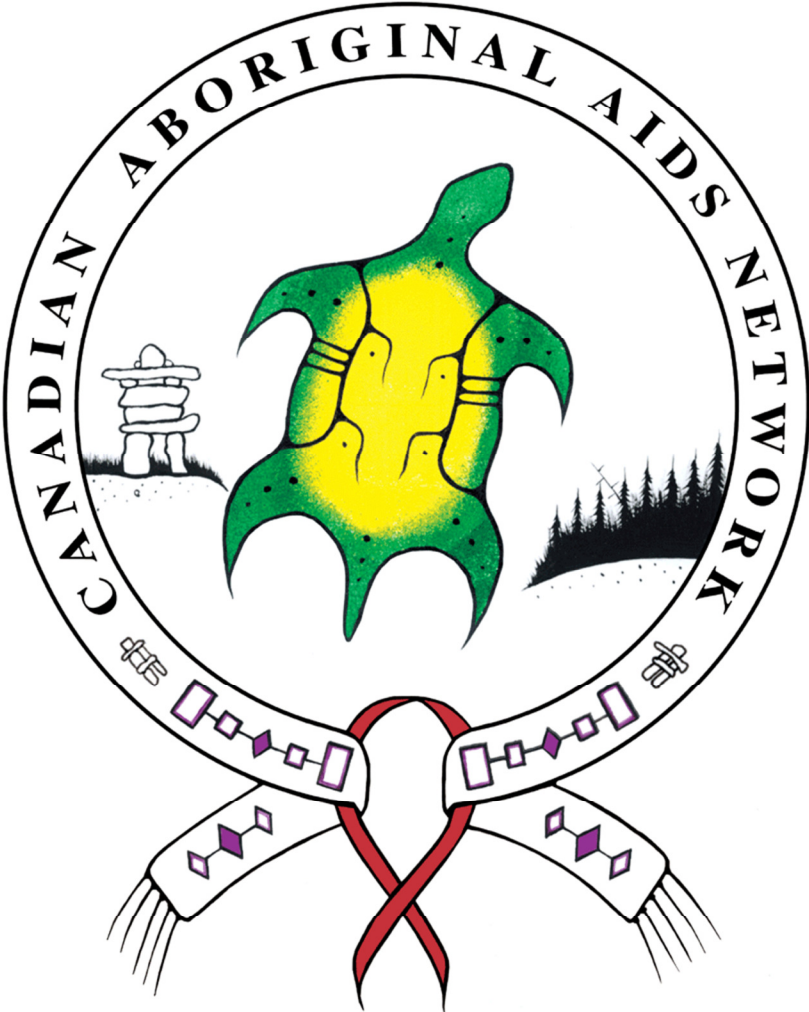


Canadian Journal of Aboriginal Community-Based HIV/AIDS Research

Volume VI, Winter 2014





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

CAAN is grateful for the participation of Aboriginal people living with HIV/AIDS and of the health care and support of professionals who shared their time and wisdom. CAAN also thanks the research team and members of the National Research Advisory Committee (NRAC).

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Canadian Aboriginal AIDS Network©

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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.

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CAAN would like to acknowledge the members of the 2014 Editorial Peer Review Board.

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INTRODUCTION

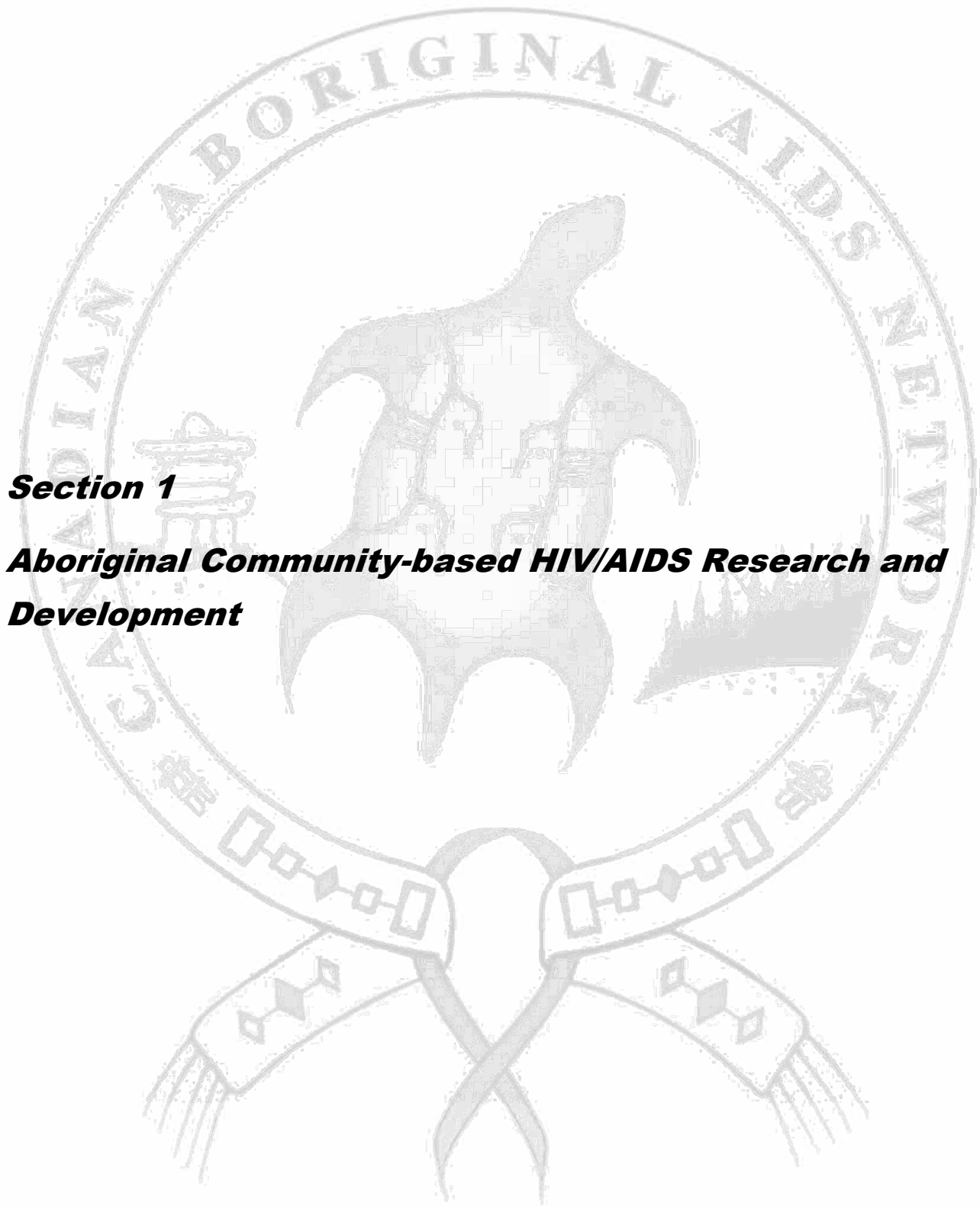
We have engaged in a dynamic review process this year and would like to extend a warm thanks to our 2014 Canadian Journal of Aboriginal HIV/AIDS Community-based Research (CJACBR) review team and all of the authors for their important contributions to Aboriginal HIV/AIDS CBR! Our reviewers have asked important questions of the authors and research teams that submitted their work, and authors have welcomed the feedback; even expressed thanks for making their contributions to Aboriginal HIV/AIDS research stronger.

As anyone in this field is well aware, working together as a team not only makes us better, but stronger in our fight against HIV/ AIDS. The articles that make up Volume VI of the CJACBR speak to the importance of collaboration in the work we do. The first two articles in Volume VI, highlight the engagement of community and Aboriginal People Living with HIV/AIDS (APHAs) in defining research priorities in different regions in Western Canada. The remaining two articles offer research results and highlight projects that would not have been as effective or as meaningful, had they not included strong community components. One investigates perceptions of alcohol use in APHAs who access health services and the other article looks at condom use among youth in Quebec.

We hope you find the articles presented here engaging, insightful, and most important, useful as you conduct CBR projects in your own communities. Please help the CJACBR continue to grow by submitting articles, commentaries and stories that you would like to share with the rest of our community. As researchers, students, academics and activists, we have so much to say!



Marni Amirault & Sherri Pooyak



Section 1

Aboriginal Community-based HIV/AIDS Research and Development

Voices from the Fire: Innovative and Collaborative Findings to Inform Effective HIV/AIDS Interventions in Aboriginal Communities

Scott D. Oddie¹, Raye St. Denys², Lisa Armstrong³, Quinn Quin⁴, Jennifer Vanderschaeghe⁵

1. Dr. Scott Oddie Chairs the Health Research Collaborative, an applied research program of Alberta Health Services (AHS) and Red Deer College, and is the AHS Director of Primary Care Research. Dr. Oddie leads collaborative teams of health practitioners, academics, community stakeholders, decision makers and students that address issues, problems or processes in our health system and/or community. These collaborative initiatives address a diverse array of health issues that include Aboriginal HIV/AIDS, enhancing independence of seniors and persons with disabilities, and community-based physical activity interventions to enhance mental wellness in children and youth as well as measuring the impact of primary care. Working together, project teams generate knowledge and evidence that is immediately applied to improve health and wellness outcomes in communities.

2. Raye St. Denys is a Métis mother and grandmother who holds a Bachelor of Education degree from the University of Calgary, a Rehabilitation Services Diploma from Mount Royal University and an Addiction Services Diploma from the University College of the Fraser Valley. Currently, she is the Executive Director of Shining Mountains Living Community Services in Red Deer, Alberta. She has previously worked with the Sto:lo Nation people in Chilliwack, British Columbia as a Family Violence Counsellor where she was invited to join the National Warriors Society against Violence. Nationally, Raye has taken part in developing the 2nd Aboriginal Strategy on HIV/AIDS, in the National Review on HIV/AIDS Funding and in the development of the Population Specific HIV/AIDS and Hepatitis C Status Report for People Who Use Injection Drugs. She also developed Métis specific HIV and other health resources and tools for use by Shining Mountains.

3. Lisa Armstrong is a research technician at Red Deer College and a recent Bachelor of Arts Psychology graduate from the University of Calgary.

4. Quinn Quin is a Métis advisor and community based researcher on the *Voices* project since its inception in 2009. He provides ongoing supports for ceremony for our advisory and research team as well as spiritual guidance. Quinn has been active in helping to educate others and advance HIV/AIDS initiatives provincially and nationally

5. Jennifer Vanderschaeghe lives in Red Deer Alberta. Jennifer has been the Executive Director of the Central Alberta AIDS Network Society for 10 years and has been working in HIV in Alberta since 1993. Currently, Jennifer is the Treasurer for the provincial coalition the Alberta Community Council on HIV. She has been a long term volunteer with the Red Deer Native

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ACKNOWLEDGEMENTS

We dedicate this manuscript to Jimmie. “Ekiwahtey imat anihī ka-pimi-nikan oh takot (Cree).” “Those who were here and are missed, we will see you again.”

Thanks to the Aboriginal field researchers that collected the stories for this project as well as all those who helped with the Voices to Action gathering. This project was awarded grant funding by the Canadian Institute of Health Research.

The authors would also like to recognize the significant contribution of Erin Konsmo.

ABSTRACT

There is a large difference in HIV/AIDS rates among Aboriginal people compared to non-Aboriginal people in Alberta as well as the rest of Canada. To address this epidemic a team came together to examine the barriers, needs and supports of Aboriginal people living with and affected by HIV/AIDS. Voices from the Fire: Visions in Truth (Voices) was a community-based research project that used storytelling to provide an Aboriginal perspective of HIV/AIDS to create education, prevention and support strategies in central Alberta. Aboriginal people received training as field researchers and collected 22 stories from individuals that had knowledge about the impact HIV/AIDS has had on Aboriginal persons, their families and communities. The main themes gathered from these stories are related to six key overarching concepts: colonialism, culture, acceptance, knowledge, community and relationships. These themes were shared and explored at a community gathering of about 42 diverse stakeholders. The objectives of the gathering were to: 1) review the messages from the Voices project; 2) develop a common language and understanding of the barriers, supports and needs identified and 3) develop action plans to improve outcomes and address the current epidemic. Action plans centered on culturally appropriate HIV education with an emphasis on Elders teaching youth. These plans have been shared with the communities involved with a goal that actions will be supported and implemented by stakeholders. It is predicted that these strategies will be effective in reducing the spread of HIV infection in the central Alberta Aboriginal population.

INTRODUCTION

Aboriginal Peoples are defined as the original inhabitants of Canada including First Nations, Métis and Inuit (Aboriginal Affairs and Northern Development Canada, 2012). There exists such a large disparity in HIV/AIDS prevalence rates between Aboriginal people and non-Aboriginal people in Canada that it continues to be an epidemic in our nation (Public Health Agency of Canada [PHAC], 2012a). In 2006, the Canadian Census found that Aboriginal people (First Nations, Métis or Inuit) constituted 3.8% of Canada's population (Statistics Canada, 2006a), yet in 2011 8.9% of all prevalent HIV cases in Canada were reported within the Aboriginal community (PHAC, 2012b). In 2011, PHAC found that Aboriginal people in Canada experienced new HIV infections at rates 3.5 times higher than non-Aboriginal people (PHAC, 2012b). It was estimated that 390 (with a range of 280 to 500) Aboriginal people were infected with HIV in 2011, accounting for 12.2% of all new HIV infections that year. To emphasize that this is a continuing epidemic, in 2008 roughly the same number of new infections were reported (i.e. 420, with a range of 290 to 550, which was 12.6% of all new infections reported that year; PHAC, 2012a).

Disparities also exist between Aboriginal people and non-Aboriginal people regarding new HIV infection exposure categories including injection drug use (IDU): 58.1% vs. 13.7%; heterosexual contact: 30.2% vs. 20.3%; male to male sexual contact (MSM): 8.5% vs. 46.6% and MSM-IDU: 3.2% vs. 19.4%, respectively; PHAC, 2012a). Aboriginal people are more likely to be diagnosed with an HIV infection at a younger age than non-Aboriginal people (33.5% of Aboriginal people diagnosed with HIV infection between 1998 and 2008 were under the age of 30 whereas only 21.2% of non-Aboriginal people in the same age category were; PHAC, 2010a). These statistics should be interpreted with caution, however, because only 29.3% of new HIV positive test reports in 2011 included ethnic identity information (PHAC, 2012a). This lack of complete and accurate representational data regarding current HIV/AIDS incidence and prevalence rates among the Aboriginal population in Canada means that the extent of this epidemic is most likely under-represented (PHAC, 2010b).

In Alberta, where the *Voices* research project took place, among First Nations people the rate of newly diagnosed HIV infections in 2011 was 25.4 cases per 100,000 First Nations persons (Government of Alberta, 2012). When compared to the total HIV rate of 6.9 per 100,000 population in Alberta that same year (PHAC, 2012a), it's evident that HIV among First Nations people is drastically higher than non-First Nations people and needs to be addressed. This is likely the case for Métis people in Alberta as well, although the impact of HIV on this specific group of Aboriginal people requires more examination.

Social Determinants of Health

The reasons for the stark differences in HIV incidence and prevalence rates between Aboriginal people and non-Aboriginal people in Canada are complex and related to a host of social determinants of health (PHAC, 2010b). One such determinant of health related to the HIV/AIDS epidemic is colonialism (Flicker et al., 2007; Larkin et al., 2007; Waldram, Herring, & Young, 2007). Colonial practices, such as the residential school system, has led to an immense loss of culture, language and traditional knowledge/practices, severed family and community connections, decimated self-esteem as well as contributed to personal and collective experiences of current and historical trauma (Barlow, 2003; DeGagné, 2007; Wesley-Esquimaux & Smolewski, 2004). Other health determinants that have been linked to an increased risk of HIV infection include discrimination (Martin Spigelman Research Associates, 2002), stigmatization (Mill et al., 2007), sexual abuse (Pearce et al., 2008) as well as poverty (Larkin et al., 2007) and unstable housing (Marshall et al., 2008) which are all disproportionately experienced by Aboriginal people. The aforementioned factors are inextricably intertwined and can increase the likelihood of an individual engaging in behaviours that put them at risk of HIV infection (PHAC, 2010b) such as injection drug use (Craib et al., 2003; Miller et al., 2006; Wood et al., 2008), sex work, (Mehrabadi et al., 2008; Shannon, Bright, Gibson, & Tyndall, 2007) and irregular condom use (Shercliff et al., 2007). Aboriginal people are not at a higher risk for HIV infection in isolation from these social determinants of health (PHAC, 2010b) which is exemplified by the quote, “Being ourselves is not ‘risky’ and can be a strength and source of empowerment. What actually puts people ‘at risk’ are colonization, racism, and not having access to culturally safe care” (Danforth, 2013, as cited in Flicker et al., 2013, p. 6).

Barriers to HIV Care

Social determinants of health, such as discrimination and stigma, can be barriers to accessing HIV/AIDS related knowledge, prevention services and treatment (Mill et al., 2007). Aboriginal people are faced with challenges of accessibility and availability, along with stigma, when trying to access culturally appropriate, safe and welcoming health care (Jackson & Reimer, 2008). Living in small communities where everyone knows everyone else can present issues of confidentiality which can deter people from accessing HIV services for fear of being ostracized (Flicker et al., 2008).

Mills et al. (2008) found that a feeling of invulnerability was pervasive in Aboriginal youth which acted as a barrier to HIV testing and contributed to the delay in accessing the appropriate services when a positive diagnosis was made. Aboriginal people in northern Alberta were also more likely have a longer time lapse between diagnosis and access to care, due to such barriers (Plitt et al., 2009). Aboriginal people living in British Columbia were less likely to access antiretroviral therapy after a positive HIV diagnosis as well (Wood et al., 2003). This lack of access to timely and appropriate health care can result in dire consequences such as the finding

that Aboriginal individuals who do access highly active antiretroviral therapy (HAART) experience shorter survival rates and a mortality rate 3.12 times higher than non-Aboriginal people (Lima et al., 2006). Furthermore, in an analysis of AIDS-related deaths in Vancouver it was found that First Nations individuals became acutely ill earlier, had more hospital admissions and hospital days per admission, spent fewer days on antiretroviral therapy, had less palliative care as well as a shorter life from HIV diagnosis to death (Goldstone et al., 2000).

The HIV/AIDS epidemic in the Aboriginal population in Canada calls for Aboriginal communities and organizations along with researchers, service providers, policy makers and other key stakeholders to unite in an effort to overcome the gaps and barriers that discourage or prevent Aboriginal people from accessing HIV testing, treatment and prevention services and supplies (Steenbeck, Amirault, Saulnier, & Morris, 2010). Numerous studies have emphasized the necessity to approach this objective, of ultimately reducing the HIV incidence rates in the Aboriginal population, with cultural appropriateness and sensitivity. Such an objective should be guided by the OCAP principles of Ownership, Control, Access and Possession (First Nations Centre, 2007) as well as done in collaboration with Aboriginal people, communities and services to ensure the utmost quality of research (Kurtz, 2013). *Voices from the Fire: Visions in Truth (Voices)* was a community-based collaborative research initiative that stepped up to answer that call. Aboriginal individuals living with HIV, Aboriginal social and health service organizations, academics and students came together in a collaboration to examine the needs to develop a culturally sensitive and community-based approach to reduce the high rates of HIV/AIDS among Aboriginal Peoples in Central Alberta. A Collaboration Charter was used to state the objectives, benefits, values and principles that guided the conduct of the Collaboration.

Project Objectives

The purpose of *Voices* was to inform Aboriginal HIV/AIDS education, prevention and support strategies in Alberta with the goal of ultimately reducing the incidence of HIV/AIDS in Aboriginal communities. *Voices* was a project where Aboriginal people received field researcher training and accreditation and then collected stories from Aboriginal individuals and others who had knowledge about the barriers, supports and needs of Aboriginal people living with HIV/AIDS. Once those stories were collected, youth, Elders, Aboriginal people living with HIV/AIDS, community members and service providers were invited to attend a gathering to: 1) review the messages from the *Voices* project; 2) develop a common language and understanding of the key messages and 3) develop action plans to reduce barriers and enhance supports to improve outcomes and address the current epidemic.

METHODOLOGY

Design

Funding agents are encouraging research with the Aboriginal population, however, there is a lack of funding going towards research initiated by Aboriginal people (O'Brien-Teengs, 2010). O'Brien-Teengs (2010) states 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" (p.32). What was positive and unique about this research was that it was initiated by a local Aboriginal community service organization, includes Aboriginal people on the research team and adheres to the OCAP principles. Our project was designed, implemented, analyzed and disseminated with the leadership of Aboriginal people and community advisors.

