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

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ABSTRACT

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

BACKGROUND

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

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

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

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

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

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

PROJECT OBJECTIVES

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

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

SEXUAL HEALTH WORKSHOP

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

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

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

WORKSHOP RESULTS

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

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

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

Accessibility

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

Communication

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

Culturally Appropriate Services

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

Collaboration

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

Normalization

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

Confidentiality

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

Support

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

Prevention

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

Ceremony

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

NEEDS ASSESSMENT TOOL

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

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

DISCUSSION

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

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

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APPENDIX A

Focus Group Questions (morning & afternoon sessions)

A. Sexual Health Services (morning session)

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

B. Youth Sexual Health (Afternoon session)

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

C. Adult/Elder Sexual Health (Afternoon session)

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

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

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

APPENDIX B

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

APPENDIX C

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

APPENDIX D

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

APPENDIX E

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