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HIV Prevention with Aboriginal Youth: A Global Scoping Review

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ABSTRACT

HIV infection is a serious and ongoing health concern among young people in Aboriginal communities, both locally and globally. This paper summarizes lessons learned from a global scoping review of both peer-reviewed literature (n=38) and community reports (n=14) on 'wise' practices in HIV prevention with Indigenous youth. Results include the importance of (a) reaching youth at a younger age; (b) adopting peer education approaches; (c) leveraging partnerships; (d) addressing colonial impacts in HIV prevention efforts; (d) attending to diversity; (e) addressing stigma; (f) revising current educational practices; (g) adopting a harm reduction approach; (h) identifying testing as a potential point of prevention intervention; (i) incorporating arts-based approaches into prevention initiatives; (j) adopting culturally sensitive/decolonizing approaches to research conducted in partnership with Indigenous communities. The discussion focuses on what has been learned from this collective body of knowledge and makes recommendations/suggestions for future research and practice directions.

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INTRODUCTION

In the third decade of the HIV epidemic, there is a wide body of globally available evidence that has contributed to our in-depth understandings of the possibilities for HIV prevention. There is also a growing body of work specific to Indigenous/Aboriginal youth, but there have been few efforts to synthesize this knowledge in an integrated way. This lack of attention has implications with respect to both future research directions and applied decision-making. In order to assist with policy and practice planning, it is important that findings from discrete studies are presented in accessible and useable formats [1]. The goal of this paper is to systematically review the published literature focused on HIV prevention with Aboriginal/Indigenous youth and to synthesize findings into an integrated whole by drawing out dominant themes and suggesting future directions.

This review came out of our desire to build on what was already working in the field of HIV prevention with Aboriginal youth in Canada. Consistent with CAAN's Aboriginal Strategy on HIV/AIDS in Canada (2003), the term 'Aboriginal' is used to include Inuit, Métis, and First Nations (Status and Non-Status) peoples. Furthermore, we wanted to learn from other parts of the world where Indigenous peoples are considered 'minority' populations. We recognize that there is tremendous diversity in terms of language, culture, lifestyles and perspectives between and within these groups. "While this diversity makes lumping people together under generic terms like 'Aboriginal' or Indigenous' profoundly misleading, most groups nevertheless share a common social, economic, and political predicament that is the legacy of colonization" [2, p 607, 3]. As argued below, it is precisely this common encounter with colonialism that puts Aboriginal/Indigenous communities at elevated risk for HIV.

HIV/AIDS AMONG YOUTH IN INDIGENOUS/ABORIGINAL COMMUNITIES

Young people are at the center of the global HIV pandemic with an estimated 11.8 million youth living with HIV/AIDS [4]. Each day nearly 6 000 young people between the ages of fifteen and twenty-four acquire HIV, accounting for half of all new infections [5]. Globally, Indigenous youth are also disproportionately affected by HIV/AIDS and available epidemiological evidence suggests that Canada's Aboriginal First Nations, Inuit and Métis youth are among them.

Presently, there are roughly one million Aboriginal peoples living in Canada, accounting for approximately 3.3% of the total population. However, the Public Health Agency of Canada estimates that "[Aboriginal peoples] are estimated to account for 7.5% of persons living with HIV in Canada at the end of 2005 and 9% of all new HIV infections in 2005. This shows an estimated overall infection rate in Aboriginal persons that is nearly 3 times higher than among non-Aboriginals."[6] In addition, the profile of Aboriginal AIDS diagnoses differ from non-Aboriginal diagnoses in three important ways: gender, age and exposure category: women, youth and injection drug users. Available epidemiological data shows that Aboriginal youth are at increased risk for HIV infection with the shift in median age at onset of HIV infection from 32 years to 23 years of age [7]. The increasing Aboriginal youth infection rates coupled with a recent surge in sexually transmitted infections [8] and a decline in youth knowledge about HIV[9] are signs of the potential for the further spread of HIV amongst youth in Canada.

