates than tribal councils with lower scores. The study claims to have provided evidence of the importance of culture in determining health outcomes. However, the results of the study should be interpreted with caution since using community-level data to make inferences concerning what may be occurring at an individual level (e.g. suicide) may or may not be accurate.

As seen from various studies (DeGagne, 2007; Larkin et al., 2007; Chandler and Lalonde, 1998), whereas colonialism, residential schools and poverty are negative determinants of health, Aboriginal culture, and self-determination are key determinants positively affecting the health of Aboriginal populations. From a socio-cultural perspective, the idea of using a health determinants approach among Aboriginal Peoples is not new. “The

general model of the 'Medicine Wheel', found today throughout many different parts of Aboriginal Canada, has been developed to explain health determinants in a manner that reflects Aboriginal world views" (Waldram, Herring, & Young, 2007, p. 74). Learning from the cultural appropriateness of using the Medicine Wheel vis-à-vis determinants of health, it is important to examine health care that is relevant to Aboriginal populations.

HEALTH CARE OF ABORIGINAL PEOPLE

"What is the role of health care services in improving the health of Aboriginal people? How can the health of Aboriginal people be improved?" (Young, 2010, p.2). These are important questions to consider in reviewing health care of Aboriginal people. It has been reported by others that Aboriginal people have inadequate primary care and, in particular, specialist care (Martens, Sanderson, & Jebamani, 2005; Shah, Gunraj, & Hux, 2003; Wardman, Clement, & Quantz, 2005). Furthermore, within the context of HIV, "a feeling of invulnerability was a barrier to [HIV] testing [and f]or those who tested positive, there was often a delay in accessing health services" (Mill et al., 2008, p.1). Some of these issues have been indirectly identified in the previous section of this paper addressing determinants of health; however, in order to fully appreciate these concerns, there is a need for specific studies on Aboriginal health care.

Plitt et al. (2009) estimated the stage of HIV disease at time of diagnosis and examined the time between diagnosis and access to care among HIV infected persons. The study population was persons newly diagnosed (case) with HIV in Northern Alberta from May 1998 to December 2003. Of those 526 persons newly diagnosed with HIV, approximately 41% identified as being Aboriginal. Aboriginal ethnicity was defined as North American Indian, Inuit, and Métis. Aboriginal persons had longer median time to care at 38 days ($p = .001$) in comparison to non-Aboriginal groups (i.e. Caucasian, 27 days; African-Caribbean, 20 days; Asian, 22 days; and others, 19 days). A similar study conducted by Wood et al. (2006) investigated access to antiretroviral therapy (ART) among Aboriginal IDUs who were ART naïve. This prospective cohort study took place from 1996 to 2003, and included 91 IDUs (both Aboriginal and non-Aboriginal people). These individuals were recruited into the study from Vancouver's Downtown Eastside using street outreach and self-referral. ART initiation was ascertained by means of record linkage to a treatment registry. Both groups had similar HIV RNA levels and CD4 counts at baseline and at the time when ART was initiated. At 24 months into the study, the use of ART was lower among Aboriginal participants (29% vs. 53%, log-rank $p = .023$). Using multivariate analyses, these findings were consistent where Aboriginal participants had initiated ART at a slower rate than non-Aboriginals ($p = .035$).

Findings from both the Plitt et al. (2009) and the Wood et al. (2006) studies encourage future research to examine barriers to accessing HIV treatment in a timely manner among Aboriginal persons. This is not surprising since challenges exist for health services planning as described by others (Minore, Katt, & Hill, 2009). In their study, Minore, Katt, and Hill (2009) reviewed existing data management systems and identified requirements necessary to implement an Aboriginal health services data collection system in Ontario. Results of the study included a review of 177 published documents, and 20 key informants. Key issues identified were data coverage and quality (e.g. linking data sources, small sample sizes, low participation rates), and jurisdictional issues (e.g. lack of standardization of data and infrastructure, and inconsistencies among regions). One noteworthy jurisdictional issue they identified pertained to self-governance of Aboriginal Peoples (i.e. research). This issue will be further explored and elaborated upon in the next section of this paper dealing with future directions in Aboriginal Health research and policy.