Voices used a retrospective case study design. It was guided by a community-based participatory approach (CBPR) which emphasizes research collaboration and partnerships with communities rather than in or on communities (Israel, Schulz, Parker, & Becker, 1998). This community-partnered orientation builds mutual respect, focuses on capacity building at the individual and community levels as well as promotes a balance between research and action (Israel et al., 1998). This orientation to research is uniquely relevant to approaching issues of complex health disparities and aims to minimize the risk of upholding existing colonial power inequalities and roles (Minkler & Wallerstein, 2010). The team working for the *Voices* project recognizes that Aboriginal people and communities need to be key partners in addressing HIV/AIDS in their population. Aboriginal individuals along with their service providers have perspectives and local knowledge that are imperative to understanding and implementing a relevant and effective HIV response (Restoule, Campbell McGee, Flicker, Larkin, & Smilie-Adjarkwa, 2010).

In order to engage active community participation in our research, Aboriginal field researchers were trained in the skills of CBPR, research ethics and conversation facilitation with the purpose that these individuals would be able to appropriately ask people in their community to share their stories in order to effectively gain a perspective about HIV/AIDS informed by Aboriginal people. They also participated in the Shining Mountains Living Community Services 2009 central Alberta Aboriginal HIV/AIDS Conference: Positive Changes, at which a storytelling workshop was held as well as Elder-lead storytelling groups. Storytelling was chosen as a methodology for this research project due to its traditional role in Aboriginal culture for sharing and building knowledge systems. Furthermore, not only does training Aboriginal individuals to conduct interviews foster trusting, open and honest relationships between the researchers and the participants which often contributes to more valid and relevant data to Aboriginal people's lives (Israel et al., 1998), it builds research capacity and skills in these Aboriginal individuals (Masching, Archibald, & Jackson, 2009). Training Aboriginal field researchers also puts the research process in the power and control of the community, because they decide who and how to interview. Lastly, using this methodology is an attempt by our team to go beyond the OCAP

principles, which have been alleged by some Aboriginal people as based in colonial ideology; “if we [Aboriginal people] 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” (O’Brien-Teengs, 2010, p. 32).

Procedure

Aboriginal field researchers identified participants living with HIV/AIDS, or those with significant knowledge of HIV/AIDS (such as individuals working in the field or loved ones of people living with HIV/AIDS) from their communities. It should be noted that given the stigma surrounding this health issue, field researchers found it a challenge to identify individuals to participate in the study, especially youth and young adults. However, youth were included in the *Voices to Action Gathering* (see below).

Field researchers then conducted semi-structured interviews using a Story-Telling/Interview Guide (Figure 1). The guide was developed by Aboriginal peoples living with HIV and our Community Advisory Group. It was given to participants prior to their semi-structured interview and helped them to consider the multiple and complex ways that HIV can affect an individual, their family, community and society from spiritual, physical, mental and emotional perspectives.

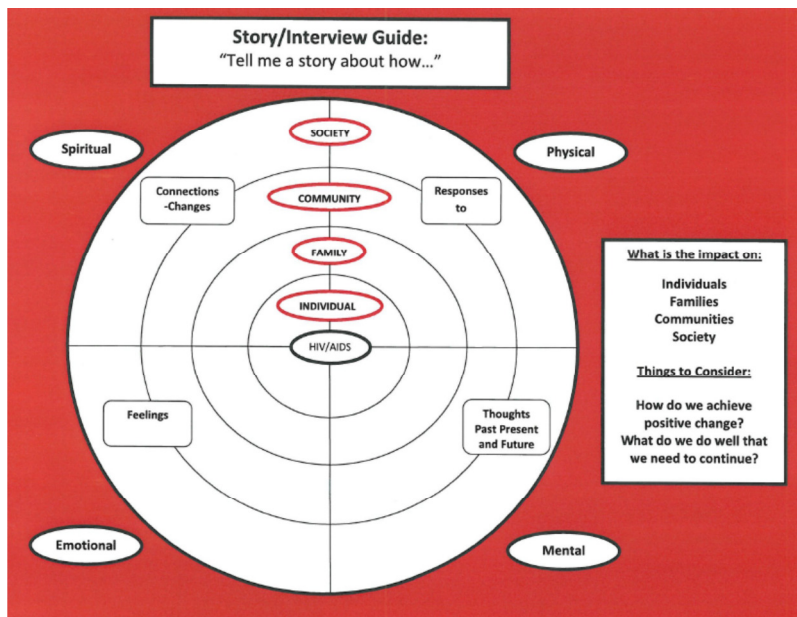


Figure 1. Story-Telling/Interview Guide used for semi-structured interviews. Field researchers provided participants with this guide to help them reflect on stories, experiences and perspectives they shared during the interview process.

Twenty-two stories were collected from different people in diverse locations within Alberta. All had knowledge about HIV/AIDS from an Aboriginal peoples’ perspective and/or how it has affected their community. The majority of stories were collected from individuals in central Alberta with an additional few from the Edmonton area. Of the interviewees, 17 were female and 5 were male, most were First Nations and/or Métis people and ranged in age from 18 to Elders.

Urban and rural community members were represented and included: 1) People that were living with HIV/AIDS; 2) Family and/or friends of people living with HIV/AIDS, 3) People working with an Aboriginal HIV/AIDS organization; 4) Former IDUs and mothers of IDUs; and 5) a mix of people with relevant perspectives that included a retired nurse, an individual who worked to educate Aboriginal women/college students/high school students about HIV/AIDS and an Aboriginal advisor in the penitentiary system. The relatively low number of stories collected is indicative of the difficulties the Aboriginal field researchers faced when trying to identify people who were willing to share their perspective about this stigmatized disease.

Interviews and stories collected were digitally recorded and guided by questions that asked participants to share stories about the physical, mental, emotional and spiritual impact that HIV/AIDS has had on them as individuals, their families and their community (see Figure 1). “Participant autonomy was achieved through the community-based research method that ensured the following: 1) Through informed consent, participants were told they would remain anonymous and what they shared would be confidential until all stories could be examined to identify emerging themes; 2) Participants were told the purpose of the information to be collected (identify supports and gaps to inform service development); 3) Community-based researchers were used in the design so that trust could be established early in the research process; and 4) Participants were told that they would be able to review the stories they shared and remove any part, or all of the content if they wished.”

ANALYSIS

Digital recordings of interviews/stories were transcribed and then thematically analyzed using Interpretative Phenomenological Analysis (IPA) to identify key themes (Creswell, 2012; Smith, Flowers, & Larkin, 2009). Researchers identified key themes, indicators of impact and suggestions for improvement that were prevalent in the stories shared. Two independent coders were involved and inter-rater reliability was high (approximately 90%), as both coders agreed on the themes identified. Discrepancies in interpretations were discussed until 100% agreement on key themes was established. Interviews were concluded when saturation of themes was reached. That is, new themes were no longer emerging in the stories/interviews collected.

Voices to Action Gathering

In order to invoke positive change about the key messages/themes, the research team hosted a *Voices to Action* community gathering in May 2014. This event focused on disseminating the themes found from the *Voices* project to the local Aboriginal communities, HIV/AIDS service organizations, health care providers and other key stakeholders. Building a common language around these themes was crucial at this gathering so that detailed action plans could be created. These action plans address the gaps, barriers and needs identified from the participants of the

Voices interviews and stories as well as from the added perspectives shared by the guests of the *Voices to Action* community gathering.

Gathering Participants

Approximately 42 individuals attended the *Voices to Action* gathering. Guests were diverse in age, culture and professional background and included Aboriginal youth (13 – 16 years of age) from a local group home, local Aboriginal people living with HIV/AIDS, interested and invested Aboriginal- and non-Aboriginal community members, Red Deer College (RDC) Aboriginal students and health program students, as well as representatives from local, regional, provincial and national HIV/AIDS organizations. Service providers represented various health service areas (e.g., population and public health; Aboriginal peoples' health) and representatives from a host of different HIV/AIDS organizations were in attendance including the Canadian Aboriginal AIDS Network (CAAN), Central Alberta AIDS Network Society (CAANS), the Alberta Community Council on HIV (ACCH), the Métis Nation of Alberta, the Lethbridge HIV Connection, the BBP (Blood Borne Pathogens)/STI (Sexually Transmitted Infections) Prevention Program as well as Shining Mountains Living Community Services.

RESULTS

From the 22 stories collected, six themes emerged: colonialism, culture, acceptance, knowledge, community and relationships.

Themes from *Voices*

Culture: Culture and the importance of cultural identity to Aboriginal people, especially those affected by HIV/AIDS, were shared by participants.

When their culture is a broad-based vision within which they conduct themselves a particular way, how they envision their lives to be, this has an incredible effect in preventing HIV; in allowing people who are affected and infected with HIV to find a means to live their lives, to get help that they need.

Cultural practices and traditional medicines were discussed in relation to HIV/AIDS as well, including the lack of culturally appropriate HIV services.

I know that there's some old men out there, they knew that medicine for that HIV/AIDS, but you live in the city and you don't have access to those medicine people and you don't have access to those ceremonies. Culture can bring about a willingness to listen to each other and support each other. It can create a place where people with HIV/AIDS and the community around them can open up their hearts and minds. Culture provides a space of love, support and attention.

“[Health care providers] They say, ‘This is what’s happening with you’ but as far as culturally, no, I don’t think that’s [traditional medicines and cultural practice] available.”

Acceptance: Acceptance by family, friends and of oneself/others after a positive diagnosis was mentioned by participants as a means to cope with HIV/AIDS.

You know just the turnaround in people, the willingness to listen to each other. The willingness to support each other and then you open up that door, then you start bringing in people who have this HIV and AIDS and people open up their hearts and their minds.

Community acceptance was a subtheme and participants mentioned the importance of ensuring that individuals who are HIV positive are not shunned or banned from the community.

Because it’s so much more than just a person having HIV/AIDS, it’s a person with HIV/AIDS being accepted by their community. I mean, it’s just needing that support and understanding, an understanding community of somebody who’s impacted by HIV/AIDS.

What I think would be outstanding is to see that person come to a place of tremendous sense of belonging. If it is a sweat lodge or a smudge, some sort of ceremony, say, ‘You are a member of our community. You are a person of value and we’re going to work with you and we’re going to support you and find a way to get that to you to a place of health; get you to a place where you are happy’.

Personal acceptance was another subtheme in which respondents talked about their coming to accept their diagnosis or the diagnosis of a close individual in their life. A few participants mentioned how their diagnosis contributed positively to their life.

I think it’s because of HIV that I learned some of the information that I did and I decided to change my life in certain ways that I did. So in a way I could say it’s impacted me positively.

Knowledge: There was a perceived lack of knowledge about HIV/AIDS reported by many participants which was believed to increase the risk of HIV infection.

I mostly learned from my friends growing up, as my parents didn’t really have much knowledge on HIV and AIDS. And we briefly learned about it in school but mostly ... ‘wear a condom, it’s the only way to protect yourself’.

I see HIV as high risk because people in the Aboriginal community aren’t aware of the consequences, especially on reserves because they’re not informed or don’t think it can happen to them.

Education and the importance of culturally appropriate teachings were discussed as key to preventing HIV/AIDS in Aboriginal communities.

When we went into a community it wasn't for a half hour presentation or an hour presentation. I mean we were in each community for a week; we were in prisons for a week. 'Cause it takes time, our old people they say it takes at least four days for the mind to make its journey to the heart. When it makes that journey, that's when knowledge happens; information turns into knowledge. But they don't follow those practices anymore because there aren't Aboriginal people involved. You know, First Nations and Métis and Inuit people involved in preventing this disease or involved in getting that knowledge to our people.

I'm one of how many other people that have just lectured them on, 'Don't do this, and you shouldn't do that' which comes across as judgment, right? But if I sit in a circle with them and say, 'Let's talk about this. What are your fears around this? Maybe I can answer some questions in this area. If I don't know, I'll make a point of trying to find out and let you know.' And in that way you get meaningful exchange of dialogue, and that's the most effective way for Aboriginal people.

I think for the Aboriginal people the most significant education comes from the Elders; because for [Aboriginal] women, they come and they learn through ceremony.

Community: The importance of community support, working in Aboriginal communities and the value of focusing on the community itself in addressing HIV/AIDS in the Aboriginal population was discussed by many participants.

You see those programs that bring people together, to share, to strive together, motivate together, to attain health together. You're creating community and community is, I mean I do personally hold community up very high, because I think that's so much the answer to a lot of our issues, especially when we're looking at the Aboriginal community.

You know, as an Aboriginal person living in inner-city, living under strife and instability, we had every opportunity to engage in all of the behaviours that make you susceptible to HIV and to AIDS. And why didn't we? It came down to understanding who we were and who we were in the community. I'm an Aboriginal person that has a sense of belonging, that I understand the value, to some degree, of my culture.

Relationships: Participants discussed how HIV/AIDS is not a disease that impacts individuals only; rather that it impacts human relationships. These relationships can also be used as support for those living with or affected by HIV/AIDS.

I believe that there is a lot more of an impact and there's a lot more of a success in terms of outcomes when individuals are able to share with other individuals their stories, their knowledge, and compassion and their ability to help, a giving of themselves; that can prevent somebody from contracting HIV.

The Elders said HIV/AIDS has so much compassion for us, it's here to teach us how to have healthy relationships with each other, how to respect one another.

Sharing, caring, honesty and respect are the way to maintain healthy relationships. Those are the things that are going to prevent this disease in our communities. And those are very cultural values on sustaining healthy relationships.

Colonialism: Many participants understood colonialism as a contributor to the high rates of HIV/AIDS in the Aboriginal population.

I don't think it's a big stretch to say that Native people in general, because of the societal conditions and the long history... are more vulnerable to HIV.

Some participants noted the relationships between colonial ideology and risky behaviours such as unsafe sexual practices.

I mean, the Europeans come in and we all know that they conquered the country. They have everybody sitting on reservations. I think the government set it up that they created a people of dependence not independence. ... So when you have people who are dependent on somebody else for all their means and livelihood or whatever, you have to somewhere along the line expect that you're going to have some low self-esteem. You're going to have some problems with drugs and alcohol ... then you have them practicing unsafe sex and I suppose unsafe needle use.

There is in the society at large, you know, has a very patriarchal society. There's a lot of misogyny. It makes our Native women particularly vulnerable to infection, because of the high prevalence of prostitution [as well as] women involved in the sex trade, because of their vulnerability, socially.

These participants' responses are consistent with the notion that colonialism has resulted in risky behaviours. Respondents also mentioned that HIV/AIDS organizations have colonial approaches for addressing HIV in the Aboriginal population which are problematic.

HIV/AIDS organizations, they're so territorial ... they won't let us own that issue, that's their issue. You know and even though we're suffering so much from it, they won't allow us the freedom to work on it by ourselves. We've got these gate keepers now ... they have the information, they have the knowledge, they have the practices, they have the language, they have the attention of governments, they have the attention of medical establishments. ... They're a barrier to us representing ourselves when it comes to addressing this disease.

We continue to have institutions that are completely colonial. The whole, the way in which HIV/AIDS organizations are set up is very colonial. They think that equality, it's translating to sameness. And sameness is not equality.

Devaluing of personal identity through marginalization and racism was a subtheme that emerged from this colonialism concept. Participants shared their knowledge of the discrimination experienced by Aboriginal people and how that relates to the HIV/AIDS epidemic.

We have, depending upon where you sit in Canada, 200 to 500 years of alienation and isolation and racism and discrimination and essentially giving Aboriginal people almost an intrinsic feeling of not belonging in their own skin, never mind in their own country.

So many more Aboriginal people are underprivileged, I guess you could say; so as long as that difference remains that's going to continue how HIV continues to affect Aboriginal people.

Voice to Action Gathering: Creating a Common Language

Following analysis of the *Voices* stories and identification of the emerging themes/messages, there was a need to share themes/messages with the Aboriginal community, discuss them to create a common language around each theme/message, and then collectively create an action plan to determine the next steps that communities could take to create positive change. At the *Voices to Action Gathering*, guests discussed their interpretations of the messages collected from the participants of the *Voices* stories/interviews. Creating this common understanding of the key themes/messages was critical to successful action planning which followed. Diverse perspectives of these key themes/messages needed to be shared and deliberated so the community could come to a common understanding of the issues and supports needed. This section will share the community interpretations that were discussed for each theme.

For the theme ***culture***, gathering participants discussed their own definitions for the term “culture” and what it means to them individually. One definition arrived at is that “culture is a state of being that determines who we are, how we live and how we express our humanity.” Participants discussed how culture should come from Elders through oral traditions because stories are powerful healing devices. It was also discussed that subcultures need to be integrated into talks about HIV/AIDS such as the subculture of Aboriginal people who are living on the street.

Interpretations of the theme of ***acceptance*** included an emphasis that HIV/AIDS education can be an important way to create better understanding and thus acceptance towards individuals living with HIV/AIDS. Participants also discussed that the more people talk about HIV/AIDS, the more easily and openly it will be able to be talked about and this open communication about

it will create more acceptance. Education can also be a key to opening up these lines of communication. Participants considered how community members should accept not only a person living with HIV/AIDS but also how and when that person chooses to share their diagnosis. Lastly, the need to support youth was mentioned so that they can learn to respect themselves which will help them gain a sense of purpose and subsequently give them feelings of acceptance.

Interpretations about the messages of *knowledge* discussed different types of knowledge including practical knowledge (such as access and use of preventative measures) as well as experiential knowledge (ex. knowledge gained from listening to those living with HIV/AIDS) and that educational teachings should include both. Information also needs to be holistic, that is, teaching more than just about the disease itself but also about all the factors surrounding the disease (such as the related social determinants of health).

For the theme *community*, participants underscored the importance of welcoming those living with HIV/AIDS as that will strengthen not only that individual's sense of community, but their own as well. If people living with HIV/AIDS are shunned then the community will not be as strong without them. Participants felt that people living with HIV/AIDS should be able to speak out about their experience with the disease, educate the community and become leaders.

Interpretations of the theme regarding *relationships* emphasized that it is important to build a positive relationship with one's self first before trying to build a positive relationship with others. Teaching youth how to build self-esteem and self-respect will help them build those positive relationships. Relationship building with others also takes time and requires accepting where the other person is at and honoring their style of communication. Honest communication is crucial because it can overcome HIV/AIDS myths and thus stigmatization so positive relationships can be built.

For the theme *colonialism*, gathering participants emphasized that there is a lack of understanding between non-Aboriginal and Aboriginal people with regard to Aboriginal culture. It was proposed that it is this lack of understanding that creates judgement. Participants also added that they feel many non-Aboriginal groups interact with Aboriginal people with a self-serving agenda, they stated that it should be about building relationships first, then building business later.

Recommendations and Action Plans

Once the guests of the *Voices to Action Gathering* reviewed the themes from the *Voices* project and created their own language and understanding around those themes, they were asked to create action plans. These action plans identified what the group wants to do to "support good things, or prevent bad things", regarding HIV/AIDS in the Aboriginal community. They were asked to develop these action plans to include details of what action will occur, who will carry it

out, when will it take place and for how long, what resources are needed to carry out the action as well as communicate who should know what.

The most prominent three action plans that emerged from discussions at this gathering all relate to education. They include education about 1) facts about HIV/AIDS as a disease, 2) cultural traditions and 3) how to build positive relationships would have a large impact on reducing the incidence of HIV/AIDS in the Aboriginal community. These education plans would be rolled out in Aboriginal communities in central Alberta where Elders of the respective Aboriginal communities would carry out these gatherings with the help of Aboriginal facilitators. A large part of such gatherings should focus on Elders teaching youth through traditional stories about the three main topics and more. These gatherings would begin by the end of this year and continue preferably multiple times per year.

Resources that are necessary for these types of gatherings can come from the provincial government for off-reserve and Métis community gatherings and national government funding for those held on-reserve. HIV/AIDS organizations in central Alberta should also help with funding. Free transportation to and from gatherings is also something that would need to be provided. Aboriginal facilitators would need to be trained in facilitation and Elders need to be provided with accurate HIV/AIDS information. Those that need to be aware of this initiative include the communities hosting the gatherings, Elders, Aboriginal community members that could be potential facilitators, the provincial and national government Aboriginal health divisions as well as the local HIV/AIDS organizations.

An important piece to the first action plan (facts about HIV/AIDS as a disease) is providing Aboriginal Elders with accurate HIV/AIDS facts and information directly from HIV/AIDS organization representatives. The purpose of this education is to reintegrate traditional forms of knowledge transfer as Elders would take the knowledge shared by the HIV/AIDS organization representatives and disperse it back to their communities. Having the Elders lead the discussions, would ensure that information sharing is done in a culturally appropriate way and in a manner that Aboriginal people can best receive and use.