Accounting for rates of HIV Infection in Aboriginal Communities

Indigenous peoples are vulnerable to a number of socioeconomic and systemic factors that increase vulnerability to HIV infection. While there is diversity among Indigenous groups, there are a number of structural similarities. Local, as well as global research indicates that HIV follows patterns of inequity [10, 11], with marginalized groups most at risk. Globally, Indigenous peoples are more likely to be economically disadvantaged, displaced from their lands or live in rural locations, have lower educational attainment and have poorer health outcomes than their non-Indigenous counterparts [12]. Locally, these outcomes can be linked directly to historical and ongoing systemic oppression. Specific factors facing Aboriginal peoples in Canada include racism, assimilation, the legacy of residential schools, persistent economic inequality and cultural and social isolation [13-20]. As a result, Aboriginal peoples are disproportionately affected by many social and behavioural factors that increase their

vulnerability to HIV infection, including higher rates of substance abuse, (sexual and physical) violence, sexually transmitted infections, and limited access to, or use of, health care services [21].

Learning to cope with hardships such as poverty, violence and racism as a result of colonialism may put youth at risk [22]. Common coping mechanisms are associated with high risk behaviours such as trading sex for food, shelter or drugs, alcohol and substance abuse, inconsistent condom use, sex with multiple partners and sharing needles or other drug equipment [22]. While most HIV prevention approaches tend to focus on individual behaviors, an active engagement with the social, political and historical determinants of health (e.g. colonialism) that shape these behaviors may be crucial to reaching Aboriginal youth [23]. In order to address HIV prevention and education, strategies need to consider the socioeconomic and systemic factors that put youth at risk in the first place [23-26]. This shift in focus moves away from pathologizing individuals and it emphasizes the social and structural factors that shape risk.

What can be done about this situation?

Despite this daunting portrait, the good news remains that HIV is 100% preventable. National prevention campaigns targeted towards youth in countries as diverse as Thailand, Uganda, Zambia and Brazil have managed to successfully change the course of their epidemics [5]. It is recognized that the National prevention campaigns which have been successful in the above-mentioned countries, may not work in Canada. Aboriginal youth in Canada have many unique talents, skills and assets that have yet to be fully harnessed towards prevention initiatives [27]. An important step in moving forward is reviewing the scholarly and community-based literature to see what has been done, which approaches have worked and which have not. Given the unique ways in which Indigenous/Aboriginal youth experience the epidemic, [28] there is an urgent need to develop and document preventative initiatives that attend to these vulnerabilities.

As such, this paper summarizes lessons learned from a global scoping review of both peer-reviewed literature and community reports on 'wise' practices in HIV prevention with Indigenous/Aboriginal youth. The discussion focuses on what has been learned from this collective body of knowledge and makes recommendations and suggestions for future research and practice directions.

Methodology & Search Strategy

Using a collaborative approach, a team of graduate students, Aboriginal scholars and a university-based researcher conducted a systematic scoping review of 'wise' practices in HIV prevention with Indigenous youth.

Scoping reviews are specifically designed to identify gaps in the evidence base where little research has been conducted. A scoping review enables researchers to map out a field and examine the extent, range and nature of research activity [29]. What makes a scoping review different from other kinds of systematic reviews is that it is welcoming of all relevant literature regardless of study design, which may be particularly important in an Indigenous research context [30]. Furthermore, scoping reviews are specifically designed to identify gaps in the evidence base where little research has been conducted. They differ from other types of reviews in that they follow a strict protocol and ensure that as much relevant research as possible has been considered and that studies are synthesized in a valid way. For reviews to be reliable they need to be carried out vigorously and the process should be documented in sufficient detail to enable the study to be replicated by others.

