

Final Report

The Impacts of the Criminalization of HIV Non-Disclosure on Indigenous People Living with HIV/AIDS: An Urban Case Study of Regina

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The Urban Aboriginal Knowledge Network, the UAKN, is a community driven research network focused on the Urban Aboriginal population in Canada. The UAKN establishes a national, interdisciplinary network involving universities, community, and government partners for research, scholarship and knowledge mobilization. For more information visit: www.uakn.org



Introduction

Questions about disclosing HIV-positive status to a sexual partner raise complicated issues pertaining to sex, consent, relationships, privacy, well-being, and the role of the state in relation to these issues. In Canada, criminal law is used as a formal state response to questions about HIV non-disclosure, though there are other ways that non-disclosure is regulated and criminalized (e.g., interactions with people in social services). In Canada, non-disclosure has been regulated through interpretations of existing criminal laws.

Non-disclosure is not a straightforward issue. People living with HIV/AIDS can experience stigma and discrimination, making it difficult to disclose one's HIV status. As noted by the Canadian HIV/AIDS Legal Network (2016), "HIV-related stigma and discrimination intersect with other forms of stigma and discrimination such as those based on sexual orientation, race, immigration status, poverty, drug use and/or sex work" (p.6). The intersection of HIV stigma and other forms of discrimination create situations where marginalized people with HIV are especially vulnerable in relation to disclosure, and can become more regulated than others. Such is the situation for Indigenous people living with HIV/AIDS.

This research addresses an urgent issue that urban Indigenous communities are facing. It is based on a collaborative project with All Nations Hope Network (ANHN). ANHN promotes Indigenous-centred and culturally-informed approaches to HIV in Indigenous communities. A focus on the specific impacts of laws related to non-disclosure is intended to complement the important work being done in community, so as to support Indigenous people living with HIV, and to address the epidemic of this disease in Indigenous communities. Even though injection drug use is the most common way that HIV is transmitted among Indigenous people (PHAC, 1), urgent questions about HIV non-disclosure during sexual activity remain pertinent, given that sex is a part of people's lives and can relate to well-being. Examining the impacts of laws related to non-disclosure is critical because of: the high rates of HIV in Saskatchewan and in Indigenous communities; the multiple intersections of stigma; and the relentless criminalization and surveillance of Indigenous peoples by settler-colonial institutions. These contexts, combined with the reality that many Indigenous people in urban centres are living in poverty, speak to the complexity and need for research about non-disclosure laws that centres Indigenous people and priorities.

Research Objectives

The main objectives with this research were to identify and understand:

- 1. the leading impacts that laws related to HIV non-disclosure are having on Indigenous people in Regina;
- 2. the implications of the law for HIV community organizations providing services to Indigenous people in this urban centre;
- 3. the needs and recommendations from Indigenous people living with HIV and from HIV organizations working with Indigenous people, regarding policy and legal responses that centre Indigenous knowledge and perspectives:
- 4. a base of relevant information from which future research directions can be created.

The overall goal with this project was to create research where the priorities of Indigenous people living with HIV are listened to and respected. This project also recognizes and respects the expertise of ANHN. The purpose of this research was to be collaboratively created (in a way that respects the time and obligations of the community partner and participants) so as to be mutually beneficial. In addition, the intention with the policy recommendations was to articulate them in ways that work for Indigenous people and work to challenge settler-colonial impositions of policies and laws on Indigenous peoples. Indigenous sovereignty and self-determination are the starting points for this work, and that includes self-determination related to the body, sexuality, and law.

Brief Literature Review

Research on HIV non-disclosure laws in Canada is somewhat sparse. Of the literature that exists, much of it focuses on technical aspects of the law and concerns about criminalization (Grant, 2008; Dej & Kilty, 2012; Mykhalovskiy, 2011). The largest study to date on the impact of non-disclosure laws on HIV positive people's lives included some Indigenous people (Adam et al., 2016), though they were not adequately represented in the research nor was colonial context accounted for. The impacts of HIV non-disclosure laws for already marginalized people (Symington, 2013) have been looked at for women (e.g., Mackinnon & Crompton, 2012; Patterson, 2015); the LGBTQ community (Arnold, Rebchook & Kegeles, 2014); and black communities (Larcher & Symington, 2010; Arnold, Rebchook & Kegeles, 2014). A study called WATCH (Co-PI's: Dr. Saara Greene and Canadian HIV/AIDS Legal Network) is examining surveillance and the impacts of the criminalization of HIV non-disclosure on women – of which Indigenous women are included. The scope of that project is national (BC, SK, ON), whereas our focus is on urban contexts in a particular province. Overwhelmingly, the academic literature about non-disclosure does not account well for Indigenous-specific impacts, experiences, or contexts regarding settler-colonialism.