Additionally, the educational gatherings would promote knowledge transfer from Elders to HIV/AIDS organization representatives about how service providers can more appropriately work with Aboriginal communities. A relationship/partnership between Elders, Aboriginal communities and HIV/AIDS organizations needs to be established in order for this action plan to be successful. The educational gatherings would be held in Aboriginal communities; transportation to and from the gatherings would need to be provided. Funding is also needed, along with knowledgeable staff from HIV/AIDS organizations to share accurate information and supports with Elders. However, all staff members need to be assessed for, and thoroughly trained in cultural sensitivity. A goal would be to build sustained relationships with Elders prior to knowledge transfer activities. Relationships take time to build and so, it was recommended that

HIV/AIDS organizations begin cultural sensitivity training with their staff within the next three months and then begin building those relationships afterwards. Also, as identified by community stakeholders at the *Voices to Action* gathering, interpreters should be available as some Elders do not speak English or speak very little.

A third action plan is to have education about HIV/AIDS, factors surrounding it such as unsafe sex, injection drug use, peer pressure and consent be a mandatory and large part of school curriculums and Aboriginal youth teachings. These teachings should be required and on-going throughout the grades. Ways of teaching should be culturally appropriate for Aboriginal students as well as engaging to youth such as by using technology and social media. However, these methods should first be approved and guided by Aboriginal Elders so that they are conducted in a culturally sensitive way. Teachers would carry out this plan but it would take a collaborative team of teachers, Elders, parents, community members and public health nurses to bring this action plan to their respective School Boards for approval and implementation. Resources needed to carry out this plan include accurate HIV/AIDS information, cultural sensitivity training for teachers as well as technology to make the lessons engaging.

DISCUSSION

The *Voices* research project provided training to accredit Aboriginal field researchers to conduct interviews and collect stories that described the impact that HIV/AIDS has on individuals, families and Aboriginal communities. Key messages collected by researchers pertained to the: 1) ways colonialism has impacted the HIV/AIDS epidemic, 2) necessity of acceptance of oneself and others living with HIV/AIDS, 3) need for community support and a sense of belonging, 4) importance of culture, 5) significance of good knowledge and 6) impact of relationships.

At a gathering held among Aboriginal HIV/AIDS stakeholders to understand key messages from the *Voices* project, action plans to reduce HIV infection rates and improve health for Aboriginal communities in Alberta were created. HIV/AIDS prevention education, with a focus on culturally appropriate teachings for Aboriginal youth, was a main action plan shared by the guests of the *Voices to Action* gathering. Other researchers have suggested that Aboriginal youth are one of the most in need demographics of sexual health services (Hampton, McKay-McNabb, Jeffery, & McWatters, 2007), such as HIV prevention education (National Aboriginal Youth Council on HIV and AIDS [NAYCHA], 2010) because they are at an elevated risk of HIV infection compared to non-Aboriginal youth (Miller et al., 2006). The desire to have more culturally-sensitive and youth-relevant HIV/AIDS education was also suggested by research conducted by Restoule et al. (2010) in which youth participants in their research shared concerns about the lack of engaging and appropriate sexual education in school curriculums. Both the community stakeholders at the *Voices to Action* gathering and youth participants in Resolute et al.'s research suggested that HIV prevention and harm-reduction education that focuses on the social determinant factors surrounding the disease, such as gender and income, may be more

effective in reducing the incidence of new HIV infection than just abstinence-based education for this population (Dworkin & Ehrhardt, 2007). Furthermore, reducing the incidence rate can be accomplished by increasing utilization of prevention measures such as condoms, yet there is little evidence suggesting programs solely teaching HIV infection and transmission knowledge are enough to increase condom use (Mitchell & Kaufman, 2002; Wulfort & Wan, 1993).

A meta-analysis of 354 HIV-prevention interventions over the last 17 years found that the most effective interventions did not rely only on educational information but also included behavioural skills and attitudinal arguments as well as behavioural skills training (Albarracin, Gillette, Ho-Ho, Earl, Glasman et al., 2005). Tailoring such HIV prevention programs to the specific demographic being taught (i.e. gender, age, on-reserve or urban, etc.) is also more effective than a one-size-fits all approach (Albarracin et al., 2005; Restoule et al., 2010).

Peer-based learning, first person accounts and Elder involvement were also mentioned by both *Voices* interviewees and stakeholders at the *Voices to Action* gathering as necessary components of an effective youth HIV/AIDS education prevention strategy. Aboriginal youth in Flicker et al. (2013)'s study described their perception of "HIV workshops" as condescending - non-Aboriginal adults preaching statistics and handing out condoms. These workshops have not been found to be effective and instead many of the youth that participated in such educational programs thought they were boring, lacking interaction and engagement as well as sometimes embarrassing to be at (Flicker et al., 2013). Connecting youth with their Elders to learn not only about HIV/AIDS prevention but also about their culture, rites of passage as well as traditional ceremonies and healing practices will improve the health of youth and by extension the Aboriginal community, as suggested by the guests of the *Voices to Action* gathering as well as the researchers at the First Nations Centre (2010).

Racism and marginalization of Aboriginal people is still prevalent, otherwise, it would not have emerged as a subtheme to colonialism in this research. While service providers have promoted cultural-sensitivity training (ex. Alberta Health Services [AHS], 2009), continued discrimination of Aboriginal people, especially of Aboriginal people living with HIV/AIDS, demonstrates a lack of cultural awareness and sensitivity training of service providers (Jackson & Reimer, 2008; Miller et al., 2006). As such, the implementation of educational gatherings between Elders and HIV/AIDS organization representations would increase mutual knowledge transfer so as to help overcome the longstanding experience of racism and marginalization felt by Aboriginal people.

Having Aboriginal Elders guide such educational and youth gatherings would also promote the teachings of holistic health, which include the mental, physical, emotional and spiritual aspects of wellbeing (Hunter, Logan, Goulet, & Barton, 2006) as well as the social, political and historical determinants of health (Reading & Wien, 2009). Other studies have highlighted the necessity of such a holistic approach when addressing Aboriginal health issues (Myers et al., 1999; Ten Fingers, 2005). Focusing on Aboriginal peoples' traditional health teachings and

practices is fundamental to revitalizing Aboriginal culture (Waldram, Herring, & Young, 2007), which emerged numerous times in conversations with the *Voices* research participants and the *Voices to Action* gathering guests as essential to overcoming the HIV/AIDS epidemic. Calling attention to the surrounding factors contributing to the higher HIV risk experienced by Aboriginal youth (such as holistic health and the health determinants) in prevention education may be the key to increasing Aboriginal youth's capacity to understand and prevent HIV (Flicker et al., 2008; Larkin et al., 2007; Restoule et al., 2010).

CONCLUSION

Voices from the Fire: Visions in Truth was a research project where Aboriginal field researchers received training and accreditation to collect interviews and stories from Aboriginal people with personal experience with HIV/AIDS in Alberta communities. From these stories, six themes emerged including colonialism, culture, acceptance, knowledge, community and relationships. Time and again the non-Aboriginal academics on this collaborative research team were told by the Aboriginal research members, community advisors and partners that the messages heard from this research must be shared with the larger community and something must be done about them. As a result, a key knowledge transfer mechanism was established as a critical piece of this research: the *Voices to Action* gathering. The purpose of this gathering was to share, discuss and interpret the knowledge gained from the *Voices* research among community stakeholders. The guests of this gathering also came together to create action plans, address needs and barriers as well as create supports for those living with or impacted by HIV/AIDS. These actions have been shared with the communities involved with the expectation that designated people and organizations will take responsibility to carry them out. It is predicted that these strategies and actions will be effective in reducing the spread of HIV infection in the central Alberta Aboriginal population, specifically among youth.

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Moving Mountains to Address HIV/AIDS in Northern BC through Community Based Research

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INTRODUCTION

The traditional territory of the Lheidli T'enneh First Nation in the community of Prince George, British Columbia (BC) was the site of the *Moving Mountains: HIV/AIDS Community Based Research Conference* on June 17-19, 2014. This three-day event saw researchers, academics, leaders in Aboriginal HIV research and services, and peers explore community-based research (CBR) in HIV/AIDS in Northern BC. It was the first step in what is hoped will be a long-term process to support the development of intersectoral, cross-disciplinary community-driven HIV/AIDS research in the region.

Context: HIV/AIDS in Northern British Columbia



Northern BC is a region that comprises more than half the province – at approximately 500,000 km sq., it is larger than California or Japan and twice the size of the United Kingdom (Figure 1). The Northern Health Authority (NHA), the northernmost regional health authority in BC, provides healthcare services to a total population of 285,300 residents (Government of British Columbia, 2014). There are three distinct Health Service Delivery Areas (HSDAs), which are the geographic operating divisions that make up the region, including: Northern Interior (light blue),

Figure 1. Northern Health Authority Region (Northern Health Authority, 2014a)

Northwest (dark blue), and Northeast (white) as seen in Figure 1. As of the most recent demographic statistics in 2012, the population of each area is: 141,700 in the Northern Interior, 73,103 in the Northwest and 68,102 in the Northeast (Government of British Columbia, 2014).

It is important to distinguish between each of these HSDAs. Although they share many similarities; they also host many demographic and socio-economic differences. The Northeast HSDA, for example, is a temporary home to many migratory oil and gas workers who have helped transform the rural and urban landscape, as the result of a resource boom (Markey, Halseth, & Manson, 2009). Similar booms have changed areas in the Northern Interior and Northwest, but not with the same regional effect over a similar period of time. One similarity in the entire NHA region, however, is the large proportion of Aboriginal peoples who represent 17% of the total population (Northern Health Authority, 2014b).

In terms of HIV/AIDS, the Northern Interior and Northwest HSDAs, had the second and third highest rate of new positive HIV tests in BC in 2012, at 5.5 and 5.3 per 100,000 population, respectively, compared to the provincial rate of 5.1 (British Columbia Centre for Disease Control, 2012). Further, from 1995 to 2012 there have been 210 cases of HIV reported in the Northern Interior, 87 in the Northwest, and 21 in the Northeast (Northern Health Authority, 2013). Accompanying these rates are worrying trends among the populations at greater risk for HIV/AIDS, most prominently including Aboriginal peoples, people who use illicit drugs, and sex trade workers. These groups are party to unique regional trends, including mobility between home communities and larger urban centres (Callaghan, Tavares, & Taylor, 2007) and between urban centres, such as Prince George and Vancouver's DTES (Spittal, Craib, Teegee, Baylis, Christian, Moniruzzaman, & Schechter, 2007). As in other parts of the country, the numerous Aboriginal communities in Northern BC face unique and persistent challenges in shouldering the impact of HIV/AIDS (Duncan, Reading, Borwein, Murray, Palmer, Michelow, . . . Hogg, 2011).

Prince George, the largest urban centre in Northern BC, is home to many of the services for HIV prevention, treatment and care, including those for people living in marginalizing circumstances due to intersecting disadvantages, such as poverty, historical trauma, discrimination, stigma, and violence. However, available services do vary for priority populations and by region, throughout Northern BC. For example, Prince George in the Northern Interior and Smithers in the Northwest host a primary or receiving needle exchange site, as well as accessible satellite or secondary sites, yet similar services are difficult to locate in larger communities in the Northeast, such as Dawson Creek and Fort Nelson (Northern Health Authority, 2013, 2014a). In addition, Prince George hosts a number of HIV specific non-profit Community Based Organisations (CBOs), such as Positive Living North: No kh̄yoh t'sih'en t'sehena Society, the Northern BC Aboriginal HIV/AIDS Coalition, and the Northern HIV and Health Education Society. All CBOs have regional capacities, but are located in a central community in the region. Access to HIV treatment is also available through select providers in various locations, such as through the Central Interior Native Health Society, also in Prince George, and has been increased through the

provincial STOP HIV/AIDS and *From Hope to Health: Towards an AIDS-Free Generation* (2012) strategies. General delivery of harm reduction services, including HIV testing and counselling, condom distribution, prevention and treatment of STIs, hepatitis C, and TB, and sexual health and HIV education are available on a wider basis throughout Northern BC.

The challenges associated with healthcare intervention delivery within such an expansive and diverse geographic area are multiple. Beyond the capacity of healthcare providers, additional barriers such as travel distances and costs, limited human resources, diversity in health intervention delivery and access, lack of culturally appropriate care, stigma and discrimination, and the limited number of healthcare professionals working on HIV/AIDS in BC's North pose unique challenges.

The Planning Phase of Moving Mountains

Sometimes addressing significant issues, such as HIV/AIDS, in such a large, diverse region can feel insurmountable – like scaling a high mountain. Community-based research (CBR) can be a tool for identifying what kind of information is needed in each community, and for bringing diverse stakeholders together to develop shared agendas and move research to action (Minkler, 2005). The *Moving Mountains HIV/AIDS CBR Conference*, and ancillary activities, was born out of this desire to bring Aboriginal and non-Aboriginal people together to review research underway, build the capacity to participate in CBR, and to identify gaps in information and priorities for future research – all with the goal of strengthening the local response to HIV/AIDS.

Bringing a range of people together, some for the first time, to build relationships and to collaboratively develop research priorities was seen as an essential step in building the capacity to engage in research that might be fruitful in reinforcing assets and catalyzing solutions. Through the dedicated work of a research collaborative consisting of researchers from the University of Northern British Columbia (UNBC), a CBR specialist from the Pacific AIDS Network and the CBR Collaborative Centre (a program of the CIHR Centre for REACH in HIV/AIDS) and a community organization representative, funding for this vision was obtained through the Canadian Institutes for Health Research (CIHR) HIV/AIDS Community-Based Research Planning Grants. As part of this process, the team interacted with other several interested community representatives and a Peer Research Associate (PRA), who all provided letters of support for the initiative. In addition to CIHR funds, the Canadian Association of HIV/AIDS Research (CAHR) sponsored the event as part of their workshop series.

Once funding was secured, an Advisory Committee (AC) was formed that brought together both Aboriginal and non-Aboriginal members. Most of the AC members had provided letters of support for the initiative. Invited AC participants was made up of members from national, provincial and regional, Northern BC non-profit organizations, municipal government, academics, including trainees, health professionals, peer researchers and interested community

members. Members of the AC were proficient in a diverse range of fields including, for example, public health, nursing, frontline service provision, politics, research, and education. Participation in the designing and planning of the process was in itself an opportunity for AC members to build relationships, and therefore trust, with one another, another key element of successful CBR (Christopher, Watts, McCormick, & Young, 2008).

The June 2014 *Moving Mountains* conference was one component of what is hoped will be a long-term process to support the development of intersectoral, cross-disciplinary community-driven HIV/AIDS research in communities throughout Northern BC. Event participants included those interested in and committed to this development. A targeted invitation list was developed by the research planning team with input and suggestions from the AC, with the goal of using a personalized approach to drawing in a diverse group of participants. In addition to these invites, the conference was open to anyone of the general public who wished to attend, and promotions were made through local networks and email lists, as well as through mainstream media (Fondahl, 2014; Hinzmann, 2014; Jan, 2014; O'Connor, 2014). The sole qualifying factor that limited participation was the availability of individual financial support to travel to the conference, although travel assistance was made available upon request.

Both the planning and event phases of this project were rooted in the CBR principles of being community driven, having community relevance, promoting equitable partnerships, incorporating capacity building, attending to process, and having action-oriented outcomes (Christopher, Watts, McCormick, & Young, 2008; Minkler, 2005). The principles of the Greater/Meaningful Involvement of People Living with HIV/AIDS (GIPA/MIPA) and the Tri-Council Policy Statement, Chapter 9 (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada, 2010) – research involving the First Nations, Inuit, and Métis peoples of Canada, which underscores the collaborative process in working with Aboriginal communities – guided this project through active participation and involvement of both people living with HIV/AIDS and Aboriginal peoples whenever possible, throughout all phases of planning, implementation and analysis. It is notable that, despite the involvement of one person living with HIV/AIDS in the grant-writing phase, the AC did not succeed in recruiting a replacement for participation in the event planning – a shortcoming that became an important point of discussion.

Community agency representatives on the AC spoke to barriers to involvement that people with lived experience face when getting involved in research, including the lack of supports to facilitate involvement, the isolation faced by some peers working as Peer Research Associates in the region, and how HIV-related stigma keeps people from disclosing in such a “public” way. In light of these challenges, the AC put specific attentions towards creating an event that would be accessible and interesting to people with lived experience. The AC felt this would be achieved by hosting the *Moving Mountains* event downtown instead of at UNBC, for example. Additionally,

a session by and for peer researchers was included in the program, and arts-based and visual methods were used in the priority setting activity. APHAs were also offered honoraria for attending.

The AC and a smaller Logistics Planning Committee (which met more frequently) developed the conference to include a specific orientation. As this was the first time that many of the participants were meeting to discuss HIV/AIDS CBR in Northern BC, it was determined that the conference should include the following components: a public event with music and food; findings from research underway or recently completed be “brought back” to community; a peer-focused session, and; an interactive session that would engage participants in sharing their thoughts on what priorities for future research should be. Following the conference it would then be the work of the research team, with the continued support from the AC, to report on the activities and further develop the key priorities.

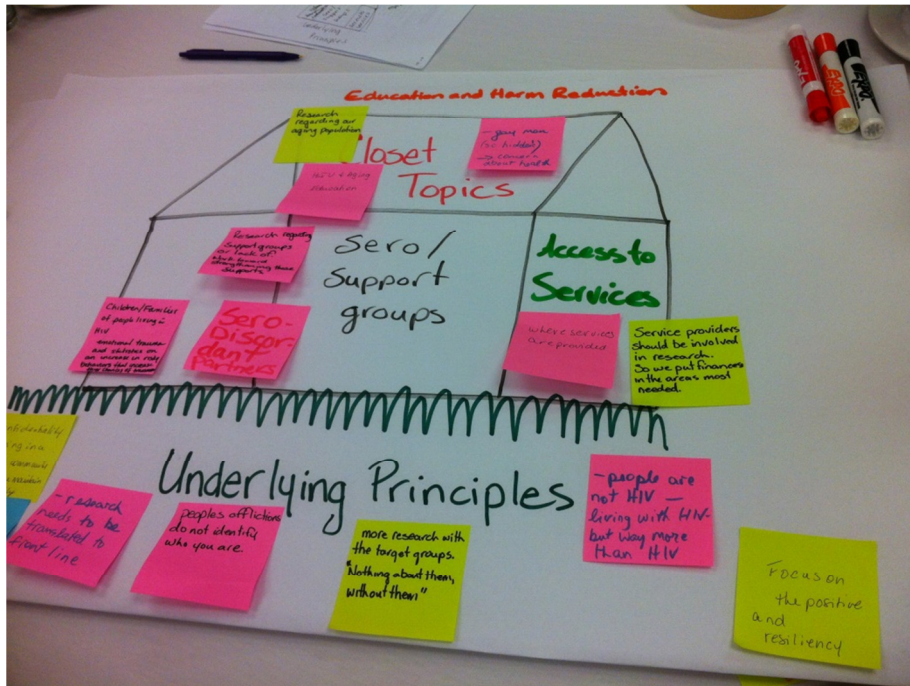
Bringing People together to Move Mountains

Marking the opening of the conference with a community event was very important to the *Moving Mountains* advisory committee. On the evening of June 17, 2014, the doors of the Power of Friendship Hall were opened wide at the Prince George Native Friendship Centre. Both conference attendees and interested members of the public gathered to share food, network, and to be welcomed by the Lheidli T’enneh Drummers, and join in song and dance. Keynote speaker Carrielynn Lund, a passionate and accomplished Métis health researcher from Alberta, set the tone for the conference with her opening talk entitled “Circle or Cycle?” She used stories to highlight important reflections on community readiness and process in CBR in northern, rural and/or remote areas.

The first day of conference, programming focused on setting the stage – bringing research findings back from recent or on-going studies, exploring key CBR concepts and methodologies (including Indigenous methodologies), and exploring how “no mountain can be moved” without peer involvement. The second and final day of the conference, focused on hands-on activities and engaging the group in activities to stimulate the identification of research priority areas, beginning with an arts-based workshop led by Virginia Russell and Dahne Harding, which had participants expressing research priorities and exploring meaningful collaboration in a tableaux-painting activity. The groups were then lead through a deliberative priority setting process to come to consensus in order to establish research priorities and identify information gaps. The methodology used was ‘concept-mapping,’ (Campbell, 2010) a process used with small groups to engage them in a facilitated activity to brainstorm, share ideas, and collaborate on bringing these ideas together into a diagram or map to link related concepts (see example in Figure 2). During the concept mapping session, groups created and discussed their maps, and came to consensus on 3 to 5 leading priorities to share back with the larger group of participants. The

entire list of ideas was captured on flip charts and would be shared back with participants following the event. Therefore, the priority lists were seen as “belonging” to the whole group.

Figure 2: Image of one of the concept maps created by participants.



The conference did not require the approval of a research ethics board. The information gathered throughout the conference (particularly during the above priority setting session) was collected as a group, and using general themes that were further developed by the Advisory Committee and research team; consensus was reached on releasing these publicly. Permission to use photographs of individuals in knowledge mobilization products was collected prior to the onset of the conference.