Included in this systematic scoping review are peer reviewed articles on HIV prevention with Indigenous youth. Fifteen databases were systematically searched[A]. After mapping out key words, search terms included (a) adolescent or adolesc* or teen* or youth; (b) HIV or AIDS or sexual health or sexually transmitted disease

[A] Medline, Web of Science, Applied Social Sciences Index and Abstracts, CSA Social Services Abstracts, CSA Sociological Abstracts, CSA Worldwide Political Science Abstracts, Digital Dissertations @ Scholars Portal, Education: A SAGE Full-Text Collection, Health Sciences: A SAGE Full-Text Collection, PsycINFO, Science Citation Index Expanded (1982-1993), Science Citation Index Expanded (1994-1999), Science Citation Index Expanded (2000-2004) and Science Citation Index Expanded (2005-current).

or sexually transmitted infection; (c) Indigenous or Native and First Nation* or Aborig* or Indian[B]. Articles included were limited to those published in English. Due to the limited number of relevant articles that matched our key words search, all papers regardless of the year of publication were included.

After systematically combing each database and removing duplicate copies, 539 abstracts were retrieved. Using specific exclusion/inclusion criteria, all of the abstracts were reviewed in order to determine which articles were relevant. Abstracts were excluded if they: (a) did not relate to HIV, STI, STD or sexual health, (b) did not relate to adolescents, teens or youth (ages 12-25), and (c) did not relate to Indigenous peoples. Two reviewers independently screened studies that met inclusion criteria, checking disagreements with a third reviewer. After reviewing 539 abstracts, a total of 140 abstracts met the inclusion criteria.

All 140 articles were located and reviewed. Detailed information was extracted (when available) and entered into a summary table. After reading the articles, only 34 studies met the search criteria. An additional 4 peer reviewed papers were identified by community contacts. Once the summary tables were complete, the research team reviewed the tables and relevant papers and met for a day long intensive session, to critique and discuss the findings. The 38 relevant studies were further broken down according to methodology: (a) cross-sectional (n=16), (b) mixed methods (n=7), (c) longitudinal (n=5), and (d) interventions, descriptions and evaluations (n=10).

Knowing that some of the most promising programs are rarely disseminated through peer review channels, the research team contacted experts in the field in hopes that they might be able to refer us to other kinds of documents -- specifically program reports, helpful website links, agency evaluations and other kinds of community-based or government reports that would help us learn more about effective strategies and approaches for HIV prevention with Indigenous youth. After systematically searching literature through peer review channels, the research team contacted 133 individuals representing over 100 different organizations with a mandate to work with Indigenous communities both locally and globally. There was an immediate positive response from organizations that worked directly with Indigenous youth and deliver HIV education and prevention programs. Many individuals that we contacted were happy to hear that more research was being conducted on HIV prevention with youth. If the organization did not have any material to share, they gladly forwarded contacts they thought could assist us in our search. Those that had materials sent us documents or directed us to appropriate web links.

The methodology used for collecting grey material was similar to that of snowball sampling technique. Snowball sampling is a technique for developing a research sample where existing study subjects recruit future subjects from among their acquaintances, thus the sample group appears to grow like a rolling snowball [31]. Our contact list grew by process of referral. Another useful technique was contacting individuals and community organizations from a mailing list that was obtained from a conference whose focus was on community based research and Aboriginal health.

Similar to the review of the peer reviewed abstracts, two reviewers independently screened each website link and document to ensure they pertained to HIV prevention among Indigenous youth. The team reviewed 20 website links and 40 papers, manuals or reports. After reviewing the material, 10 reports met the search criteria. The most common reason why material was excluded was because it did not focus on Aboriginal/Indigenous youth or HIV/AIDS. Detailed information was extracted (when available) and entered into a summary table. The 10 relevant documents were further broken down according to document type: (a) program evaluation (n=3), (b) prevention messages based on research findings (n=3), and (c) manuals and activities for HIV education and prevention (n=4).

Summary tables were created for each paper reviewed (see attached). Various members of the team then met on several occasions to draw out lessons learned from the literature and map out main areas of research findings, policy and practice.