FUTURE DIRECTIONS IN ABORIGINAL HEALTH RESEARCH AND POLICY

Upon reviewing the issues identified in this paper thus far (i.e. health status, health determinants and health care), it is evident that innovative solutions are required to address HIV among Aboriginal populations. Furthermore, such solutions should be based upon excellent research, supportive infrastructure and effective policy. To date, many initiatives have begun to lay the groundwork for future directions in Aboriginal health research and policy.

Namely, the Indian and Inuit Community Health Representative Program established in the early 1960s; the Aboriginal Nurses Association of Canada (established in 1975); Health Canada, Indian and Inuit Health Careers Program (1984); First Nations Regional Longitudinal Health Survey (1997); National Aboriginal Achievement Foundation (1998); Aboriginal Healing Foundation (1998); Canadian Institutes of Health Research – Institute of Aboriginal Peoples` Health (2000) and its Aboriginal Capacity and Developmental Research Environments program (2001); and the National Aboriginal Health Organization (2000) and its Journal of Aboriginal Health (Waldram, Herring, & Young, 2007). Dedicated to addressing HIV/AIDS, the Canadian Aboriginal AIDS Network (CAAN), first established in 1997, “provides leadership, support and advocacy for Aboriginal people living with and affected by HIV/AIDS” (Canadian Aboriginal AIDS Network, 2006, p. ii). In 2006, this organization published its inaugural edition of the *Canadian Journal of Aboriginal Community-Based HIV/AIDS Research* (Canadian Aboriginal AIDS Network, 2006). While all these initiatives are directly relevant to Aboriginal populations, each one incorporates Aboriginal culture and traditions in a unique manner which is very encouraging. Despite the significant losses of traditional Aboriginal medicine due to epidemic diseases and colonialism, for example, many traditional health practices have begun to reemerge (Waldram, Herring, & Young, 2007). Studies have indicated the necessity of including traditional Aboriginal approaches (i.e. epistemology and ontology) in addressing Aboriginal health while understanding competing paradigms between modern medicine and Aboriginal traditions (Cochran et al., 2008; Bartlett, Iwasaki, Gottlieb, Hall, & Mannell, 2007; Hunter, Logan, Goulet, & Barton, 2006; Labun & Emblen, 2007; Myers et al., 1999; Ten Fingers, 2005). Notwithstanding the challenges of incorporating traditional Aboriginal health and healing practices with Western medicine and health sciences “...it is clear that ‘traditional’ Aboriginal healing, with its attendant base in spirituality, continues as an essential corner-stone of Aboriginal cultural revitalization” (Waldram, Herring, & Young, 2007, p. 292).

Given the social epidemiological perspective concerning the health of Aboriginal people discussed thus far (e.g. poverty, HIV, mental health, culture, and health services planning and research) what becomes apparent is the need for self-determination of Aboriginal Peoples. That is, Aboriginal populations taking control of their own health services on one end of the self-determination spectrum, and Aboriginal self-government on the other end. “It was the federal government’s new ‘Indian Health Policy’, unveiled in 1979, that sparked the process of self-determination in Aboriginal health care....What was required was increased input by Aboriginal people themselves” (Waldram, Herring, & Young, 2007, p. 264). While self-determination in Aboriginal health care presents many challenges, it also provides invaluable opportunities and future directions as discussed by others (O’Neil, Elias, & Wastesicoot, 2005; Jebamani, Burchill, & Martens, 2005; Daniel et al., 2009; Kirmayer, Simpson, & Cargo, 2003; Getty, 2010).