An integral part of the *Moving Mountains* process was the commitment by organizers to write a community report (Reschny, Langlois, Daniels, & Duddy, 2014), which would include a synthesis of the generated priorities and articulation of next steps. Therefore, following the event all priorities generated through the concept maps were reviewed and analyzed by the research team according to concepts or themes. These themes were then divided into two distinct categories: research topical areas/themes and research needs. The topical areas/themes included areas identified for potential research projects; whereas the second group, research needs, included areas identified to support and encourage ongoing research in the region. Initial concepts and themes identified as priorities (1-3) and research needs (4) are as follows. However, it is important to note that these represent a starting point in this process and that further

discussions, activities, and processes may need to take place to add texture, and define points for action.

1) Improved HIV Prevention, Treatment and Care

A third research theme that participants identified was the need for ethical and culturally appropriate provision of services to those living with or affected by HIV/AIDS. This includes additional sub-themes such as: what people in the region would consider ethical support for people living with HIV/AIDS in rural areas and on reserve; or through greater involvement of people living with HIV/AIDS in research and; service development and provision. Specific issues relating to services were HIV/AIDS and aging, trauma and HIV prevention, engagement and adherence to treatment, community readiness, and resilience.

2) The impact of natural resource-development industries, worker migration and economic boom in the region on the HIV/AIDS epidemic

This research theme includes the impact of the natural resource-development boom on the HIV transmission, testing, and the provision of culturally appropriate services. Additional areas of research include, for example, factors that contribute to the further transmission of HIV in the region, such as increased alcohol and substance use or increased demand for sex trade workers.

3) Stigma and discrimination

At the conference, what was perceived as a growing regional apathy towards HIV and other blood borne viral infections among the general public featured prominently in discussions. This included indications that there is a need for implementation-research to focus on sexual health and basic HIV knowledge education in the regions. This concept was highlighted in stories of silence on some First Nation's reserves, as well as contrasting stories of both community and individual resilience.

4) Research models and approaches that are regionally responsive

Aside from the highlighted research topic priorities, many participants felt that additional discussions are needed with regards to how research is developed and carried out in the region. These potential discussion topics included, for example, the need for research to be done outside of urban centers; how to do research in a way that is ethical and takes into account what happens after projects end; how to conduct research that is responsive to cultural needs; and, how to move research to action, specifically within health and service programming. Due to the multiple issues selected for future research, the group also identified the need for the incorporation of an intersectionality framework, which is the study of inter-related phenomena including the health, social and structural inequities that may influence health outcomes (Hankivsky, 2012; Smye, Browne, Varcoe, & Josewski, 2011), and for research that is able to explore several overlapping

issues at once, for the sake of financial efficiency and to reduce possible research fatigue among individuals and communities.

Continuing the Journey

While the event was the first step in this journey, the research team has completed a community report which was shared with all participants and is available online <http://pacificaidnetwork.org/wp-content/uploads/2014/09/Moving-Mountains-Community-Report-2014-Final.pdf> (Reschny, et al., 2014). The research team has also begun a systematic literature review, building off an environmental scan presented at the event (Jackson & Reschny, 2014), which focused on mapping out HIV/AIDS research in northern, rural and remote regions in Canada. This additional information will inform discussions around new research initiatives and capacity building activities, and the momentum will be used to provide opportunities for greater collaboration and partnering for researchers and communities. For example, the Pacific AIDS Network, the CBR Collaborative Centre (a program of the CIHR Centre for REACH), and the Aboriginal HIV and AIDS Community-based Research Collaborative Centre (AHA Centre), are already using the identified priorities to inform their future CBR strategies and endeavors.

Following the release of the report and final meeting of the AC for this project, the group decided to leverage the substantial interest generated by the event and sent an open call to participants of the conference to become part of a Research Working Group (RWG). The purpose of the RWG is to further develop a research project(s) based on one or more of the identified research priority themes listed in this article. At the time of publication, this group has since met by teleconference and is currently planning an in-person project development workshop in early 2015. The objective of this RWG will be to design, develop and submit a grant application or applications to continue this work on facilitating community-driven HIV/AIDS research in communities throughout Northern BC.

In community-based research, the development of research initiatives is a process; one that engages communities in developing research agendas by creating spaces in which all knowledge – experiential knowledge, Indigenous knowledge, community knowledge, and academic knowledge – are equally valued and can be shared. The *Moving Mountains* process was the first of its kind for the region – one that carries with it the promise of greater collaboration in the region and progress towards addressing HIV/AIDS through collective effort and the promise of research that is responsive to community needs.

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Section 2

Dissemination of Results Findings

Condom use-related beliefs in adolescents of First Nations communities of Quebec

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2 Marie-Pierre Gagnon is trained in sexology and holds a Ph.D. in community health. She is currently associate professor at the Faculty of Nursing of Université Laval and holder of the Tier 2 Canada Research Chair in Technologies and Practices in Health. She is also researcher at the CHU de Quebec Research Centre. Her expertise covers the evaluation of information and communication technologies (ICT), the determinants of ICT integration in health care systems, as well as knowledge translation and evidence-informed decision-making.

3 Bernard Roy holds a Ph.D. in anthropology. In 1986, at the outset of his career path as a nurse in Aboriginal communities, he became interested in type 2 diabetes. Along the road he has raised many questions, including the following: Why do diabetic Aboriginals adhere so little to the teachings and prescriptions of health professionals? Why is there so much diabetes among First Nations people? His work on diabetes soon became the focus of numerous publications. In 2005, for his work *Sang sucré, pouvoirs codés, médecine amère* (sugared blood, coded powers, bitter medicine), Bernard Roy was awarded the Luc-Lacourcière medal for excellence attributed to an ethnology work published in French in North America. Since 2004, he has been a professor at the Faculty of Nursing of Université Laval, teaching, among other things, the foundations of the community health nursing approach. Alongside his teaching career, Bernard Roy is regularly called upon to work on issues concerning First Nations health.

4 Marie-Noëlle Caron M.D., M.SC, M.CS in clinical sciences (Université de Sherbrooke, 2003) completed a residency in Community Health (Université Laval, 2009). Since 2009, she has held the position of public health advisor at the First Nations (FN) of Quebec and Labrador Health and Social Services Commission (FNQLHSSC), where she is a resource person in public health for FN communities and organizations.

5 Nancy Gros-Louis McHugh studied and graduated in communications at Université Laval. She worked abroad for a few years, expanding her horizons on health issues affecting Aboriginal peoples in North America. Since 2002, she has worked at the FNQLHSSC. As manager of the research sector and head of a multidisciplinary team, she has coordinated several community research projects on various topics related to health while promoting a holistic approach. She was very actively involved in the process of developing the research protocol of the Assembly of

First Nations of Quebec and Labrador. She also wishes to help improve the well-being of First Nations (FN) by disseminating new knowledge derived from research-related activities, while creating new information sources for FN communities and regional organizations.

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ABSTRACT

Background: The First Nations of Quebec and Labrador Health and Social Services Commission, hereafter the Commission, has identified sexually transmitted infections, including HIV/AIDS, as a priority health issue. Drawing on its interest in telemedicine and e-Health, the Commission agreed to a partnership approach aimed at studying the feasibility of interventions using information and communication technologies (ICT) to promote sexual health among adolescents and young adults of Quebec First Nations (FN) communities. As a complement to the feasibility evaluation, this study was conducted in order to formulate exhaustive recommendations for the development of evidence-based interventions that also take into account the characteristics of the target population.

Purpose: To identify the factors underlying condom use among 13-18 year olds from FN communities of Quebec.

Methodology: A focus group and a questionnaire (Appendix A) were used to document the perceptions of high school students from participant communities with regards to different aspects of sexual and reproductive health, particularly condom use.

Results: The modal salient beliefs related to the benefits of condom use were the prevention of sexually transmitted infections/diseases and the prevention of pregnancies, while most of the respondents found no disadvantages. The positive referents mentioned most were parents and boyfriend/girlfriend, while the negative ones were sexual partner and lover/boyfriend. Always having some (condoms) on hand, and having proper information were highlighted as the most important factors facilitating condom use, while not having any condoms, or being drunk/unconscious were mentioned as obstacles to its use.

Conclusion: The conception of sexual health by the respondents positioned them as a potentially receptive target for interventions aimed at promoting condom use. Our study has highlighted important beliefs that provide avenues for designing interventions to promote condom use for a healthy sexual life among Aboriginal youth.

BACKGROUND

Sexual and Reproductive Health (SRH) is an important aspect of human health. According to the World Health Organization (WHO-Regional Office for Africa, 2009), people have the right to a responsible, satisfying and safe sexual life, and the freedom to decide if, when and how often to reproduce (WHO ROA, 2009). SRH is influenced by a complex web of factors ranging from sexual behaviour, attitudes and social factors, to biological risk and genetic predisposition, and includes the problems of HIV and sexually transmitted infections (STIs)/reproductive tract infections, unintended pregnancy and abortion, infertility and cancer resulting from STIs, and sexual dysfunction (Public Health Agency of Canada, 2008). The variability of sexual health issues should be noted here, and as a consequence, their unequal distribution by age as well as by country and socio-cultural and economic contexts.

In Canada, the distribution of HIV/AIDS prevalence shows a great inequality among different socio-cultural groups. In accordance with Article 35 of the Constitution Act of Canada, the definition of the term “Aboriginal people” by the Union of the Municipalities of Quebec refers to all original peoples of Canada and their descendants, including three groups, Métis, Inuit, and First Nations, the latter being a term used since the 1970s to replace the word “Indian” which some people consider offensive (UMQ, 2006). Although representing 3.8% of the total Canadian population (in 2006), Aboriginal people accounted for approximately 8% of all those living with HIV (including AIDS) in Canada and represented 12.5% of all new infections in 2008 (Public Health Agency of Canada 2010). For that same year, the HIV infection rate for Aboriginal people was, overall, 3.6 times higher than among other Canadians (Public Health Agency of Canada 2010). From 1998 to 2006, persons aged between 0-29 years accounted for up to 32.4% of all HIV diagnoses among Aboriginal people, compared to 21% for non-Aboriginal diagnostics (Canadian Aboriginal AIDS Network, 2009).

Canada’s Aboriginal population is also facing higher rates of STI, such as chlamydia and hepatitis C (Health Canada, 2005). According to the portrait of sexually transmitted and blood-borne infections (STBBIs) in Quebec in 2012, chlamydia and gonococcal infections in Nunavik are respectively 9 and 73 times higher than the average rate in the rest of Quebec (Gouvernement-du-Québec, 2013). In Terres-Cries-de-la-Baie-James, these rates were respectively 7 and 11 times higher than in the rest of Quebec (Gouvernement-du-Québec, 2013). Nunavik and Terres-Cries-de-la-Baie-James have high proportions of Aboriginal people and are also areas where the epidemiological situation of STI is most frequently encountered (Gouvernement-du-Québec, 2013). In 2007, The First Nations of Quebec and Labrador Health and Social Services Commission highlighted that the prevalence of genital chlamydia and gonococcal infections was about 10 times higher than the average rate in the rest of Quebec among some indigenous populations (FNQLHSSC, 2007). The Commission has therefore identified STBBIs, including HIV/AIDS, as a priority health issue. The Aboriginal Strategy on HIV/AIDS estimates that to be effective, interventions to prevent HIV/AIDS should target

different groups, including Aboriginal youth (CAAN 2009). In this regard, the familiarity of the younger generation with new technologies positions the use of information and communication technologies (ICT) as a highly promising avenue in the field of STIs and HIV/AIDS prevention among adolescents and young adults. We have recently examined the habits and preferences of adolescents and young adults of Quebec First Nations in relation to ICTs (Djossa, M., Adoun, S., Roy, B., Gros-Louis, N., Caron, M. & Gagnon, M.-P., 2013). That research was part of a feasibility study¹ aimed at analyzing the current context of FN communities in order to consider innovative and effective intervention strategies with youth. To complete this process and enable the formulation of recommendations for the development of interventions, this study focuses on the factors determining condom use among adolescents in Quebec FN communities.

Literature review

What do we know about determinants of condom use in FN adolescents?

The high rates of STIs and HIV/AIDS reported above could be attributed to a higher level of sexual risk-taking. Indeed, a survey of Quebec FN adolescents and young adults on sexual behaviour, attitudes and knowledge regarding STBBIs revealed several at-risk behaviours, including sexual precocity, having multiple partners, substance use (alcohol or drugs) before sex, and inconsistent condom use (FNQLHSSC, 2011). According to the report on social determinants of Aboriginal health, Aboriginal youth are more sexually active than other Canadian youth of the same group age and could have a greater potential for indulging in unprotected sex (Reading, 2009). Statistics Canada also indicates that the probability of failing to use a condom is nearly twice as high among Aboriginal male youth as among the non-Aboriginal Canadians (Rotermann, 2005). Nevertheless, very little is known about the factors that influence condom use in the specific population of Aboriginal adolescents and young adults. The report on the survey by the Commission (2011) seems to attribute the non-systematic use of condoms among First Nations adolescents in Quebec to a lack of knowledge regarding STBBIs, among other factors. However, simply increasing knowledge may not reduce such sexual risk-taking among adolescents where several intrapersonal and behavioural factors could be significant predictors of current consistent condom use (Alvarez, Villarruel, Zhou, & Gallegos, 2010; Haley, Puskar, Terhorst, Terry, & Charron-Prochownik, 2013). As such, knowing about the other determinants of condom use among Aboriginal youth could help better promote this behaviour for STI/HIV prevention.

Several studies have addressed the issue of condom use among adolescents and young adults in general. Many authors have studied the determinants of the intention to use condoms

¹ Feasibility study on interventions using Information and Communications Technologies (ICT) for the promotion of sexual health and the prevention of HIV/AIDS among First Nations adolescents. Study funded by the Canadian Institutes of Health Research (CIHR), Catalyst Grant, Fall 2010. (Report in preparation)

([Donald, Lucke, Dunne, O'Toole, Raphael, 1994](#); Bosompra, 2001); others have focused on predictors of condom use (Harley et. al, 2013; Nuwaha, Faxelid, 1999; Sheeran and Taylor, 1999; [Jemmott, Jemmott, Vallaruel, 2002](#); [Villaruel, Jemmott, Ronis, 2007](#); Alvarez, Villaruel, Zhou, & Gallegos, 2010), or factors associated with that behaviour (Peltzer, 2000; Kanekar and Sharma, 2007); and other authors have explored the beliefs underlying condom use among young people from different contexts (Norris and Ford, 1992; [Gillmore, Morrison, Lowery, Baker, 1994](#); Norris and Ford, 1994; Nicholas, 1998; [Oliveira, Abreu, Barroso, & Viera, 2009](#)). Caron, Godin, Otis, & Lambert (2004) reported the salient modal beliefs underlying the use of condoms among multiethnic adolescents attending an urban high school in Quebec, Canada. However, as highlighted above, Aboriginal adolescents and young adults show greater rates of STIs and HIV/AIDS and participate in higher levels of sexual risk-taking. As such, the beliefs about condom use in this specific population could be different from those in non-Aboriginal populations. Moreover, most of the authors merely explored beliefs about outcomes of using condoms (e.g. study by Gillmore, 1994) or about outcomes and referents (e.g. study by Oliveira, Abreu, Barroso, Viera, 2009), and very few investigated the beliefs underlying all the psychosocial constructs that we consider in the present research. The study by Gagnon (2010) explored the factors underlying attitude, subjective norm, perceived control, and moral norm with respect to condom use among Aboriginal young adults in Nunavik. However, the participants in the study in Nunavik were older (18-29 years), compared to the population of interest in our study.

To the best of our knowledge, no data was available regarding the salient beliefs related to condom use, specifically among 13-18 year olds of Quebec FN communities. Our study aimed at filling this gap.

Theoretical framework

The conceptual framework that guided this study is an adapted model of the Theory of Planned Behaviour (TPB) (Ajzen, 1991; Ajzen, 2006). This theory was chosen because of its relevance to understanding factors underlying the intention to adopt and maintain safe sexual behaviours among Aboriginal young adults, as shown in a previous study conducted in two Nunavik communities (Gagnon, 2010).

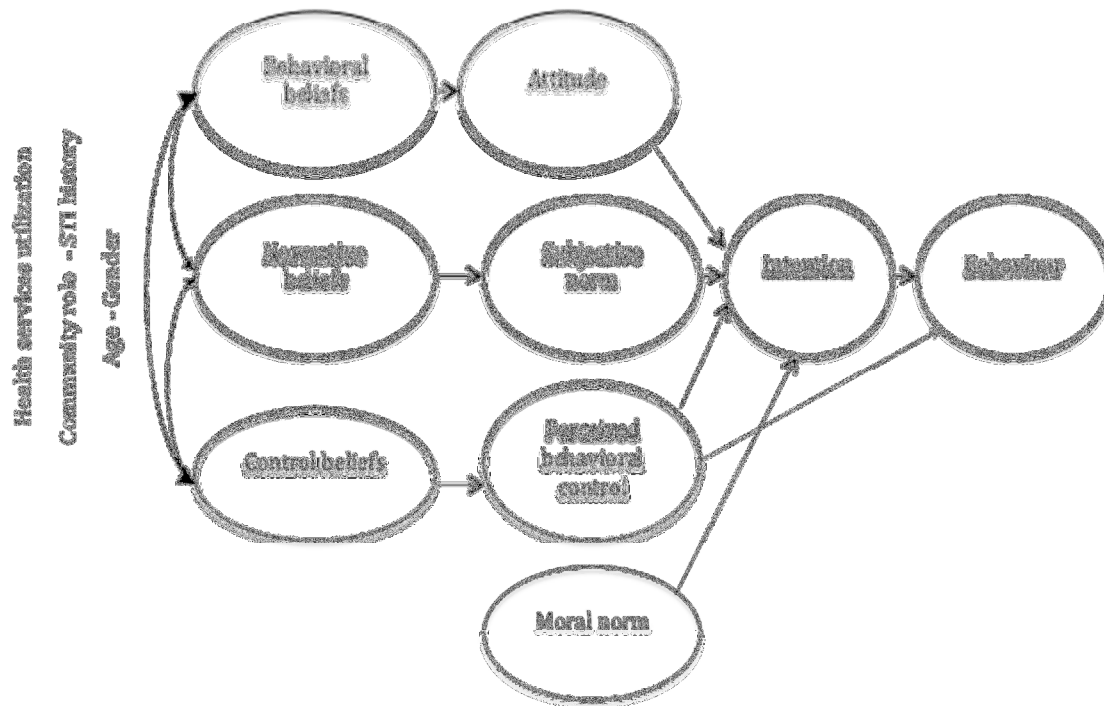


Figure 1: Adapted model of the theory of planned behavior (Source: Gagnon, 2010, 26)

According to the TPB (Ajzen, 1991), intention is the immediate determinant of individual behaviour. However, under less volitional conditions, perceived behavioural control is also supposed to add to this prediction. In turn, intention is influenced by three direct constructs, namely attitude, subjective norm, and perceived behavioural control. Attitude reflects the individual’s evaluation of the consequences, favorable or not, of adopting a behaviour. Subjective norm is the perception by the individual that particular persons or groups of people who are important to him or her would approve or disapprove of the individual’s adoption of the behaviour. Perceived behavioural control is defined as the perceived ease or difficulty of adopting a behaviour (Godin, Gagnon, Lambert, Conner, 2005).

The TPB also posits that each behavioural determinant (attitude, social norm and perceived behavioural control) is based on specific beliefs, which represent indirect constructs. According to Ajzen (2006), behaviour is guided by three considerations: beliefs about the likely consequences of the behaviour (behavioural beliefs); beliefs about the normative expectations of others (normative beliefs); and beliefs about the presence of factors that may facilitate or impede the performance of the behaviour (control beliefs). Beliefs can inform about the reasons that lead individuals to maintain certain behaviours, providing avenues for the development of behavioural interventions. According to Ajzen (1991), all constructs from the TPB should be measured in relation to specific rather than general behaviour. In the model (Figure 1) adapted by

Gagnon (2010), the adoption of sexual behaviour not only depends on motivation or intention; it is also based on internal or external non-motivational factors that interfere with behavioural intention. As such, moral norm, which measures the feeling of personal obligation towards the adoption of a behaviour, was added to the list. Differing from subjective norm, moral norm refers to rules of personal conduct and to the moral principles of an individual (Gagnon, 2010). Moral norm was also identified as an important determinant of intention to use condoms in heterosexual adults from three ethnocultural populations ([Godin, Gagnon, Lambert, Conner, 2005](#)). Finally, two types of variables are included in the adapted model. There are socio-demographic variables, such as age and gender, and environment-related variables, namely a history of STIs, use of health services, and role of the community. In fact, decision-making about a sexual behaviour like condom use could be different among men and women, or moreover, involve the cooperation of two sexual partners shaped by power dynamics (Gagnon, 2010). The inclusion of environment-related variables was based on the importance of community norms and of the social environment in determining sexual health in an Aboriginal context (Gagnon, 2010).