[B] Denotes variations of the term i.e. adolesc* or adolescents or teen* or teens

RESULTS

Key findings from this scoping review [32] point to a number of emerging 'wise' practices. These include:

Reaching youth at a younger age

Prevention messages need to reach youth before the age of 15. There is a documented gap for appropriate programming for children ages 7-12 [22, 23, 25]. Education that addresses risks, consequences and prevention needs to begin by sixth grade. Continued education and information on "safe" sex practices i.e. condom use is necessary throughout middle and high-school to reinforce the messaging [33-35].

Adopting Peer education approaches

Peer education is an effective choice for HIV prevention with Indigenous youth [13, 16, 17, 22, 25, 36, 37]. Using peer educators as part of an intervention strategy can have both positive impacts on the peer educators and the youth they are targeting [13, 26, 34, 36, 38, 39]. It is important to honor youth (participation) publicly [34, 39]. Involving members of the target population will not only build capacity among youth, but it will increase the likelihood that initiatives are maintained [22]. In addition, when youth can see the results of their efforts every day and share pride in learning, their skills improve quickly [38]. Even though it can be challenging, the rewards and educational benefits to youth are even greater. Empowering youth to make decisions in the area of their own sexuality, can increase self-esteem and self-confidence.

Leveraging Partnerships

All members of the community need to be a part of the solution. Collaboration with various members of the community including, youth, Elders, front-line workers, community members, nurses and community organization is necessary [7, 14, 17, 18, 22, 25, 35-37, 40-43]. Involving leaders in the community builds awareness in the community [22]. The importance of adult role models (both familial and otherwise) was highlighted [44, 45]. Having counselors available on-site, effective debriefing and consistent support was crucial to the success of some groups [26, 38]. Nurses can also act as advocates for sexual abuse awareness and HIV prevention programs in high schools and high-risk communities [17, 18, 35]. It was recommended that all service delivery requires Aboriginal involvement to validate and provide culturally appropriate assessments of the services offered [15]. Recommendations include: networking with schools and mainstream health providers serving Aboriginal youth; provide training to Aboriginal frontline workers on how to conduct sensitivity and awareness training for mainstream service providers; training should allow workers to convey the context of urban Aboriginal youth issues [22, 25].

Addressing colonial impacts in HIV prevention efforts

Historical and current systemic factors facing Aboriginal youth include racism, assimilation, residential school system legacies and isolation.[13, 14, 16-19, 46] In order to address HIV with Indigenous youth, prevention and education strategies need to consider the socioeconomic and systematic factors that put youth at risk in the first place. [22, 23, 25, 26, 38] Young people may adopt a fatalistic outlook and may be less able to negotiate with partners about safe behaviours, or they may be seeking consolation or affirmation through risky behaviour after dealing with stressful situations.[47] Culturally based HIV education/outreach that speaks directly to the root cause of why Aboriginal people are at high risk is important [26].

Attending to diversity

Culturally attuned HIV prevention services and education are needed.[7, 13, 15-17, 19, 21, 40, 41, 46, 48-50] Taking a pan-Aboriginal approach to HIV prevention will likely be unsuccessful. Youth are not a homogenous group and they represent diverse and distinct cultures that need to be addressed and respected.[22, 23] Messages need to be

sensitive to the environment youth live in. As such, urban, on-reserve, rural and Northern youth may respond quite differently to similar messages.[22, 51] Furthermore, many Aboriginal youth are seeking services from non-Aboriginal organizations or migrating to urban centres due to the lack of youth-specific or youth-friendly AIDS prevention programs [22]. Therefore, attention needs to be paid both to building the capacities of Aboriginal-specific agencies as well as mainstream organizations. As such, providing clear messages is more effective than blanket messages targeting all Aboriginal youth.