There is important and growing research about Indigenous people and HIV/AIDS in Canada. For example, research about treatment (Milloy, 2016), coping strategies, and support (Jaworsky et al., 2016). The ongoing impact of colonial oppression, including the legacies of historical trauma, shape Indigenous peoples' experiences with HIV not only in terms of policies and access to services, but in terms of the socio-economic conditions that have enabled this epidemic to flourish in Indigenous communities (Pearce et al., 2008). In a study about Indigenous people living with HIV/AIDS in Regina, many participants had been removed from their home as a child, been in residential schools, or been in foster care. Moreover, over half of the participants had been incarcerated at some point in their lives (CAAN, A-Track Survey, 2013, p.3). The A-Track data (of which ANHN was a project advisor) offers valuable contextual information about Regina. The gendered aspects of this HIV epidemic are also pertinent, with Indigenous women experiencing higher rates of infection than men, and Indigenous women facing unique socio-economic factors because of gendered, racialized experiences with colonial oppression (Ship & Norton, 2001; Hawkins, Reading, & Barlow, 2009; Canadian HIV/AIDS Legal Network, 2017). Despite this existing work, there is still a great need for more research about colonial and gendered contexts that shape Indigenous people's experiences with HIV, including the impacts of the use of law related to non-disclosure. A gap exists in the literature where laws about non-disclosure and Indigenous contexts are not being examined together.

Methods

Semi-structured interviews were done with Indigenous people living with HIV, and with key informants (some of whom were also HIV positive) who are community workers (people volunteering and working to support this community in Regina). The interviews were held at ANHN in order to provide community- and culturally-based support, and they were conducted by Krista Shore. Information about the interviews were posted on social media and through ANHN's networks, as well as through snowball sampling/word of mouth in the community. The research followed UAKN and ANHN's principles for ethical community-based research, and was in line with Tri-Council Policy guidelines.

Findings

The findings in this research are based on 26 interviews. Of the 26 participants:

- 96% (25 people) were Indigenous.
- 81% were women (21 women and 5 men).
- 65% were Indigenous and HIV positive.
 - o 14 people were community members who are HIV positive;

- o 3 people were community workers and HIV positive;
- o 9 people were community workers and not HIV positive.
 - 6 Elders were involved (none of whom were HIV positive).
- Participants have been HIV positive from a couple of months to over 20 years, though for most participants they have been positive for less than 10 years.
- Participants have lived in Regina from a couple of months to most of their lives.

Below is a **summary of the key findings** of this research:

- The criminalization of HIV non-disclosure is impacting Indigenous people who are HIV positive in distinct and negative ways. The legal impacts on Indigenous people are complex with multiple layers and experiences of stigma and discrimination intersecting. Indigenous women who are HIV positive are especially impacted.
- An urban context, with a focus on Regina, is also part of what is shaping Indigenous people's experiences with HIV and the law in this case study.
- While some participants were familiar with the *issue* that there could potentially be repercussions for not disclosing one's HIV status to a sexual partner, participants were generally not familiar with the *details* of the legal issues.
- Overall, it was expressed that there is a need for more accessible information related to the law and HIV

 for people who are HIV positive, for people in the community, for support workers, and for legal and healthcare professionals. Participants expressed the need for Indigenous people, especially Indigenous people who are HIV positive to be centred in research and to be central in frontline work.
- It was expressed by the majority of participants that there is a need for revised and expanded services in Regina for Indigenous people who are HIV positive.
- Understanding the findings from this case study necessitates an analysis of colonialism and the ways in which settler laws are imposed on Indigenous peoples and can undermine Indigenous legal responses and practices.
- The impacts of Canadian HIV non-disclosure legal practices on Indigenous people who are HIV positive need to be acknowledged, analyzed, and further researched. It is also evident that there is a need for broader research on the experiences of Indigenous people who are HIV positive.
- Despite significant challenges and the need for several recommendations, it is also important to recognize the strengths and resilience of the participants and Indigenous communities more broadly.

A full discussion and analysis of the research will be available through a policy report, which will posted here shortly.

Knowledge Mobilization Activities

The knowledge mobilization from this research is ongoing and includes:

- A community presentation at ANHN (which took place in January, 2018).
- A presentation at an academic conference (which took place in January, 2018).
- A community report of the research findings.
- A policy report of the research findings, which includes recommendations.

• An academic publication (a journal article).

Collaborating Urban Aboriginal Organization

All Nations Hope Network

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