METHODS

The project was developed in close collaboration with the Commission. This collaboration started during a feasibility study² that we planned and conducted in partnership with the Commission. To do so, a first draft of the research project was sent to the Commission's administration. The draft was accompanied by a letter explaining our motivations as well as the potential benefits of the project for the Commission and, subsequently, for First Nations communities. The Commission was a key player in refining the proposed research project, as the organization clearly identified STI / HIV / AIDS as a priority health issue in the "*Blueprint Quebec First Nations Health and Social Services 2007-2017*" (CSSSPNQL, 2007). The interest of the Commission for the proposed project was stemmed from the fact that this organization wanted to develop a strategic framework for the implementation of telemedicine and e-health. Finally, the Commission found in this project the opportunity to eventually tackle other health promotion interventions using ICT, so as to address other issues such as sexual health.

It was clearly stated that the content of the project draft consisted only of the ideas proposed by researchers and that the methodological choices as well as the implementation of the project were to be discussed with the Commission. This organization was the main Aboriginal actor in the participatory process. All decisions were discussed with this partner at all stages of the research.

² Feasibility study on interventions using Information and Communications Technologies (ICT) for the promotion of sexual health and the prevention of HIV/Aids among First Nations adolescents. Study funded by the Canadian Institutes of Health Research (CIHR), Catalyst Grant, Fall 2010. (Report in preparation)

STUDY DESIGN

A mixed-method was used. A qualitative phase was planned in order to elicit salient beliefs among FN young people, following the methods suggested by Ajzen (2006). A qualitative method was also used by Gagnon (2010) in an exploratory study involving youth between 18 and 29 years old from two indigenous communities of Nunivak. However, further to the failure of our initial data-collection technique, a quantitative approach was adopted.

Qualitative Phase

We planned four focus groups in each participating FN community, with each group involving 8 high school students between 13 and 18 years of age. The number of focus groups advocated was meant to ensure homogeneity (one with girls and one with boys in each of the following categories of age: 13 -15 years and 16 -18 years). Indeed, when discussing sensitive issues, such as sexual health, too much heterogeneity can be a threat to participants and can inhibit the disclosure and sharing of personal experiences (Wong, 2008). However, this technique did not produce the expected results. First, despite the involvement of resource persons identified in the community, the research team faced great difficulty in recruiting participants wishing to address the issue of sexuality through a focus group. Thus, of the four focus groups planned (in our first participating community) only one was conducted with female students between 13 and 15 years of age. Moreover, the students who agreed to participate in the focus group were not really involved in the discussions. Basically, there was almost no information collected at the end of the focus group. The situation was analyzed with the Commission. It emerged as an explanatory hypothesis that the focus group would probably not be the best technique to address the issue of sexuality within our target population, making it necessary to find other alternatives to collect information. Thus, it was decided that data would be collected during the First Nations Youth Forum held in Quebec City in August 2012. The Forum provided an opportunity to initiate informal meetings with young people from different FN communities of Quebec and Labrador. Two objectives were targeted through these meetings: 1) To estimate the degree of understanding of the questions used to elicit salient beliefs in the FN youth population in order to know whether this parameter contributed to the non-success of our initial attempt at data collection; and 2) to collect FN youth perspective on the potential means and modes of administration that they considered most relevant to address issues of sexuality with their peers. The young participants in the First Nations Youth Forum contributed significantly to our research, as we adjusted our methodological approach according to their suggestions, adopting a quantitative approach.

Quantitative Phase (questionnaire development)

Past research in Aboriginal communities has revealed significant conceptual difficulties in defining “sexual health” (Gagnon, 2010) and has shown that the popular conception of health

among the Aboriginal population can influence the adoption of health-related behaviours (Roy, 2002). As a result, the first items of our questionnaire (Appendix A) were designed to identify the conception of health and particularly of “sexual health” among our target population. Those items asked the respondent to choose from among 12 (or 14 for sexual health) statements the 5 elements that contribute the most to creating his or her “circle of health” and “circle of sexual health.” The statements included different aspects of the World Health Organisation’s definition of health (and sexual health) and other conceptions that have emerged from past research in FN communities (Roy, 2002; Gagnon, 2010).

Questionnaire items (Appendix A) were designed to identify salient beliefs underlying attitude (advantages and disadvantages); subjective norms (important people who would approve or disapprove); the perception of control (factors that can make it easy or difficult); and moral norm (coherence with personal values) of FN young people related to using condoms during all instances of sexual intercourse. Our original elicitation questions were reworded in order to offer some choices of responses. Proposed responses were modal salient outcomes, referents, and control factors derived from content analysis of the answers provided by young participants in the First Nations Youth Forum. There were also open-ended questions to allow respondents to express other opinions. A final question documented, from the perspective of respondents, the means that communities could implement to promote the use of condoms during all sexual intercourse among young people. Two teenagers from a non-participant FN community reviewed the questionnaire (Appendix A) to ensure that all questions were well understood.

Setting and participants

In the participatory space established with the Commission and the FN communities involved, the expected role of the target population (FN adolescents and young adults) is to provide information on, among other issues, their conception and beliefs with respect to health, sexuality, sexual health, and specific sexual behaviour, such as condom use. The purpose of the information is to develop interventions using ICT to promote sexual health. To do so, two FN communities were pre-identified with our collaborators from the Commission for participation in the feasibility study, based on a number of criteria. The partnership with the Commission was essential to ensure that the research would respect FN communities’ reality, values and needs, and would provide knowledge that could be used by FN people. The Commission was seen as a legitimate body empowered to establish first contact between the research team and the communities. Thus a Memorandum of Understanding was sent to the chief of the band council of each of the selected communities, which included a protocol describing the objectives, methodology and impact of the project. All stakeholders signed this document: the project coordinator, the person in charge of the research sector at the Commission, and the Chief of the band council. The signing of the document by the band council finalized the tripartite agreement intended to frame our research in each participating community.

High school students were the population of interest in each participating community. This research was in line with a previous study on sexual behaviours, attitudes and knowledge related to STI (First Nations of Quebec and Labrador Health and Social Services Commission, 2011), in which high school students from selected FN communities participated. Our research was another step towards intervention to improve sexual health in this target population.

The school administration was associated with the research team, which also benefited from the help of resource persons identified in targeted high schools. We presented the project to the students of each school on the first day, making sure that everyone understood the process. We then distributed consent forms to students interested in taking part in the study. Students who were interested in participating were asked to sign the forms, or to get their parents' or guardians' signature if they were minors. The next day, the research team went through the classrooms and collected signed consent forms. The students who had their consent forms signed were then given a questionnaire that they completed in the classroom. Data were collected in the two participating FN communities during fall 2012 and winter 2013 respectively. As an incentive, we held a draw for a participation prize (a Sony headset) among respondents in each participating high school. The Commission also offered condoms and prevention pamphlets.

Analysis

Answers to the questionnaire were compiled in order to list the salient beliefs within each category (behavioural, normative or control beliefs). The frequency of mention was calculated for each salient belief. The salient beliefs were placed in descending order of frequency of mention, which allowed us to identify the modal salient beliefs. The modal salient beliefs were identified following the recommendation that the sum of their frequency should reach 75% of all mentions (Gagné & Godin, 1999).

Ethical considerations

The involvement of the research sector of the Commission made it possible to ensure the conformity of methodological choices and the application of the First Nations of Quebec and Labrador Research Protocol. The study received approval from Université Laval's Committee of Research Ethics. Given the changes made in the data-collection process, the protocol was re-submitted for amendment. The study also received First Nations approval, which was expressed in the tripartite agreement signed by the Commission and the band council of each participating community. Participation in the research was on a voluntary basis. Each participant signed a consent form and had his or her parents or guardians sign an assent form in the case of minors. Moreover, it was clearly stipulated in the consent form that respondents could stop participating in the research and withdraw their consent at any time, without prejudice.

Results

Thirty-two (32) young people participating in the First Nations Youth Forum rather easily

answered the questions that we initially prepared for the focus group. There were no clarification requests or suggestions for reformulation. This suggests that the questions were easily understood and that the focus group technique could indeed be the reason for the failure of our first experience. In addition, the young people whom we met recommended the use of modes of administration offering more anonymity to address issues relating to sexuality. The young First Nations people whom we met during the First Nations Youth Forum were mostly over 18 years of age and could not be representative of the population of interest in our research. It was still necessary to investigate the initially targeted 13-18 year old persons of FN communities of Quebec. We then adjusted our methodological approach accordingly and developed a questionnaire (Appendix A) for the population of interest.

Sample characteristics

A total of 129 students were interested in participating in our study and received a consent/assent form. Of these, 51 participants completed the questionnaire, which corresponds to a response rate of 39.5%. Table 1 summarizes the socio-demographic characteristics of respondents. The mean age of the respondents was 16 years (SD=1.8). Girls represented a proportion of 65%, and 55% of respondents had completed their third year of high school.

Mean age (standard-deviation)	16.05 years (1.80)
Gender	
Female (%)	64.7
Male (%)	35.3
Highest level of education completed	
Elementary school (%)	2.0
First year of high school (%)	7.8
Second year of high school (%)	21.6
Third year of high school (%)	54.9
Fourth year of high school (%)	13.7

Table 1. Socio-demographic characteristics of respondents

Conceptions of health and sexual health

Figure 2 and Figure 3 present the five elements making respectively the circle of health and the circle of sexual health, as chosen by respondents. In each of these two figures, the first graph indicates an overview of all the choices of statements by participants. It shows the percentage of respondents who chose any given statement. The second graph is designed to illustrate the relative importance of each of the five most rated statements in the “circle of health” / “circle of sexual health.”

The five elements most rated by respondents for making their circle of health referred, first, to

their feelings. Some 70% of respondents chose the fact of feeling good about oneself and being capable of taking care of oneself. Then the fact of not having any diseases was rated by more than 60% of respondents, as was being well in one's family. The other element mentioned by over half of respondents was being comfortable in one's community. For almost half of respondents, being able to make decisions was an important element, as was the adoption of healthy behaviours. Referring to the second graph of this figure, the statements related to individual level considerations (feeling good, able, and without diseases) are the ones that contribute most (63.3%) to the respondents' circle of health.

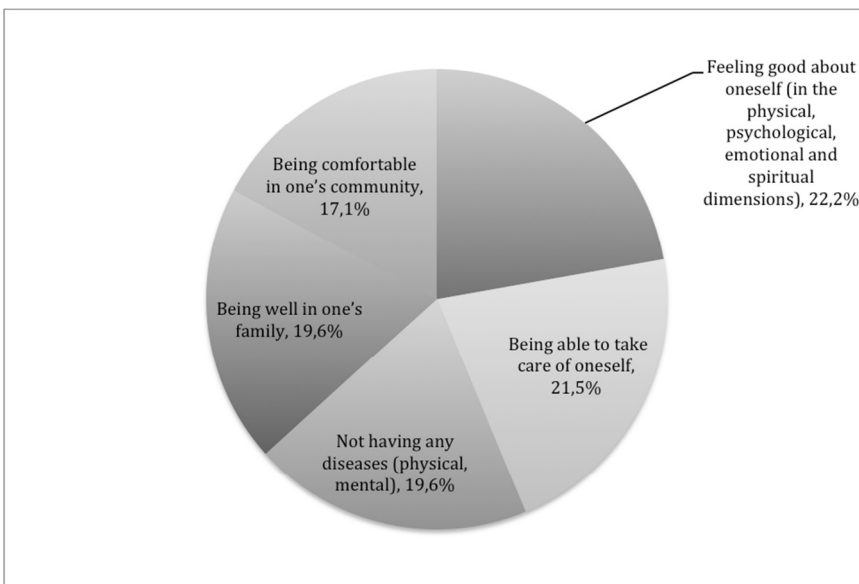
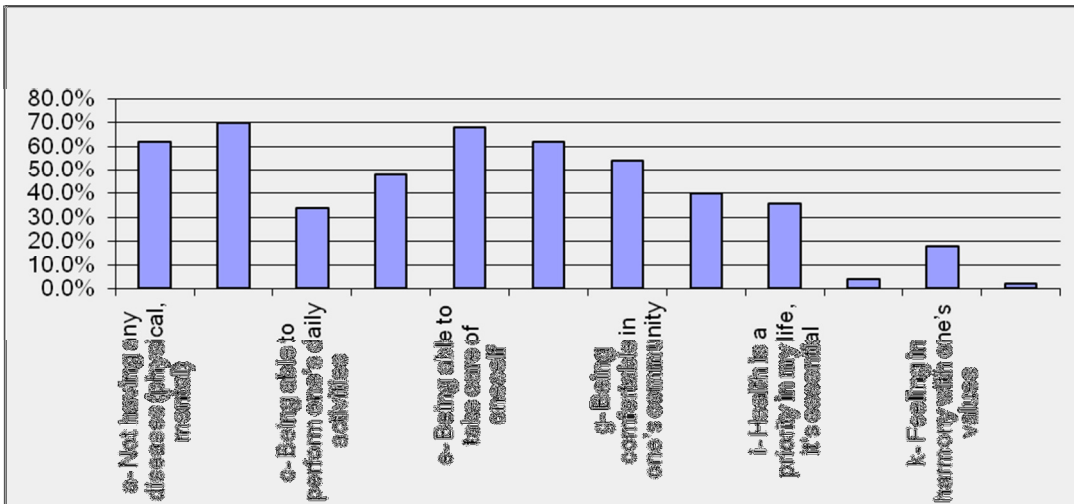


Figure 2. Elements forming the circle of health among 13-18 year olds of two First Nations communities in Quebec

Concerning the circle of sexual health, the element chosen by over 90% of respondents was not having sexual infections. The other two elements rated most frequently (by 60% of respondents)

referred to respect of their choices and of their privacy, which they underlined as indicating the desire to talk to someone trustworthy. The fact of being respected by authority figures was also identified as making an important contribution to the circle of sexual health for approximately 40% of respondents. The same proportion mentioned the importance of having sexual relations without fear of contracting diseases and the necessity of being informed on sexuality. Having sexual relations without the risk of unwanted pregnancy and having a stable sexual partner were considered relatively important elements that would contribute, in the respondents' opinion, to making up their circle of sexual health. From the second graph of this figure, it appears that elements related to the absence of sexual infections and the fear of contracting diseases contribute to about half (44.9%) of the sexual health circle.

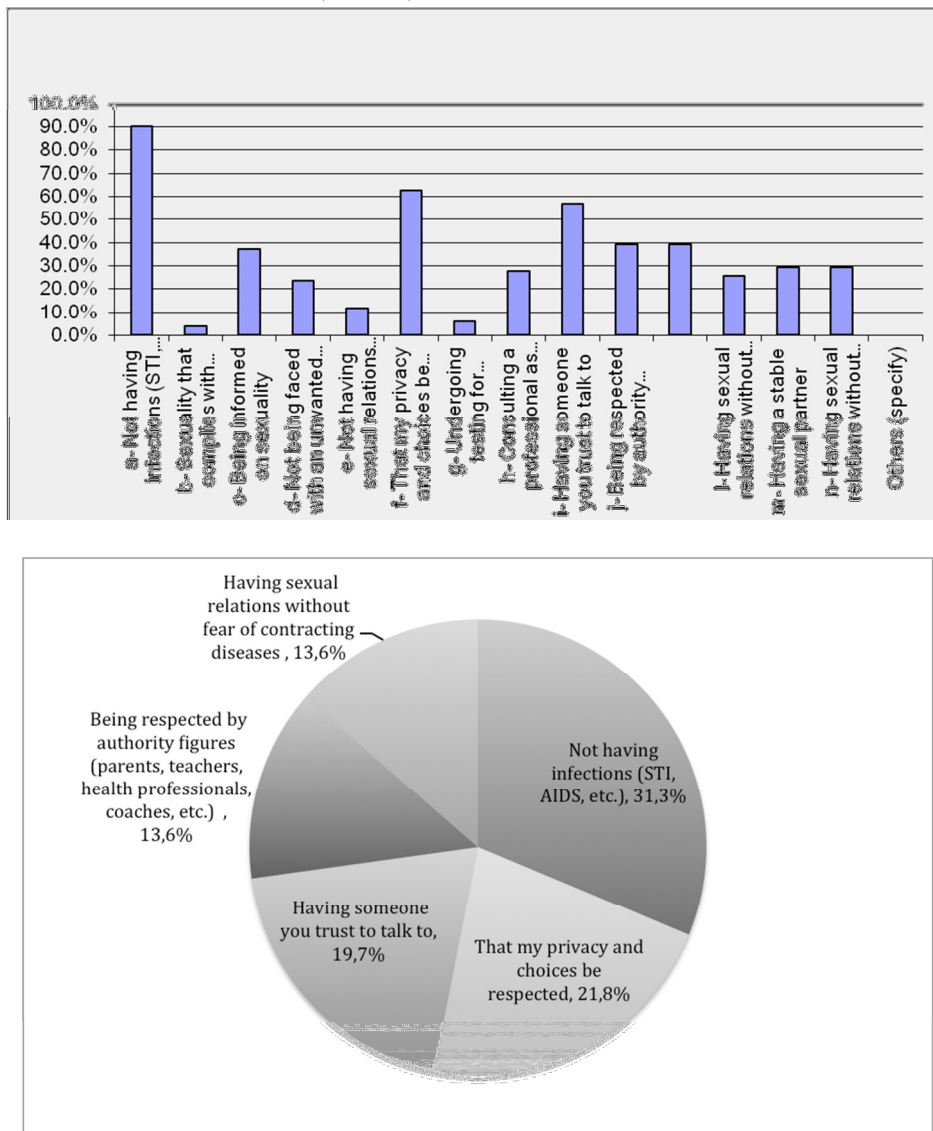


Figure 3. Elements forming the circle of sexual health among 13-18 year olds of two First Nations communities in Quebec

Participants were also asked to rate their personal sexual health according to their own definition. Respondents described their own sexual health as being excellent (20% of respondents), good (33%), quite good (43%), and bad (4%).

Beliefs concerning condom use for all instances of sexual intercourse

The salient beliefs related to attitude, subjective norm, and perceived control concerning condom use for all instances of sexual intercourse are presented in Table 2. These salient beliefs appear in descending order of frequency of mention. Regarding attitudinal beliefs, the effectiveness of condoms in protecting oneself and one's partner from sexually transmitted infections/diseases and in preventing unwanted pregnancies represented the modal beliefs related to using condoms for all instances of sexual intercourse noted by most respondents. Over half of respondents did not see any disadvantages in this regard. However, some mentioned that condom use reduces sensitivity and is less intimate.

Related to modal normative beliefs, persons or groups having a favorable opinion about condom use at each instance of sexual intercourse were essentially parents, the sexual partner (including boyfriends/girlfriend), family, and health professionals. Some respondents also identified the partner (exclusively male in this case) as an important person who would not be in favour of using a condom for each sexual encounter, while more than half of respondents found none.

Concerning control beliefs, always having condoms in one's possession and worrying about getting pregnant were mostly mentioned as factors facilitating the use of condoms. Having proper information on STI and on condom use, discussion between partners, and partner consent were the statements that completed the modal salient control beliefs mentioned. Not having any condoms on hand was the most important identified barrier to condom use. "Being drunk – having consumed too much alcohol," "The immediate desire to have sex," and "Being unconscious" were the other modal beliefs on the factors that would make it difficult to use a condom each time one had sex. The other perceived barriers were not having money to buy condoms, having used drugs, lack of practice, and not being properly informed. In relation to moral norm, a large majority (89%) of participants stated that using a condom at all times during sexual intercourse is part of their personal values. When asked for explanations, all the arguments that the respondents mentioned related to outcome beliefs. Lastly, the means that communities could implement to promote the use of condoms at all times during sexual intercourse among youth, as suggested by respondents, include the distribution of condoms (by 62% of respondents), and various actions, including workshops on sexual health and STI, prevention (of STI/VIH) in schools, and discussing more about these issues (by about half of respondents).

Table 2: Salient beliefs about condom use

Perceived advantages		Perceived disadvantages	
Protecting myself from STI/STD	38	None	29
Protecting myself	32	Decreased sensitivity	99
Avoiding unwanted pregnancies	31	Less intimate	6
Reducing the transmission of STI	20	Being frowned upon by friends	4
No stress to sexual diseases or unplanned pregnancies	16	Allergies to latex	4
Avoiding getting someone pregnant	16	Irritation	4
People approving		People disapproving	
Parents	34	None	13
My boyfriend/girlfriend	22	Sexual partner	12
Family	20	My boyfriend (lover)	12
Health professionals (physicians, nurses)		Guys in general	11
Sexual partner	17		
Grandparents	12		
Other	9		
	3		
Making easy		Making difficult	
Always having some on hand	26	Not having any on hand	30
Worried about getting pregnant	25	Being drunk –having consumed too much alcohol	24
Having proper information on STI and condom use	17	The immediate desire to have sex	11
Discussion between men and women – if it was discussed with my partner		Being unconscious	6
Having them consented to – if my partner agrees	11	Other	6
Having some within reach	10	Having used drugs	4
Talking about it more	9	Not having any money to purchase them	3
Discussion with parents – if my parents would talk about it with me	8	Shyness – when we don't assert ourselves	3
Friends who practice sexual health – if my friends used them	8	Lack of practice (never having used any)	3
Practice – if I was more used to them	4	Not being appropriately informed on how to use a condom	2
If they were accessible at all times	3		1
Other	3		
	1		

Note: For each question, the participants could choose several answers or even register any unlisted response. The numbers represent the number of times that the belief was mentioned.