Addressing stigma

Despite public education, stigma still exists and more efforts are needed to dispel myths and clarify confusion about HIV/AIDS. Stigma and negative attitudes towards people living with HIV is present and stereotypes about who can become infected are prevalent [13, 50, 52]. Breaking the silence and shame that surrounds HIV/AIDS is important. It is both a human rights imperative as well as a key prevention opportunity. Addressing the ways in which stigma intersects with HIV risk is key [22, 50, 53]. As such, anti-fear, stigma and discrimination campaigns are needed [22].

Current educational practices

Youth reported not being happy with what they were taught in school. Youth report that education needs to illuminate the fact that HIV/AIDS can happen to anyone [23]. Providing youth with life skills education such as negotiation and conflict resolution, self respect, job skills and self-confidence are effective ways to reduce risky behaviour [22], and speak to the importance of the situation of HIV within a social determinants of health framework. Taking a collaborative approach and involving key members of the society is important to the success of an HIV/AIDS intervention [16]. Guest speakers and or counselors have the most impact when they participate in group activities alongside group members [38]. The use of traditional knowledge in sex education and curriculum works better in some communities than others [22, 25]. Some communities/individuals no longer practice their traditional cultures. HIV prevention strategies do not necessarily have to be traditional to succeed[39].

Adopting a harm reduction approach

It is important to address the links between substance use and HIV risk factors [22, 25, 26, 38, 47, 49, 54-58] and the ways that histories of physical and sexual violence exacerbate HIV risk [14, 25, 26, 35, 38, 47, 57, 59-61]. Harm reduction programs are needed to address existing or exacerbated vulnerabilities [15, 47, 58]. Many youth IDUs are not accessing methadone maintenance therapy and are not benefiting from education and needle exchange [46]. Culture and skill-based information on HIV risk/harm reduction activities is a highly effective way of drawing high-risk community members into HIV education and prevention [38]. It is important to situate condom use in the context of youth lives, and address issues of access [21-23, 25, 47, 62]. Embarrassment in obtaining condoms was a deterrent to condom use; condoms should be available anonymously and confidentially in reserve [21] and urban communities.

Identifying HIV testing as a potential point of prevention intervention

There is a need to improve services to reduce access barriers to public health or primary care, HIV testing and HIV treatment. Many youth are seeking services from non-Aboriginal organizations or migrating to urban centres. As such, HIV prevention, testing and counseling and new treatment options need to be made more relevant for Aboriginal youth [22, 23, 42, 48, 63]. Current HIV testing services are inadequate for a variety of reasons including remoteness of some communities, cultural differences and a failure on the part of the health care system to address needs of Aboriginal communities. Youth reported concerns regarding confidentiality, establishing trust, client-health care provider relationships, improving services to reduce access barriers to testing and treatment [23]. There is a lack of appropriate HIV testing services on reserves; given the shortage of physician services in rural communities, public health units need to increase the rate of HIV testing and greater access to primary care is needed [48, 64].

Arts-based approaches

Incorporating arts-based approaches into prevention initiatives may be particularly effective ways of working with Aboriginal youth. Arts-based approaches to HIV prevention have been successfully employed in a variety of contexts with Aboriginal youth.[26, 38, 39] Disseminating HIV information in creative ways has been shown to engage and mobilize Aboriginal communities in strategies for prevention in other contexts. [36] Arts-based strategies helped young people remain engaged and enthusiastic about the program [36]. Disseminating HIV information in creative ways engaged and mobilized Aboriginal communities in strategies for prevention.

Adopting culturally sensitive and decolonizing methodologies

Adopting culturally sensitive research approaches and 'decolonizing' methodologies [30] is an imperative for research conducted in partnership with Indigenous communities. Many projects reported extensively collaborating with the local community and designing culturally appropriate methods for collecting data improved research outcomes. [14, 21, 48, 58, 65]. The importance of adhering to Indigenous ethical guidelines and protocols was highlighted repeatedly. [14, 42, 58, 66] Taking a collaborative approach and involving key members of the society is important to the success of an HIV/AIDS intervention [16]. Success in recruitment and retention of participants was attributed to using Indigenous project staff [36].