Within the context of health research, there are some lessons to be learned from O’Neil, Elias, and Wastesicoot (2005) who reported on a relationship-building process between the Assembly of Manitoba Chiefs and the University of Manitoba regarding a feasibility study to develop a National Longitudinal Aboriginal Survey. Aboriginal partners agreed to such an initiative provided they were included in all aspects of the study including First Nations ownership of all research derivatives (e.g. copyright). It was recommended that University researchers should consider relinquishing control (i.e. research processes) if partnerships with First Nations are negotiated, and that First Nations should be seen as the principal partner with the university, even at the expense of alienating other partners.

In support of research processing, Jebamani, Burchill, and Martens (2005) studied linking the Manitoba health database with the Health Canada, First Nations and Inuit Health Branch, Manitoba Region-managed Status Verification System (SVS). The SVS is based upon the Indian and Northern Affairs Canada-managed Indian Registry file. Upon negotiations with interested parties (e.g. Assembly of Manitoba Chiefs), the linkage involved anonymous files for the period 1994 to 1999. The multistage linkage process involved different variations of matched variables (e.g. Manitoba Health registry number, name, sex, birth year) with and without support of a manual review. Jebamani et al. (2005) were able to match the two databases 70%, 94%, 99% and 96% of the time on surname, given name, sex and birth year, respectively. Although this represented a 20% decrease in SVS

records, the linkage yielded an increase of 20% over the Manitoba health data. Consequently, the study yielded a more complete data repository of registered First Nations living on and off reserve in Manitoba.

In addition to those research infrastructure challenges studied by Jebamani et al. (2005), other data-specific issues exist but not without their own solutions as described by others (Daniel et al., 2009). In their study, Daniel et al. (2009) evaluated an instrument (a 19-item rating tool) which was developed to assess the appropriateness of health and social indicators based upon both scientific merit and cultural relevance to the indigenous communities from Canada, New Zealand and Australia. The outcome of the study was the development of a final 16-item rating tool. It is noteworthy to mention that the scientific validity-items were assessed independently by parties trained in scientific methodology.

From a health determinant approach to HIV prevention and treatment, there are lessons to be learned from the study conducted by Kirmayer, Simpson, and Cargo (2003) where they researched Aboriginal health issues (e.g. social, individual, intergenerational, community) within the context of colonialism, and developed strategies that were culturally appropriate for Aboriginal people. It was revealed that mental health problems among Aboriginal populations are associated with their cultural oppression. They recommended that mental health promotion strategies aim at strengthening cultural identity and empowering the Aboriginal community. Furthermore, the Kirmayer et al. (2003) study revealed a number of events and initiatives which support the process of reversing the oppression and cultural marginalization of Aboriginal people: (1) Aboriginal people gaining the right to vote in 1967; (2) the 1990 "Oka crisis"; (3) the 1991 Royal Commission on Aboriginal Peoples (RCAP); (4) the 1993 establishment of the Native Residential School Task Force supported by the Royal Canadian Mounted Police to investigate residential schools; (5) the 1998 federal government response to the RCAP report; and (6) the establishment of new organizations supporting Aboriginal health (e.g. the Aboriginal Healing Foundation, the Canadian Institutes of Health Research - Institute of Aboriginal Peoples' Health, and the Truth and Reconciliation Commission).

Consistent with and even building upon the findings from the Kirmayer et al. (2003) study, Getty (2010) conducted a qualitative study and provided a narrative of her own experience as a "white" researcher planning to conduct research with First Nations (Mi'kmaq) men using an advocacy/participatory paradigm. The study used qualitative methods, a critical theory (post-colonial) framework, and narrative as a research methodology. The study involved the researcher and three Mi'kmaq men. The results of the study included the researcher's initial use of a postcolonial framework which was later abandoned and replaced by a critical indigenous framework using a Mi'kmaq ontology and epistemology. This change in perspective was to support Mi'kmaq in being an integral part of the research process whereby the research was based upon Mi'kmaq's own experience and understanding instead of being conducted from the researcher's viewpoint. The researcher realized that if she continued using a postcolonial framework to carry out the research, the externality validity (i.e. authenticity) of the research itself would be limited. The strength of the study is that it supported Mi'kmaq research using an advocacy/participatory paradigm whereby the outcome was to emancipate the Mi'kmaq (i.e. Mi'kmaq self-determination) from hegemonic groups.

