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

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### **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).

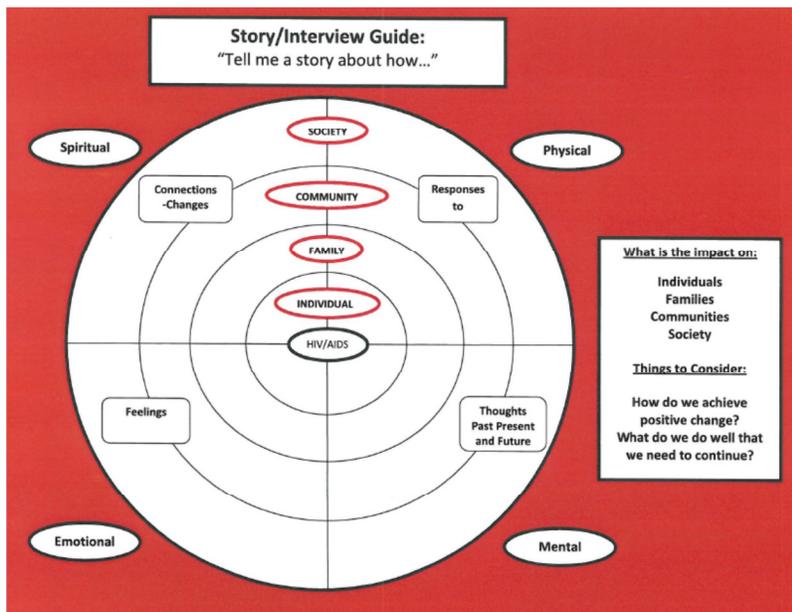
In order to engage active community participation in our research, Aboriginal field researchers were trained in the skills of CBPR, research ethics and conversation facilitation with the purpose that these individuals would be able to appropriately ask people in their community to share their stories 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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