DISCUSSION

This study explored the salient beliefs related to condom use in 13-18 year olds of Quebec First Nations communities. After the failure of the focus group technique, a questionnaire (Appendix A) was used. First, the questionnaire (Appendix A) explored the conception of health and of sexual health among participants, using the symbol of a circle interrupted at five areas. The five elements most chosen by respondents to complete this circle prioritize the feelings of the individual, the absence of disease, and being at ease within one's family and community. Concerning the conception of sexual health, statements regarding the absence of disease and fear of infections were highly rated.

Regarding the conception of health, two major differences can be noted between our findings and those of Roy (2002). Firstly, his results place the family as the fundamental variable in the development of the feeling of "being healthy" in Aboriginal areas (Roy, 2002). In our study, statements referring to the biomedical conception of health were included in the circle of health by more than half of respondents, while these statements were positioned very low in the popular perception of health described in the findings of Roy (2002). These differences are probably due to study populations, as the responses reported by Roy (2002) come from young people, adults and seniors met in three Atikamekw communities and four Innu communities, while our data were collected in a more homogenous sample (13-18 year olds of one Atikamekw community and one Algonquin community). Indeed, as pointed out by Roy (2002), significant variations can be found regarding the conception and perception of health, depending on the study groups, which may reflect economic, political, generational or even gender interests (Roy, 2002). The influence of the biomedical conception of health among participants in our study can also be seen in the choice of elements to build their circle of sexual health.

This conception of sexual health is in line with the one reported by a study of 18-29 year olds of two indigenous communities of Nunavik. The participants in the Nunavik study considered the fact of not having an STI, HIV or cancer as being indicative of sexual health (Gagnon, 2010). They thus associated the avoidance of behaviours involving risk of infection or the adoption of risk-reduction behaviours, namely the use of contraceptive methods and avoidance of multiple sexual partnerships or extramarital sexual relations, with their conception of sexual health. The importance of respect (of their choice and privacy and by those in authority) expressed by many participants in our study was also reported in the Nunavik study, in terms of being careful with oneself and with women (Gagnon, 2010). Finally, the cognitive dimension associated with knowledge and expressed in our study through the importance of being informed about sexuality was also noted in the findings of Gagnon (2010), where respondents mentioned that adolescents should know about sexual risks and reproduction and contraception issues.

Overall, the conception of health appears nuanced depending on groups of interest. The conception of sexual health seems to be similar as regards the young people who participated in

our study and participants in the study conducted in Nunavik. The conception of sexual health that emerges both in our research and in the findings of Gagnon (2010) is quite heavily based on a biomedical model. Apart from the needs for respect and privacy, the elements chosen by the participants in our study lead us to see them as potentially receptive targets for interventions aimed at promoting the use of condoms as a means of both STI/STD protection and contraception.

The modal salient beliefs underlying the use condoms during all sexual intercourse in our research are mostly similar to those reported in other studies. The study among young adults in Nunavik also reported that prevention of diseases and pregnancies represented the salient advantages linked to condom use and that the majority of participants identified no disadvantages (Gagnon, 2010). Caron, Godin, Otis, & Lambert (2004) reported, in a study among multiethnic adolescents attending an urban high school in Quebec, that using condoms was seen as a way of protecting oneself from pregnancy, STDs, and AIDS. This study also mentioned the fact that respondents were afraid of experiencing less pleasure with condom use (Caron, Godin, Otis, & Lambert, 2004). A study among 13-19 year old teenagers attending public schools in Porto, Portugal reported that the advantages of using condoms were the prevention of STDs, pregnancy, and AIDS, whereas the disadvantages found were risk of breaking, decrease of pleasure, and discomfort (Oliveira, Abreu, Barroso, & Viera, 2009). In the study by Widdice, Cornell, Liang, Halper-Fiesher (2006), the major benefits mentioned for using condoms were also pregnancy prevention and STI/HIV prevention, where 32.5% of adolescents participating in the research project responded that there was no risk in using a condom. Most reported disadvantages from this study involved possible condom malfunction, namely, “can break,” “can come off,” and “might not work” (Widdice, Cornell, et al. 2006). Other studies have shown that condom use among adolescents and young adults is influenced by perceived benefits, namely avoidance of sexually transmitted infections/diseases (STIs/STDs), including AIDS, and prevention of pregnancy, and by beliefs that condoms reduce pleasure, are unromantic, and interrupt sex (Orr & Langefeld, 1993; Gillmore, Morrison, Lowery, & Baker, 1994; Bosompra, 2001).

With respect to normative beliefs, our data revealed that these are mostly related to parents and the partner, referents also reported by the study in Nunavik (Gagnon, 2010) and by other studies on condom use among youth (Caron, Godin, Otis, & Lambert 2004; Heeren, Jemmott, Mandeya, & Tyler, 2009; Oliveira, Abreu, Barroso, Viera, 2009). Other positive referents highlighted by our analyses are family and health professionals, also mentioned in studies by Oliveira, Abreu, Barroso, Viera, (2009) and Bosompra (2001) respectively.

In terms of control beliefs, the facilitating factors mostly mentioned by participants in our study were the fact of having a condom on hand and having proper information about it. The unavailability of a condom when intercourse occurs would make its use difficult. The study by

Gagnon (2010) also reported that the availability of condoms would facilitate their use, as would their being free of charge. Other studies have suggested that having a condom on hand would increase the chances of its being used (Maxwell, Bastani, & Warda, 1999; Diclemente, Wingood, Crosby, Sionean, Cobb, Harrington, Davies, Hook, & Oh, 2002). Discussion between partners about condoms is another factor that would facilitate condom use, as highlighted both in our study and the study in Nunavik (Gagnon, 2010). An important factor that would make it difficult to use a condom, as mentioned by participants in our study, is the fact of being drunk (having consumed too much alcohol). Substance use (alcohol and drugs) is associated with unprotected sexual intercourse in different adolescent samples (Hingson, Strunin, Berlin, & Heeren, 1990; Kingree, Braithwaite, Woodring, 2000; Tapert, Aarons, Sedar, & Brown, 2001). Concerning moral norms, our respondents did not mention any morally related element to justify whether the use of a condom at each instance of sexual intercourse is part of their personal values or not. Similarly, Widdice et al. (2006) reported a paucity of morally related outcomes (no responses related to marriage, religion or “it being wrong to have sex, or wrong to use or not use a condom, etc.”) in their study (Widdice, et al., 2006).

In summary, there are considerable similarities between the salient beliefs underlying the use of condoms in our First Nations adolescent sample and another Aboriginal sample (Gagnon, 2010), as well as among adolescents from non-Aboriginal samples. Our study provides exploratory data on beliefs related to factors that might influence the use of condoms among 13-18 year olds from FN communities of Quebec. The implications of our findings are to be discussed with the Commission in order to help define practical strategies related to the promotion of condom use and the prevention of STIs and HIV/AIDS among Quebec Aboriginal youth.

Strengths and limits of this study

This research was planned and conducted in partnership with the Commission, which facilitated contact between our team and participating communities and helped in adjusting the methodological choices to fit with FN communities’ reality and values. Although we did not anticipate the failure of the focus group technique, we were able to find a suitable alternative to collecting data in a particular context of Aboriginal youth. A first possible limitation arises from the fact that a limited number of communities and youth took part in this study; hence our results may not be applicable to young people in all Aboriginal communities. Second, due to time and financial constraints and other restrictions related to the academic schedule of the high schools in participating communities, we were not able to go through the subsequent steps of the study that would have consisted in a survey on the determinants of intention to use a condom at each instance of sexual intercourse among Quebec Aboriginal youth based on the salient beliefs identified in this study.

DISSEMINATION

Intended as a preparatory step to action, our research aimed to explore the beliefs underlying condom use among Quebec FN youth so as to consider the possible avenues of intervention with these people. As such, our dissemination plan prioritizes key actors in the field of sexual health promotion in FN communities. To do so, the preliminary results of this study have been presented to the Commission's staff in charge of the sexual health, and to members of the Health Executive Office of each of the participating communities. The final report on this research will also be provided and discussed with those actors for a better knowledge translation plan. This paper is also an opportunity to share our findings through the channel provided by the Canadian Aboriginal AIDS Network, so that other Canadian Aboriginal communities can benefit from our research.

RECOMMENDATIONS

This study is part of a feasibility evaluation, and the findings allow us to formulate a number of recommendations for the development of evidence-based interventions using ICT for promoting sexual health among Quebec FN adolescents and young adults. First, we would recommend to decision-makers in the field of sexual health to provide resources (human, material, and financial) to perform a survey, based on the beliefs identified in this study, on the determinants of intention to use a condom at each sexual intercourse among FN youth. Also, a further study should aim at determining the relationship between beliefs and intentions to use condoms in this population. Such studies would provide a basis for the development of practical strategies to strengthen positive beliefs related to condom use and minimize the negative ones in order to promote this behaviour for a healthier sexual life among the youth of FN communities.

CONCLUSION

This study allowed us to explore the conception of health and sexual health and the factors underlying condom use among 13-18 year olds of two First Nations communities of Quebec. The conception of sexual health by participants in our study positioned them as a potentially receptive target for interventions aimed at promoting the use of condoms. Our study has highlighted important beliefs that provide avenues for designing interventions to promote condom use for a healthy sexual life in First Nations youth. The implications of our findings are to be discussed with the Commission in order to help define practical strategies related to the promotion of condom use and the prevention of STIs and HIV/AIDS among Quebec First Nations youth. During our research, we faced several challenges that we could not possibly have met without support from the Commission and collaboration from the communities. It is time to act to minimize the burden of sexual diseases in First Nations communities, and we believe that partnership is an approach that can promote the empowerment of these communities to more effectively fight against STIs and HIV/AIDS and reduce inequalities related to sexual and

reproductive health.

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APPENDIX A: QUESTIONNAIRE

Study on the beliefs associated with using a condom among those ages 13-18 years in the First Nations communities of Quebec

INSTRUCTIONS

1. The estimated time required in order to fill out this questionnaire is approximately 20 minutes. We invite you to record your answers, opinions and experiences in the questionnaire. We also ask that you fill out the “Individual characteristics of the participant” section that can be found at the beginning of the questionnaire.
2. Please note that there are no right or wrong answers. The most important thing is to express your genuine thoughts. The answers you provide will remain anonymous.

Thanks! Your collaboration is our most precious asset in order to gain an understanding.

This project was approved by the Band Council, the community Health Centre and the *Comité d'éthique de la recherche* (free translation: research ethics committee) of the *Université Laval*: **Approval no. 2012-144 A-1 / 22-10-2012**. Any complaints or critiques related to this research project can be addressed, in complete confidentiality, to the office of the Ombudsman of the *Université Laval* using the following contact information:

Pavillon Alphonse-Desjardins
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Toll free: 1 (866) 323-2271
info@ombudsman.ulaval.ca

Email:

INDIVIDUAL CHARACTERISTICS OF THE PARTICIPANT

- 1) What is your gender?
 - Male
 - Female

- 2) How old are you?
_____ years old

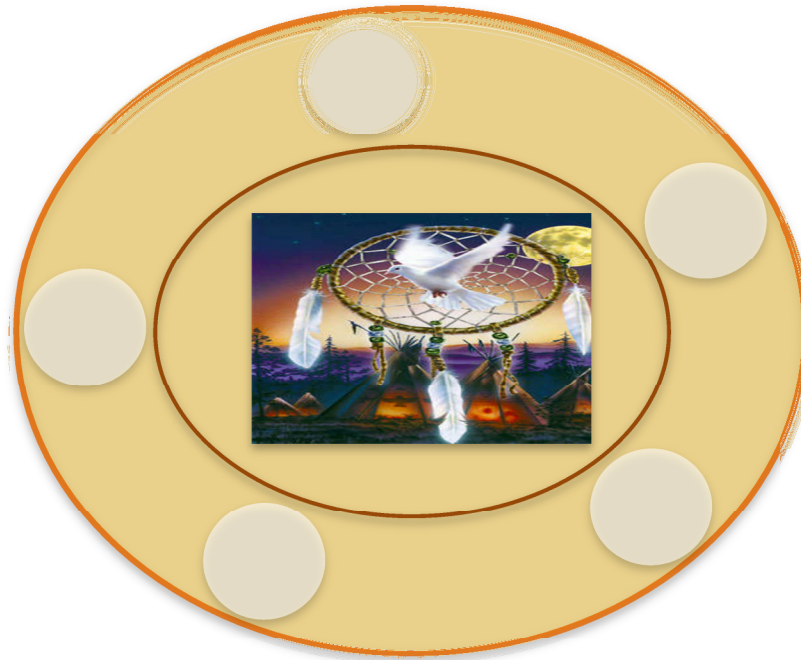
- 3) What community do you come from?
 - Manawan
 - Kitigan Zibi

- 4) Which languages do you understand and most often use?
 - French
 - English
 - Algonquin
 - Atikamekw
 - Other (specify):

- 5) What is the highest level of education you have completed?
 - Elementary school
 - Secondary 1
 - Secondary 2
 - Secondary 3
 - Secondary 4
 - Secondary 5
 - Trade school
 - Other (specify):

QUESTIONS

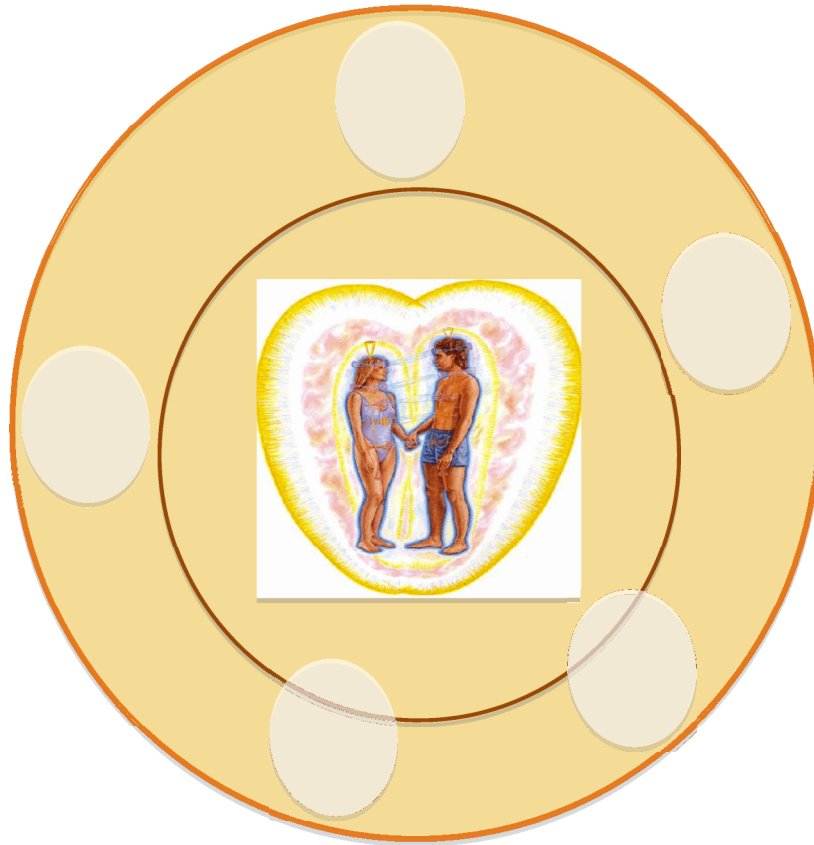
1- Let's consider that the following circle symbolises health:



Among the 12 following statements, choose the five elements that, in your opinion, contribute the most to making up your circle of health. In the empty circles within the circle, record the letters corresponding to the selected statements.

- a- Not having any diseases (physical, mental)
 - b- Feeling good about oneself (in the physical, psychological, emotional and spiritual dimensions)
 - c- Being able to perform one's daily activities
 - d- Adopting healthy behaviours (in connection with nutrition, sports activities, smoking, drugs, etc.) according to recommendations made by health professionals (nurses, physicians, etc.)
 - e- Being able to take care of oneself
 - f- Being well in one's family
 - g- Being comfortable in one's community
 - h- Being capable of making decisions (being free to do what I want)
 - i- Health is a priority in my life, it's essential
 - j- Having sexual relations on a regular basis
 - k- Feeling in harmony with one's values
 - l- Others (specify):
- 2- Does "sexual health" mean something to you? YES NO

While considering that the following circle symbolises sexual health, among the 14 following statements, choose the five elements that, in your opinion, contribute the most to making up your circle of sexual health. In the empty circles within the circle, record the letters corresponding to the selected statements.



- a- Not having infections (STI, AIDS, etc.)
- b- Sexuality that complies with one's values
- c- Being informed on sexuality
- d- Not being faced with an unwanted pregnancy
- e- Not having sexual relations against one's will
- f- That my privacy and choices be respected
- g- Undergoing testing for cytology on an annual basis (PAP-TEST for women)
- h- Consulting a professional as soon as a sexual problem appears
- i- Having someone you trust to talk to
- j- Being respected by authority figures (parents, teachers, health professionals, coaches, etc.)
- k- Having sexual relations without fear of contracting diseases
- l- Having sexual relations without consuming drugs or alcohol
- m- Having a stable sexual partner
- n- Having sexual relations without the risk of unwanted pregnancy
- o- Others (specify):

3- For question 2, you created your definition of sexual health. According to this definition, how would you describe your own sexual health? Circle your choice from the following options:

- A- Very bad B- Bad C- Quite good D- Good E- Excellent

For the following questions, place a checkmark beside the answer choices that are most in line with your point of view. You may check more than one answer.

4- In your opinion, what are the possible benefits of using a condom each time you have sex?

- Avoiding unwanted pregnancies*
- Protecting oneself from STI/STD (sexually transmitted infections/diseases)*
- No stress related to sexual diseases or unplanned pregnancies*
- Reducing the transmission of STI*
- Avoiding getting someone pregnant*
- Protecting myself and my partner*
- Other (specify):

5- In your opinion, what are the possible disadvantages of using a condom each time you have sex?

- Decreased sensitivity*
- Allergies (to latex)*
- Irritation*
- Being frowned upon by friends*
- Less intimate*
- None*
- Other (specify):

6 - Who are the important people in your life who would appreciate it if you used a condom each time you had sex?

- Parents*
- Health professionals (physicians, nurses)*
- Sexual partner*
- Family*
- My boyfriend/girlfriend*

- Grandparents**
- Other (specify):

7 Are there any important people in your life who would not be in favour of you using a condom each time you have sex?

- Sexual partner**
- My boyfriend (lover)**
- Guys in general**
- Other (specify):

8-

a. What are the factors that could get you to use a condom each time you have sex?

- Always having some on you**
- Having some within reach**
- Having them consented to – if my partner agrees**
- Worried about getting pregnant**
- Having proper information on STI and condom use**
- If they were accessible at all times**
- Discussion between man and woman – if it was discussed with one’s partner**
- Talking about it more**
- Discussion with the parents – if my parents would talk about it with me**
- Friends who practice sexual health – if my friends used them**
- Practice – if I was more used to them**
- Other (specify):

b. What are the factors that could prevent you from using a condom each time you have sex?

-
- Not having any on me**
 - Being drunk – having consumed too much alcohol**
 - Having used drugs**
 - Lack of practice (never having used any)**
 - The immediate desire to have sex**
 - Being unconscious**

- Not having any money to purchase them*
- Not being appropriately informed on how to use a condom*
- Shyness – when we don't assert ourselves*
- Other (specify):

9- Is wearing a condom each time you have sex part of your personal values (is it important to you)?

- *If so, why?*

- *If not, why not?*

10- What methods could your community implement in order to promote condom use among the youth?

- Discussing them more*
- Distribution of condoms (for free)*
- Workshops on sexual health and STI*
- Awareness-prevention*
- Providing information (documentation) on condoms*
- Prevention at the health centre*
- Prevention in the schools*
- Making condoms available to the youth*
- Setting up kiosks (information along with gifts)*
- Other (specify):

Thank you very much for your precious cooperation.