From the literature, there are lessons learned which could be used to address HIV among Aboriginal populations. These range from building effective partnerships to respecting Aboriginal culture to supporting the self-determination of Aboriginal people. However such solutions should be of the highest quality and based upon scientific excellence and relevance to Aboriginal populations. Furthermore, Waldram, Herring, and Young (2007) "...encourage concrete studies on the efficacy of Aboriginal-controlled treatment and education programs...to generate rigorous information on what works and what does not...with an eye to increasing the extent to which self-determination improves community health" (p. 288). It is by such means that the health status, health determinants, and health care for Aboriginal populations will be supported.

CONCLUSION

This paper has provided a review of the health of Aboriginal populations, and in particular HIV infection in these populations. It has discussed causes of HIV within a health status, health determinants, and health care framework. The overall health, and in particular HIV infection, among Aboriginal populations was described using a mixed methods approach (i.e. quantitative and qualitative methods). The individual-level and community-level relationships between HIV, health determinants (e.g. colonialism, poverty, mental health, culture, and Aboriginal self-determination), and health care (e.g. diagnosis, access to treatment, and health services planning) were examined. And finally the paper explored future directions and innovative solutions for addressing HIV among Aboriginal populations based upon research and infrastructure, and policy.

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Canadian Journal of Aboriginal Community-based HIV/AIDS Research (CJACBR)



Call for Papers

The Canadian Aboriginal AIDS Network (CAAN) is calling for papers to be considered for the fourth issue of the *Canadian Journal of Aboriginal Community-Based HIV/AIDS Research* (CJACBR). The CJACBR is a peer-reviewed journal, published by CAAN, which welcomes contributions from any author. Innovative HIV/AIDS research articles which demonstrate the use of Aboriginal Community-Based Research (ACBR) as well as decolonizing and/or Indigenous methods or philosophy are strongly encouraged. Submissions should be prepared in a language and manner appropriate for a diverse audience.

Articles will be accepted related to the following themes:

- **Aboriginal community-based HIV/AIDS research and development:** Either quantitative or qualitative research, community-based in design and process.
- **Dissemination of Results Findings:** These articles focus on results or recent findings related to Aboriginal Community Based HIV/AIDS Research.
- **Commentary:** Opinion pieces which speak to trends in Aboriginal community-based research, Knowledge Translation or other issues of importance to Aboriginal stakeholders.
- **Emerging Issues in Aboriginal Community-based HIV/AIDS Research (ACBR):** These articles focus on ground-breaking issues, findings and/or reports grounded in ACBR.
- **Ownership, Control, Access, and Possession:** Focus on the application of the Ownership, Control, Access and Possession principals.
- **International work that includes an Aboriginal Canadian component:** Articles written for an International audience about Indigenous peoples, HIV/AIDS and/or related issues. Articles must include a Canadian component.
- **Stories:** Personal accounts of experiences related to HIV/AIDS or accounts of successful and innovative approaches that address HIV/AIDS in Aboriginal communities.
- **Student work:** Students can submit articles (term papers, thesis, etc) that focus on HIV/AIDS in Aboriginal communities.

Submission Deadline: Monday, May 02, 2011 by 4:30pm EDT. Please submit manuscripts via e-mail to Marni Amirault (marnia@caan.ca). All submissions are blinded for peer-review. Priority will be given to an author of Aboriginal ancestry/background, should manuscripts of comparable quality be available.

Inquiries: Information and policies for the Canadian Journal of Aboriginal Community-Based HIV/AIDS Research (CJACBR) are available at www.caan.ca. Inquiries related to the suitability of manuscripts, article submission, writing style, Peer review guidelines, updates or back issues, may be directed to the Research and Policy Manager, Renée Masching (reneem@caan.ca).