Limitations

There were several specific issues that may have contributed to the limited number of studies located for this review. In our search, studies were limited to those that were written in English and those that were publicly available. This may have been problematic for cultures that might resist 'writing down' or sharing Indigenous knowledge basis. Furthermore, the nature of the term 'research' is inextricably linked to European imperialism and colonialism [30].Given the history of researcher/community relations with many Indigenous communities, there may be resistance to disseminating through traditional 'peer review' networks. Also, it is likely that many HIV interventions and prevention strategies are conducted by and for Indigenous peoples, without the assistance of researchers. As such, results may not be evaluated or publicly disseminated.

In addition, the term Indigenous is a complex term and no universally agreed upon definition exists. This created some difficulty in our search because it was not always clear whether a particular group was a minority or an Indigenous people when searching for articles globally. Finally, North American studies were over-represented here. This is likely due to a number of factors including (1) publishing bias, (2) greater resources available for dissemination, and (3) better local community contacts on our end. Care should be taken in generalizing the research globally.

It is our hope, that by documenting the wise practices in HIV prevention, we can move forward and provide meaningful direction for future work in this area. One of the most promising ways that this can be achieved is through community-based research, coupled with a decolonizing methodological framework that uses the guiding principles of ownership, control, access and possession (OCAP) [30, 67, 68]. This approach has been shown to foster collaboration amongst diverse organizations, individuals and researchers that builds on reciprocal relationships [69, 70]. As such, taking a CBR approach may itself become a community development strategy [69, 71].

CONCLUSION

This scoping review took a systematic approach to understanding the kinds of research and work being done in the area of HIV prevention with Indigenous youth. Very few studies in the peer-reviewed literature addressed HIV prevention with Indigenous youth. This is a pressing issue that deserves attention and the message is clear that Indigenous youth experience heightened vulnerability to HIV. In order to stop the spread of HIV, prevention and education strategies that address the socioeconomic and systemic factors that put youth at risk are necessary.

Working with youth is an essential part of confronting the HIV/AIDS epidemic and is one of the most promising approaches to prevention.

The academic and Indigenous community has provided some excellent recommendations for future work in HIV prevention. Nevertheless, several questions remain unanswered: What are the similarities and differences across groups of Indigenous youth in terms of resilience, assets and risks to HIV? In what ways do gender, class and sexuality intersect with cultural identity to shape or constrain risk and choice? What intervention models are, or have proven, effective for putting the power into the hands of Indigenous community to address HIV prevention? How is healthy sexual practice negotiated and experienced? Culturally, how is sexual identity constructed? How are cultures within cultures and competing identities shaped? What are the prime motivators for protective behaviours? What are effective condom distribution and uptake strategies? What are the links between structural, social, psychological and behavioural patterns? There are many other questions and suggestions for future work in this area. In laying out these questions, we hope to put a call to those in the research community to continue work in their area, and hope that many will adopt a CBR approach that attends to the principles of OCAP. A new approach and research direction is necessary and Indigenous communities need to have their voices heard as they have many intelligent suggestions in regards to HIV prevention in their own communities.

As we undertook this scoping review we attempted to put these principles into practice. Aboriginal scholars were key members of the research team. We also sought to expand the idea of what is 'relevant' evidence by explicitly seeking community reports and experience for inclusion.

Nevertheless, this scoping review pointed us towards developing further participatory research in the area. Over the next few years, we will be engaged in a research project that will further explore how Aboriginal youth in Canada link structural inequalities with individual risk, HIV and Aboriginal culture(s) using art-based methodologies. We will be involving youth, adopting a community-based research approach and adhering to the principles of OCAP [67, 68, 72]. Through this project entitled, Taking Action: Using Arts-Based Approaches to Develop Aboriginal Youth Leadership in HIV Prevention [73], recently funded by the Canadian Institutes of Health Research, we hope to fill some of these gaps and we look forward to following the work of others in this area.

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