This project was approved by the *Comité d'éthique de la recherche de l'Université Laval*:

Approval no.: 2012-144 A-1 / 22-10-2012

The Complexities of Accessing Care and Treatment: Understanding Alcohol Use by Aboriginal Persons Living with HIV and AIDS

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The research sites and contacts involved in this study: 2-Spirited People of the First Nations, AIDS Saskatoon, AIDS Thunder Bay, AIDS Vancouver, All Nations Hope AIDS Network, Blood Ties Four Directions, Healing Our Nations, Healing Our Spirit, Nine Circles Community Health Centre, Positive Living North, Red Road HIV/AIDS Network, Sandy Hill Community Health Centre, Shining Mountains Community Living Services, The Canadian Association of Nurses in AIDS Care, The HAVEN/Hemophilia Program, Vancouver Native Health Society.

Project contributors: Janet Dunbrack, health policy consultant; Joel Singer & Terry Lee, CIHR Canadian HIV Trials Network (CTN); Kevin J. Barlow, Past Chief Executive Officer CAAN; Randy Jackson, Past Director of Research CAAN.

ABSTRACT

The role of alcohol in the transmission of HIV and access to health services for persons living with HIV/AIDS is relatively unexamined across the globe. Our team's community-based, mixed methods study examined both of these questions from the perspectives of Aboriginal persons living in Canada with HIV/AIDS (APHA) and service providers (SP). A bilingual national survey was undertaken with APHAs and SPs and the findings were followed up on in peer interviews. A complex relationship was identified between alcohol use, perceptions of alcohol use and access to services. Nearly half of APHAs surveyed reported that alcohol played a role in their becoming HIV positive. APHAs and SPs differed in their assessment of the impact of alcohol in the lives of Aboriginal persons once diagnosed, with a far greater proportion of SPs identifying it as problematic. Both SPs and APHAs associated the misuse of alcohol with diminished health. Nearly half of the APHAs surveyed shared they had been told they were drinking by a SP when they were not, while over one-third reported ever being denied services because of drinking when in fact they were not. Both SPs and APHAs identified physical health and discrimination as key reasons. Notwithstanding these results that point to shortcomings in service provision, the data also reveal that most APHAs are receiving care in which their choices are respected and from providers they trust. The findings point to the need for a nuanced strategy to solidify the strengths and address the shortcomings in APHA's service provision.

The dogs in this image, that would represent us Aboriginal people, and not just for people living with HIV but for Aboriginal people that are dealing with addictions and that and how society sometimes just wants us to mush and get through all those years of history so fast and it took many, many years for all that stuff to happen and there's such a long line of stuff there that it's going to take many years of (pause) to be able to recover

from all that. And that's kind of where I feel they (pause) when I hear attitudes and feelings from other people who are not Aboriginal, that often they, you know, just push Aboriginal people, just "hurry up and get through all that stuff and start to be healthy.

-APHA Interview Respondent

INTRODUCTION

Aboriginal People and HIV

Aboriginal³ persons in Canada are disproportionately represented in reported cases of HIV and AIDS. According to the 2006 census, Aboriginal persons comprise 3.8 percent of Canada's total population (Statistics Canada, 2008), however, an estimated 8.9 percent of all people living with HIV/AIDS and 12.2 percent of new HIV infections are among First Nations, Inuit and Métis (Public Health Agency of Canada, 2011). Furthermore, of known Aboriginal HIV cases, approximately half (48.8%) of all positive HIV test reports between 1998 and 2008 were for females and two-thirds (63.6%) of cases were attributable to injection drug use (Public Health Agency of Canada, 2010). In addition, one-third (32.6%) of known Aboriginal HIV reports in the same time period were under the age of 30, compared with only 20.5% for non-Aboriginal people (Public Health Agency of Canada, 2010). Aboriginal people, and youth specifically, in comparison to non-Aboriginal people are also more likely to have a late diagnosis, become acutely ill earlier, are less likely to receive optimal medical treatment and have shorter survival times (Mill et al., 2008, p. 133; Spittal et al., 2003).

Aboriginal People and Alcohol Use

Conversely, Aboriginal people have among the highest rates of abstinence from alcohol; abstinence was reported by more than a third (35.3%) of First Nations adults in the 2008/10 First Nations Regional Health Survey (RHS) (The First Nations Information Governance Centre, 2012). However, harms from alcohol use for Aboriginal persons are particularly acute due to high levels of episodic drinking (Dell & Lyons, 2007, p. 6). The RHS reported that approximately two-thirds (63.6%) of adults who had consumed alcohol in the past 12 months met the criteria for binge drinking, defined as five or more drinks per sitting at least once a month (The First Nations Information Governance Centre, 2012). A higher proportion of males met heavy drinking criteria than females. It is well documented that alcohol contributes to a wide range of health-related harms, including injury, liver disease and cancer (Canadian Centre on Substance Abuse, 2006). In fact, according to the World Health Organization, alcohol use is the world's third largest risk factor for disease and disability (World Health Organization, 2011).

APHAs and Alcohol Use

There is a general paucity of literature specific to the use of alcohol by Aboriginal persons living with HIV/AIDS (APHA) in Canada. Of that available, one study reported that "almost all of the

³ In this paper we use the term Aboriginal as an inclusive term that recognizes the First Nations, Inuit and Métis Peoples of Canada. We honour the diversity within our populations and use this terminology to be respectful of the broad range of participants who contributed to our study, to honour our peoples, and to respect confidentiality by writing about what we have learned from the study as a whole.

72 APHA participants [in the study] reported excessive drug or alcohol use in the past or present” (Jackson, Cain, & Prentice, 2008:15). A general population study by Petry (1999) in the United States concluded that alcohol use disorders may be two to four times more frequent among persons living with HIV/AIDS in comparison to the general population. Another US study concluded that there is no significant difference in alcohol and drug use between Aboriginal and non-Aboriginal people living with HIV/AIDS (Barman, 2005). Some studies have also suggested that the use of alcohol may be a way of coping with a recent diagnosis and the stress of living with HIV and being Aboriginal (Chander, Himelboch, & Moore, 2006; Mill, Kennan, & Lambert, 2004). Other studies have linked mental health with alcohol use, such as a study that associated depression in people with HIV/AIDS to frequent alcohol use (Chander, Himelboch, & Moore, 2006).

APHAs, Alcohol Use and HIV Transmission (drinking)

It is only in the past decade or so that alcohol’s role in the transmission of HIV has been recognized (Fritz, 2011, p. 1; Shield, Shuper, Gmel, & Rehm, 2013). Numerous studies have shown that drinking alcohol before sex or being intoxicated during sex is directly linked with HIV. In Rakai, Uganda, for example, the use of alcohol before sex increased HIV acquisition by 50 percent in a study of over 14,000 women and men (Zablotska et al., 2006). Similarly, among men who visited beer halls in Harare, Zimbabwe, having sex while intoxicated was strongly associated with having recently acquired HIV (Fritz, Woelk, Bassett, McFarland, Routh, Tiobaiwa, & Stall, 2002). And in a large study of male wine bar patrons in Chennai, India, unprotected sex was found to be significantly higher among those who used alcohol beforehand (Sivaram, Srikrishnan, Latkin, Iriondo-Perez, Solomon, & Celentano, 2008, p. 1).

A recent meta-analysis, however, cautions against making a causal link between using alcohol and sero-conversion, arguing instead that people who drink have a “generalized risk-taking personality (and) may be prone to both problematic drinking and risky sex” (Rehm, Shield, Joharchi, & Shuper, 2012, p. 10). Nonetheless, a qualitative study with Australian APHAs (Thompson, Bonar, Greville, Bessarab, Gilles, D'Antoine, & Maycock, 2009) found that respondents saw their use of alcohol as a dis-inhibitor that helped to create the conditions for vulnerability to HIV (e.g., unprotected sex). Further, in a recent US Agency for International Development update (Fritz, 2011) the link between alcohol and risky sexual behaviour was identified in sub-Saharan African countries and India.

APHAs, Alcohol Use and HIV Transmission (Injection Drug Use)

There is also some evidence that points to increased injection drug related HIV-risk from drinking. The National Institutes of Health in the United States released an Alcohol Alert in 2002 stating that: “Rates of injection drug use are high among alcoholics in treatment, and increasing levels of alcohol ingestion are associated with greater injection drug-related risk behaviors, including needle sharing,” (National Institute on Alcohol Abuse and Alcoholism, 2002, p. 2). A recent qualitative study of alcohol as a risk factor for HIV transmission among American Indian and Alaska Native drug users found “very high rates of alcohol use among...active crack and injection drug users” and that “those claiming more episodes of using alcohol before or during sex, reported significantly more events of unprotected sexual intercourse” (Baldwin, Maxwell,

Fenaughty, Trotter, & Stevens, retrieved September 16, 2014, p. 1). This is an area of increasing awareness in the HIV prevention field, and there is a need for further research and understanding.

APHA Access to Health Care Services

It is well established that the attitudes of individual service providers impact APHA's access to primary and emergency care. Canadian studies have found that health care providers need to practice increased cultural competence with their APHA clients (Jackson & Reimer, 2005; McCall, Talbot, & Lunny, 2006; CAAN, 2008). APHAs who have negative encounters with their health care providers also have significantly lower rates of returning for follow-up care and adhering to their prescribed medical regime (Benoit, Carroll, & Chaudhry, 2003; Gorman, 2006; Jackson et al., 2005; Jackson & Monette, 2005; Levin & Herbert, 2004; Meen et al., 2004; Mill, et al., 2006). A 2008 study of SPs highlighted the benefits of SPs acknowledging the unique, culturally-based needs of APHAs: "While the journey itself is not Aboriginal-specific, Service Providers generally agreed that there are cultural components to how APHAs balance positive and negative experiences and how they respond to diagnosis, adhere to treatment, access support, overcome obstacles and learn to live with HIV/AIDS" (Canadian Aboriginal AIDS Network, 2008, p. 9).

When our study commenced in 2007, a review of the empirical literature revealed little on the association between actual and perceived alcohol use by APHAs and access to services—a gap that largely remains today. Related publications that do exist emphasize research findings from the prairie and pacific regions of Canada and the majority take place in urban centres, even though nearly half of Canada's Aboriginal population lives in a rural or remote area or on-reserve. The existing research is also nearly exclusively based on Western academic approaches, which tend to silence the lived experiences and voices of Aboriginal persons. Our study attempted to address these significant gaps. Our team's community-based, mixed methodology approach combined a bilingual national survey with qualitative interviews conducted with APHAs and SPs. In this paper, the key findings are situated within the related literature. The paper concludes with suggestions for a nuanced strategy to solidify the strengths and address the shortcomings in service provision received by APHAs who may or may not be using alcohol.

METHODOLOGY

Approach – Aboriginal Ethics in Research

This study applied a community-based approach to research that challenges status quo assumptions in knowledge production, and was guided by the principles of Ownership, Control, Access and Possession (OCAP™) for research with First Nations communities (Schnarch, 2004; First Nations Information Governance Centre, 2014). These principles were originally developed in Canada within the context of "a large scale social movement of anti-colonialist discourse" (Lopez, as cited in Denzin & Lincoln, 2008, p. 3). Our adherence to the OCAP™ principles informed the development of our team's Principles of Research Collaboration Agreement and allowed us to engage in a research process that we intended to be respectful of and honour the diversity of participants and other involved partners (such as health care organizations) in the

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research process. This understanding supports reference by the Canadian Institute of Health Research's to Elder Albert Marshall's concept of "two-eyed seeing" or "multiple-eyed seeing" (Institute for Integrative Science and Health, retrieved March 30, 2013, p. 1).

Research Framework

With Aboriginal Ethics guiding the study's development, it enabled our team to work from a community-based research (CBR) approach built upon decolonizing methodologies (Tuhiwai Smith, 1999) and a transformative-emancipatory paradigm (Mertens, 2003). A beginning point was acknowledging the diversity within our communities of interest—Aboriginal people living with HIV/AIDS and service providers who offer care to them. This necessarily required that attention be given to First Nations, Inuit and Métis heterogeneity, large and small urban and non-urban centres, socially complex and varied lived experiences, and gender diversity. Our team included academic and community-based peer researchers who are also: Aboriginal organizational representatives; Aboriginal people living with HIV/AIDS; of Aboriginal and non-Aboriginal descent; university based staff and students; and an Elder. Ethics approval for this study was granted by the University of Saskatchewan Behavioural Research Ethics Board.

(i) Community Based Research

Community Based Research (CBR) is a growing field of research in Canada and across the globe. CBR engages a range of research approaches, including participatory research, community-based participatory research, action research and social planning research (Walters, et al., 2009). Common among CBR is privileging critical-focused "bottom-up" approaches in which the research process mediates power differences among project members (Mendenhall & Doherty, 2007) and is both a "political and theoretical undertaking" (Cahill, 2007). CBR has been demonstrated to enhance wellness in Aboriginal and other communities and to result in more effective and sustainable policies and programs (Aspin, Brown, Jowsey, Yen, & Leeder, 2012; Henderson, Simmons, Bourke, & Muir, 2002). For example, an Australian study found that Indigenous-academic research partnerships contributed to individuals' recognition of factors important to their own well-being, such as spirituality (McLennan & Khavarpour, 2004).

(ii) Decolonizing methodologies

Decolonizing methodologies specifically challenge the dominant, Western academic research paradigm of non-Indigenous researchers doing research on 'others' (Tuhiwai Smith, 1999). It encourages the use of research approaches where inquiry comes from Indigenous communities, and with the communities thereafter involved in every stage of the research process.

Decolonizing research likewise emphasizes that the strengths of Indigenous knowledge be considered alongside Western methodological approaches. Tuhiwai Smith (1999) refers to this as telling the untold story (4). Indigenous approaches in research—and specifically a decolonizing orientation—"can be defined as research by and for Indigenous people, using techniques and methods drawn from the traditions and knowledges of those people" (p. 894). This required the inclusion of Aboriginal persons directly affected and living with HIV/AIDS in this study. As Tuhiwai Smith (1999) shares: "When Indigenous peoples become the researchers and not merely the researched, the activity of research is transformed. Questions are framed differently,

priorities are ranked differently, problems are defined differently, people participate on different terms" (p. 193).

(iii) Transformative-emancipatory paradigm

This study also draws upon a transformative-emancipatory paradigm, which is acknowledged for bridging Indigenous and Western worldviews and uses research as a strategy to achieve social justice, and specifically by marginalized groups (Mertens, 2003, p. 136). The transformative-emancipatory paradigm invites scholars to consciously collaborate with diverse marginalized individuals, groups and communities as a foundation to the research process (Denzin & Lincoln, 2008). Transformative scholars assume that knowledge is not neutral but is influenced by human interests, that all knowledge reflects power and social relationships within society, and that an important purpose of knowledge construction is to help people improve society (Banks, 1993, 1995). This corresponds with the underlying philosophies of community-based research, Indigenous methodologies and Aboriginal research ethics. This study's partnerships explored Indigenous ways of knowing and integrated traditional knowledge with modern scientific methods of inquiry (Reading, 2006). This approach contributed toward avoiding the risks of incorporating a strong bias from the dominant Western culture that could in turn lead to results that misinform next steps in policy and programming.

Data Collection

Reviewing existing community consultations and the empirical literature, our data collection was designed using a mixed methods approach over a 16 month period: APHA and SP self-administered cross-sectional bilingual surveys and follow-up in-depth bilingual interviews. The quantitative APHA survey was designed to collect information on alcohol use patterns and experiences accessing care and treatment. The SP survey was designed to collect information on experiences of providing care and treatment to APHAs who are using or are perceived to be using alcohol. The surveys were pilot-tested with an equal number of APHAs and SPs (N=20) and subsequently revised to change the phrasing of several questions and add an introductory statement to emphasize the personal nature of the questions. A prospective power calculation was undertaken to determine the number of completed surveys required for a representative sample, and a minimum of 94 completed surveys was identified to achieve a confidence interval of 10 percent. A total sample of 116 APHAs and 109 SPs from across Canada engaged in the survey. This renders the quantitative results of the survey statistically significant, meaning that the results are unlikely to be attributable to chance.

Informed by the data gathered through the surveys, qualitative, open-ended interview guides were developed for APHAs and SPs to contextualize the survey results. Two peer researchers conducted the majority of the interviews. Both were APHAs and worked as SPs in the past. Each interview began with the respondent selecting an image that symbolized their experiences with accessing care and treatment and drinking, and SPs selected an image representing their provision of care and treatment to someone they perceived to be drinking. This technique was used to facilitate a two-way, open dialogue. On average, the interviews were 45 minutes in duration and a total of 25 APHAs and 23 SPs were interviewed.

Our two study samples represent APHAs and SPs from across Canada. Of the 116 APHAs who participated in this study, over three-quarters were First Nations (primarily Status), 15 percent Métis and 6 percent Inuit. Forty-three percent identified as male, 34 percent as female and the remaining as two-spirited, trans-gendered and intersexed (16%, 5% and 2% respectively). The average age of APHA respondents was 43 years. On average, they had been living with HIV or AIDS for 12 years at the time of the survey, with approximately one-third reporting AIDS status. Fifty-eight percent reported to be on a treatment regimen from a physician that included anti-retroviral medication and 43 percent reported to have changed their lifestyle to improve their health. The primary language spoken by APHAs is English (97%) with 18 percent also speaking French, and 27 percent reported to speak at least one Aboriginal language. Just over half of APHA respondents identified their sexual orientation as straight. The vast majority reported to live in an urban centre and in a private residence (81% and 78% respectively) and approximately half (51%) felt they had treatment and care in their home city; an additional 19 percent had moved to access treatment and care, and 10 percent reported that they were considering moving. Most of the APHAs reported being impacted by residential schooling themselves (16% attended) or through their parents and/or grandparents (54% and 36% attended respectively). Just over a quarter of respondents identified as the primary caregiver in their family.

Of the 109 SPs who were reached through the study, 71 percent were female, 21 percent male and 8 percent two-spirited. Half identified as non-Aboriginal and 17 percent reported to speak at least one Aboriginal language with their clients. The SPs worked for an average of eight years in their field. Forty-three percent worked at an Aboriginal service organization and another 28 percent worked at an agency that served both Aboriginal and non-Aboriginal clients. Approximately 70 percent of the SPs offered targeted services for APHAs, however, the number of APHA cases managed by their agencies over the past two years varied widely (ranging from between 1 and 10 to over 30).

(i) Sampling Strategy

(a) Quantitative

Given our team's recognition of the long-standing absence of data collection with APHAs and APHA SPs outside of large, urban centres and English-speaking Canada, data collection in smaller urban centres and the province of Quebec was prioritized. Our national quantitative data collection with APHAs had highest concentration in Ontario (31%), followed by British Columbia (20%), Saskatchewan (18%), both Manitoba and Quebec (8%), Alberta (5%), the Atlantic provinces (2%), and Yukon (1%). Seven percent did not identify their location. Quantitative data collection with SPs was also distributed across Canada and once again responses were concentrated in Ontario (33%), followed by British Columbia (19%), Saskatchewan (17%), Quebec (12%), the Atlantic provinces (10%), Manitoba (4%), Alberta (2%), Yukon (2%) and 1 % did not answer. A limitation of the sample was that it was outside of the scope of this project to travel widely and negotiate the intricacies of research partnerships with multiple First Nations, and so no data was collected in First Nations communities.

Both APHAs and SPs were sampled by contacting AIDS service organizations, health centres and professional organizations such as the National Native Partnership Foundation, National

Native Alcohol and Drug Abuse Program and Canadian Nurses in AIDS Care. Cities were chosen based upon existing contacts of research team members and snowball sampling within a city. Contact was first made via email and then a follow up phone call reviewed the project, expectations, procedures and contributions back to the organization for participation. Surveys were mailed to the organizational contacts with honoraria for participants provided in separate envelopes (both SP and APHAs received \$20 to complete the quantitative survey & \$40 to participate in a qualitative interview). Respondents completed the survey as well as a separate form to acknowledge receipt of the honorarium. Complete and incomplete surveys and unused honoraria were returned to the research coordinators. Surveys were also distributed at one national and one sizeable provincial Aboriginal health conference (with high attendance from across the country) and an HIV/AIDS health care provider national conference. The same participation process was followed as above, with the additional specification that individuals do not complete a survey if they have already done so through their organization. Team members, and primarily peer researchers and project coordinators, issued the surveys at a display table at the conferences. An online version of the survey was also developed to help reach a network of SPs who are broadly distributed geographically through a national service provider organization, including on-reserve, however a small number of people completed it.

(b) Qualitative

The concluding question on the quantitative survey asked if respondents were interested in doing a qualitative interview. For those who indicated interest, the research coordinators followed-up and interviews were offered. A total of 25 interviews were conducted with APHAs and 23 with SPs. Qualitative data collection with APHAs similarly took place across the country, with concentration highest in Ontario (52%), followed by British Columbia (16%), Quebec, Manitoba and the Atlantic provinces (8%), Saskatchewan (4%) and Alberta (4%). Data collection was similarly distributed with APHA SPs and concentrated in Ontario (31%), Manitoba (17%), British Columbia and Quebec (13%), Saskatchewan and Atlantic provinces (9%), Alberta (4%) and Yukon (4%).

(ii) Limitations

A key limitation of this study is that the data was collected from AIDS service organizations and conferences. It follows that the study's respondents are likely to be connected with AIDS-related resources in their communities and work places. Therefore, the sample likely does not capture APHAs who are not accessing services. Similarly, it is plausible that the sample of SPs in this study are more aware of issues related to HIV than the overall population of SPs that APHAs encounter. Given this, the findings may be more troubling in areas of concern for those who are less engaged than those in our sample population. Similarly, areas of positive findings in this study may be inflated as they may represent services and/or approaches that are more frequently offered within HIV/AIDS care. Also, given our team's recognition of the long-standing absence of data collection with APHAs and SPs outside of large, urban centres, our prioritization of smaller urban centres may skew the results in that services tend to be less functional in these locations. In this case, areas of positive findings in the study may be slightly deflated, and negative findings moderately inflated.

Another limitation of the study is the minimal engagement of French speaking respondents; in fact, 96% of surveys and all of the interviews were completed in English despite French translations and translators/French speaking team members. The importance of our approach though is that it highlights centres that have been less likely included in HIV/AIDS research in Canada. And last, given the wealth of knowledge collected in this study, this paper combines responses, for example, for in-patient and community-based care; data collected on drugs other than alcohol are not presented; and multivariate statistical analyses are not presented.

(iii) Data analysis

Our team applied a constant comparative approach to data analysis, also known as a concurrent triangulation design – comparing qualitative and quantitative data analysis results throughout the data analysis phase (Creswell, 2011; Denzin & Lincoln, 2000). Drawing on the work of Kovach (2009), we brought both Indigenous and conventional Western knowledge systems and methods to our analysis. Once again, with the principles of OCAP guiding our study's development, this enabled our team to work from a community-based research approach built upon decolonizing methodologies (Tuhwai Smith, 1999) and a transformative-emancipatory paradigm (Mertens, 2003). This framework guided our work with the data.

(a) Quantitative Data Analysis Process

Survey responses for each sample were collected in a Predictive Analytics SoftWare (PASW) 18 database from which both descriptive and inferential statistical analyses were calculated. Unlike some quantitative or mixed methods studies, no participants were 'scrubbed' from the data set in order to achieve a statistically significant result: all participants' voices were treated as equally important. Analyses of the data were brought to the research team, discussed in plain language and then directly applied to inform the second stage of the data collection – the interviews.

(b) Qualitative Data Analysis Process

All interviews were transcribed verbatim and cleaned to remove any identifying information. These transcripts were loaded into Atlas.ti, a qualitative data analysis software package. An inductive approach to coding the data was adopted. At an in-person team meeting, our members divided into small groups with APHA and Aboriginal and Western worldviews represented in each. The groups reviewed a sample of transcripts together to agree upon thematic codes. The small groups then merged into a whole, in which our team reviewed the coded transcripts together and a coding framework was agreed upon. Applying the framework, each interview was coded by at least two people. The initial code list included 78 themes and was eventually collapsed to 42. From this, 9 central themes emerged. Next, our team met in person to review the coded data. Three small groups worked together to analyze a central theme each. Two team members volunteered to analyze three additional themes, and the remainder of the analysis was completed by the research coordinators with the guidance of the team. A final team meeting resulted in a team plan for reporting our key findings, all the while ensuring peer researcher and Elder participation.

RESULTS

All results draw upon analysis of the quantitative survey data and incorporate the qualitative interview data, except for demographic information about the 'impact of alcohol' which are primarily drawn from the quantitative survey data.

(i) Role of alcohol in becoming positive

Forty-seven percent of APHAs surveyed agreed that alcohol played a role in their sero-conversion. In the qualitative interviews, APHAs identified multiple ways in which they saw drinking related to their becoming HIV positive, the most prominent being a loss of inhibition or control and engaging in unprotected consensual or nonconsensual sex and intravenous drug use. One respondent shared: "I was definitely more 'influencable' when I was drinkin'. I would be more easy to say, "Yeah, okay, sure I'll go try that". Another recounted: "I'd get to the point where I'd just overdo it and drinking and something and I'd wake up and you know, sometimes I wouldn't even know where I was and I'd be in somebody else's place and that's how I contracted HIV". A respondent specifically shared how he became HIV positive when he was drunk by choosing to re-use someone's needle: "I was drunk and...he left a syringe full and it was bloody and he said 'don't touch that'... so I sat there and went 'Oh fuck', I took it and shoved it in my arm and I got high."

(ii) Alcohol Use

Alcohol use patterns varied among APHAs, from not consuming alcohol at all to drinking in excess. APHAs and SPs differed in their assessment of the impact of alcohol in APHAs' lives, with some APHAs identifying problems associated with their use and a much greater proportion of SPs identifying it. At the time of the survey, 33 percent of APHAs reported that they did not consume alcohol. Of those that did, 25 percent were not worried about negative impacts of alcohol use in their lives and 10 percent claimed it made their lives easier, such as providing emotional relief and social connection. Conversely, 22 percent reported to sometimes worry about it, 15 percent said that it makes their lives worse, and 10 percent felt that they drank too much. APHAs who identified alcohol use as negatively impacting their lives said it compromised the management of their HIV/AIDS treatment and their physical, emotional, mental and/or spiritual health generally.

In contrast to APHAs, a far greater number (88%) of SPs identified alcohol use as a general problem in the lives of at least some APHA clients under their care, with 96 percent perceiving alcohol use as having a negative impact on these clients' health. Similar to APHAs, SPs viewed alcohol as problematic in their clients' HIV/AIDS treatment, and most saw alcohol use as negatively impeding their clients' decision making and thinking abilities, healthy eating, the capacity to feel good about one's self, and the ability to believe in the Creator, a higher power or inner spirit. Fifty-two percent of SPs also acknowledged that daily use of alcohol may not, in some circumstances, have a negative impact on their clients' health.

(iii) Perceptions of Alcohol Use

The survey findings showed that APHAs experience marginalization due to both their actual drinking and the perception that they had been drinking. Nearly all SPs (92%) reported they believed their APHA clients had used alcohol at some point in their care. Some SPs shared that they were confident in their ability to discern whether a client had been drinking while others could not be so sure. Those who reported confidence seemed to share an attitude about drinking being an ‘expected’ behavior. Approximately half of APHAs (52%) said they had ever been told they were drinking by a SP when they were not, and this number increased considerably among those who reported ever drinking before seeking services (63%).

APHAs and SPs were asked for reasons why APHAs might seem to have been drinking alcohol when they were not, and the majority of responses related to physical health. An APHA shared that “(if) someone is not going for dialysis and the toxins are accumulating in their body instead of the dialysis taking them out, they cannot be thinking clearly, or be groggy”. A SP added: “I would think diabetes would be a big one, and it’s so prevalent in Aboriginal communities. And other (pause) brain damage things, and when you are talking about people living with HIV too, they are at higher risk for things that affect their speech, things that affect their coordination”. The most commonly mentioned physical indicators relayed in the interviews were smell (e.g., the use of cheap cologne, ketoacidosis—fruity smelling breath that occurs when the body breaks down fat for fuel to cope with a shortage of glucose and which is common with diabetes or malnourishment, the smell of a hangover, and the smell of poor hygiene) and behavior (e.g., drowsiness and raggedness—which could be related to missing a night of sleep, side effects from a variety of medications, stroke, thyroid problems, mental illness, a historical or recent brain injury, progression of HIV or kidney failure, and diabetes).

Discrimination was also identified as a key reason APHAs were identified by SPs to have been drinking alcohol when they were not. Both APHAs and SPs relayed that overarching discrimination was experienced by APHAs based on their Aboriginal ancestry, HIV status and real or perceived use of alcohol. To illustrate, a statistical correlation was identified in the survey data between speaking an Aboriginal language and being denied services in community based and in-patient care (e.g., in a hospital). This finding encouraged our team to explore which APHAs were most vulnerable to being denied services in our interviews. Speaking an Aboriginal language as a barrier to care was not, however, uncovered in the interviews. This may be a result of our small sample size or an inadequate representation of Aboriginal people who speak an Aboriginal language. The greatest areas of concern for APHAs accessing services in their interviews were judgmental attitudes and discriminatory practices against those with a mental illness, who use solvents, are homeless, have poor hygiene, have an HIV status and use alcohol, and are transgendered. Racism was threaded throughout these identified concerns as a common site of oppression. Although poverty was seldom identified as a primary impediment to APHAs accessing services, it was a key determinant in the lives of the above identified groups.

Both SP and APHA respondents shared experiences of systemic discrimination, and specifically racism in APHAs’ receipt of care. One APHA shared:

People will deny it but there is systemic discrimination towards Aboriginal people in every com (pause) community, within their own communities and within the larger metro community as such. If you are fair skinned, your chances are a lot better. I am fair skinned and my chances are a lot better to do anything, than one of my best friends who is (pause) has the features of being First Nations and they don't (pause) it's funny because I'll get "thank-you sir" and the other will have you know, "what d'ya want?"

(iv) Access to Services

Eleven percent of SPs reported having denied services to clients for perceived alcohol use and 11 percent also believed their organization had denied services for the same reason. More stark, just over one-third (36%) of APHAs reported ever being denied services because of drinking when in fact they were not and this number increases to 50 percent among those who reported ever drinking before seeking services. Actual and perceived alcohol use was identified as a significant barrier to HIV care and treatment by APHAs, and for those in need of health care this can lead to serious personal and health-related consequences, including death. Although the majority of APHA survey respondents reported positive experiences and trusting relationships with their SPs and accessing services, others however faced substantial barriers to their care and treatment based on exclusionary practices and judgmental attitudes, including being perceived to be drinking when they had not.

While many APHAs recalled positive experiences and trusting relationships with SPs in their interviews, this again was not the case for all. When asked to describe their experiences with SPs, a number of APHAs reported "feeling judged", "shuffled through really fast", "disrespected", "pushed off to the side", "invisible" and "belittled". One APHA shared, "I feel like a little kid, not understood and treated like I was a little kid that doesn't know what's good for me, you know?". One APHA shared the story of a friend who was denied services for perceived drunkenness when in fact he had not been drinking.

He got really sick and he uh, he went through the [health care facility], uh emergency, to get some care, 'cause he knew he was really, really bad off and uh, he was turned away because they thought he was totally impaired, but it was these effects that he was having from the illness, he was getting from the AIDS and they turned him away and he died.

Specific to accessing SP care while consuming alcohol, this sentiment multiplied. An APHA shared that they felt "weird...like I was naughty" when accessing services when under the influence. Fifty percent of APHAs who reported ever drinking before seeking services shared they did not seek services on at least one occasion for fear of being turned away; "go to detox or come back when you're sober". This was even more likely to occur among women who were pregnant.

DISCUSSION

(i) Perceptions of Alcohol Use

For the first time in Canada, this study has identified through a national survey the percentage of APHAs who have been denied care for drinking when in fact they had not been, as well as SP perceptions related to APHA alcohol use. The results are alarming. A damaging consequence of colonization has been stigma and discrimination toward Aboriginal persons generally, and specifically in relation to alcohol use and living with HIV and AIDS. This is well documented in the literature. For example, regardless of whether APHAs reside in an urban or rural area, discrimination and stigma have been found to significantly limit their access to services (Abonyi, 2006; DeForest, Snider, Krenz & Gill, 2005; Jackson & Reimer, 2008; Jakubec & Woloshyniuk, 2006; Meen, Thomas, et al., 2004). Stigma-related stresses and impacts for APHAs include racism, unstable housing, violence, survival sex work, co-infections, lack of social support, inadequate health care and lack of access to health care (Corneil et al., 2005; Douaihy, Stowell, Bui, Daley, & Salloum, 2005; Garmaise, 2003; Geduld & Archibald, 2005; Hwang, Henry, Raffa, & Gill, 2005; Jackson & Reimer, 2005; Mill et al., 2006; Shannon, Bright, Duddy, & Tyndall, 2005; Spittal et al., 2005; Wood et al., 2003). Areas of particular concern for women relate to experiences of sexual violence and HIV and AIDS-related stigma, discrimination and systemic violence (Hawkins, Reading & Barlow, 2009).

The literature also supports SP and APHA identified physical reasons for misperceptions by SPs. A review of the literature identified some explanations for behaviours that may inaccurately appear to be related to alcohol use by APHAs, such as confusion, drowsiness or raggedness. For example, Aboriginal people are three to five times more likely to develop diabetes in comparison to the rest of the Canadian population. Symptoms of hypoglycemia caused by diabetes include: cold, clammy or sweaty skin; pallor; difficulty concentrating; shakiness; lack of coordination; irritability; hostility; a staggering gait; fatigue; headache; blurred vision; dizziness; nausea; and fainting or unconsciousness (Canadian Diabetes Association, 2011). Diabetes is also a main cause of kidney failure, of which Aboriginal people are eight times more likely to suffer from than the rest of the Canadian population. Symptoms of kidney failure and kidney disease include fatigue and altered thinking (The Kidney Foundation of Canada, 2011). In addition, severe trauma, including brain injury, disproportionately affects Aboriginal people in Canada (Karmali et al., 2005). Symptoms of brain injury include memory loss, impaired reasoning, one-track thinking, speech impairment, difficulty organizing thoughts into meaningful speech, difficulty cultivating and maintaining relationships and a loss of subtle social skills (Brain Injury Association of Canada, 2011).

(ii) Role of alcohol in becoming positive

Our research is also the first known study in Canada to document through a national survey the role of alcohol in sero-conversion of Aboriginal persons. The fact that nearly half of APHAs in our study reported this is supported by the research on drinking generally. The literature reports that alcohol consumption is broadly associated with risky behaviours, including sexual risk taking and IDU, as likewise identified in our study (Cook and Clark 2005; Kalichman, Simbayi, Kaufman, Cain, & Jooste, 2007). The literature shares that people who drink alcohol engage in

more unprotected sex, multiple partnering and commercial sex than non-drinkers (Kalichman Simbayi, Kaufman, Cain, & Jooste, 2007; Zablotska et al. 2006). Some evidence has also been established between alcohol consumption and an elevated risk for injection related HIV (National Institute on Alcohol Abuse and Alcoholism, 2002; Thompson, Bonar, Greville, Bessarab, Gilles, D'Antoine, & Maycock, 2009; Fritz, 2011).

(iii) Alcohol Use

Our study also relayed an imbalance between concern expressed by SPs in comparison to APHAs regarding the impact of alcohol consumption on APHAs' health. The majority of APHAs did not see it as a potential problem whereas SPs did. On the surface this makes logical sense; if alcohol was recognized as a contributing factor to contracting HIV then one's relationship with it may change upon this realization. This finding is a contribution to the literature as there is a dearth of research on the use of alcohol by APHAs and its impact.

Both SPs and APHAs agreed, however, that alcohol misuse can negatively influence all areas of APHAs' health, including physical, emotional, mental and spiritual as well as a HIV/AIDS treatment regime. According to the World Health Organization, alcohol use is the world's third largest risk factor for disease and disability (World Health Organization, 2011). Alcohol consumption is attributed in the HIV/AIDS literature to depression (Cain, Jackson, Prentice, Mill, Collins, & Barlow, 2011; Cain & Todd, 2008; Jackson et al., 2005), non-adherence to ART (Shield, Shuper, Gmel & Rehm, 2013), increased toxicities due to alcohol interactions with ART and immunosuppressant effects which may influence the course of HIV illness (Petry, 1999) and potentially HIV-1 replication (Zha, Chen, Zhuo, Nishitani, Zack & Liu, 2004; Dole et al., 2004; Mtwisha, Seabe, Wood, & Bekker, 2006; Perretti-Watel, Spire, Riandey, & Obadia, 2004), increased rates of hospitalization (Palepu, Horton, Tibbetts, Meli, & Samet, 2004; Palepu, Horton, Tibbetts, & Samett, 2005; Palepu et al., 2005), and progression of HIV (National Institute on Alcohol Abuse and Alcoholism, 2002). Both SPs and APHAs also agreed that alcohol use may serve a positive function in some situations. Researchers, for example, have linked alcohol use specifically with managing coping (Chander, Himelboch, & Moore, 2006; Mill, Kennan, & Lambert, 2004; Chander, Himelboch, & Moore, 2006).

(iv) Access to Services

Our study also corroborates with the literature that documents the excellent care and supports APHAs receive in Canada from their service providers and an ability to readily access it (CATIE, 2014). At the same time, it confirmed what the study set out to examine; some APHAs face substantial barriers and damaging consequences to their health based on exclusionary practices and judgmental attitudes, including being perceived to be drinking when they had not been. Interestingly, it also challenged our team to broaden our focus to both the barriers and facilitators for care, treatment and support for APHAs based upon the range of responses we received.

The majority of strategies that have been shown to improve access to health care services for people living with HIV/AIDS are harm- or risk-reduction based (Callahan, Flynn, Kuenneth, & Enders, 2007; Canadian Aboriginal AIDS Network, 1998; Dell & Lyons, 2007). For example,

considerable research has shown that such community controlled strategies for alcohol and drug use enhance service access, and specifically antiretroviral therapy (ART) adherence (Greet & Connor, 2006; Marsh et al., 2006; Palepu et al., 2004; Palepu et al., 2005; Tyndall et al., 2006; Wood, Montaner, Bangsberg, Tyndall, Strathdee, O'Shaughnessy, & Hogg, 2003). For example, improving treatment access by dispensing care at user-friendly sites has been found to improve ART adherence (Shannon, Bright, Duddy, Seradis, Ishida, & Tyndall, 2004) and lead to fewer hospitalizations (Fielden et al., 2006). There is also some evidence that APHAs using the Vancouver supervised injection facility and a supervised ART program have higher rates of ART adherence and access to additional health care and support programs (Tyndall, et al., 2006). Aboriginal women have also been found to be more likely to access ART through community-based interventions and women-specific services (Shannon, Duddy, & Tyndall, 2005). This is a particular concern for pregnant APHAs.

IMPLICATIONS

The findings from this project need to be carefully considered for their policy and practice implications across the country, focusing on APHAs' access to and SPs' delivery of care and treatment. Without improvements, APHAs who use or are perceived to be using alcohol may not receive adequate treatment, may suffer more from HIV illness or other health-related complications, and may even die younger. Best practices in the field need to be shared and expanded upon and their relation explored with the empirical literature, including this study, heterogeneous lived experience (e.g., gender, age) and Indigenous and Western ways of knowing. Health is a basic human right of every person in Canada.

On many levels, however, Aboriginal people in Canada do not enjoy the same level of health as non-Aboriginal people. The findings of this study need to be placed within this context. The social determinants of health are known factors that contribute to or influence health. Aboriginal people and communities who experience inequities in the social determinants of health face numerous health disparities, and are often denied access to resources that might mitigate those circumstances. To illustrate, poverty is a key determinant of HIV infection (Fenton, 2004; Shelton, Cassell, & Adentunji, 2005). In fact, poverty increases biological susceptibility to HIV infection through elevated rates of malnutrition and sexually transmitted infections (Stillwaggon, 2002), and is linked to a lack of access to health care, lower education and illiteracy (i.e., for risk and prevention messaging), inability to afford condoms and perceptions of risk overshadowed by immediate survival needs (Larkin, 2000). The insightful reflection offered from the APHA interview respondent at the start of this paper should be heeded – context must be considered in any and all responses for progress to happen. An analysis of the contextual roots of the findings of this study would be welcomed.

CONCLUSION

The lack of documented literature was the impetus for this study's investigation into the role of alcohol in the transmission of HIV and access to health services for persons infected with HIV and AIDS. The study confirmed what many APHAs and SPs experience on a regular basis in Canada's health care system; the care is excellent. This study also uncovered a concern that had not been documented empirically until now; APHAs are being denied services for drinking by

SPs, whether it is perceived or real. There is an ongoing concern reflected in the disparity between APHAs and SPs about the potentially problematic role of alcohol in APHAs' lives. Agreed upon, however, are the holistic health impacts when it is a concern. The role of discrimination in the care APHAs receive from SPs continues to persist in deeply complex and rooted ways within Canada's colonial history. The findings point to the need for a nuanced strategy to solidify the strengths and address the shortcomings in APHA's service provision.

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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 seventh 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) methods or philosophy are strongly encouraged. Submissions should be prepared in plain language.

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 HIV/AIDS CBR, Knowledge Translation or other issues of importance to Aboriginal stakeholders.
- **Emerging Issues in Aboriginal Community-based HIV/AIDS Research:** These articles focus on ground-breaking issues, findings and/or reports grounded in ACBR.
- **Ethical CBR in the Aboriginal Community:** Articles will highlight ways of doing good, ethically sound HIV/AIDS research in the Aboriginal community.
- **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.
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Submission Deadline: Monday June 1, 2015 by 5:00pm AST. Please submit manuscripts via e-mail to Marni Amirault (marnia@caan.ca).

All submissions are blinded for peer-review. Priority will be given to authors of Aboriginal ancestry/background should manuscripts of comparable quality be available.

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