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***The Indigenous Red Ribbon Storytelling Study: What does it mean for Indigenous peoples living with HIV and a substance use disorder to access antiretroviral therapy in Saskatchewan?***

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## ABSTRACT

Indigenous peoples living with HIV are less likely than non-Indigenous peoples living with HIV to access antiretroviral therapy; however, there is not enough contextual information surrounding this issue. The Indigenous Red Ribbon Storytelling Study was conducted in part to examine how Indigenous peoples living with HIV construct and understand their experiences accessing antiretroviral therapy. Our study design was critical Indigenous qualitative research, using the Behavioral Model of Health Services Use and community-based participatory research approaches. The study was conducted in partnership with Indigenous and non-Indigenous organizations. Study participants were adults from two Canadian cities. The study methods included 20 individual and two Indigenous sharing circle interviews, six participant observation sessions, a short survey and thematic analysis. Accessing antiretroviral therapy within the context of living with a substance use disorder was an overarching theme. Indigenous peoples living with HIV felt they had to choose between living with their active substance use disorder and accessing antiretroviral therapy. They felt misunderstood as a person living with a substance use disorder and often felt coerced into using antiretroviral therapy. Despite these challenges, they persevered as Indigenous peoples living with HIV and a substance use disorder. Further research on antiretroviral therapy access among Indigenous peoples living with HIV and a substance use disorder, particularly from the perspective of health service providers, is needed.

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## INTRODUCTION

Access to antiretroviral (ARV) therapy among Indigenous peoples living with HIV (IPLWH) is important because effective treatments exist to decrease HIV-specific mortality and morbidity (Hogg et al., 1997; Palella et al., 1998; Walensky et al., 2006) and prevent transmission of HIV (Montaner et al., 2006); yet, the burden of HIV among Indigenous populations is high (Public Health Agency of Canada, 2010; Public Health Agency of Canada, 2012; Yang et al., 2010). Access refers to the availability of resources. Accessibility “is a function of social, economic and political power and resources” (Blankenship, Bray, & Merson, 2000, p. S12). The term “Indigenous peoples” in this paper is synonymous with the term “Aboriginal peoples,” and refers to groups of peoples such as First Nations, Métis, Inuit. In Canada, IPLWH, in comparison to non-Indigenous people living with HIV, are less likely to access ARV therapy (Wood et al., 2003; Wood et al., 2006). Most of the studies examining access to ARV therapy among IPLWH yield statistical generalizations (Wood et al., 2003; Wood et al., 2006) and very few of them address in any depth the circumstances surrounding this phenomenon (Newman et al., 2007). Given the paucity of empirical literature or original work conducted in this area, the Indigenous Red Ribbon Storytelling Study was conducted in part to examine how Indigenous peoples living with HIV construct and understand their experiences accessing ARV therapy.

## METHODS

The research design of the study was critical Indigenous qualitative research, which gives greater value to Indigenous knowledge than to other types of knowledge such as Eurocentric knowledge (Denzin & Lincoln, 2008). Within this context, we analyzed the data using the Behavioral Model for Health Services Use (Andersen, 2008), along with various sensitizing concepts (i.e., social structure, vulnerability and resilience, and access) (Alvesson & Skoldberg, 2009; Auerbach, Parkhurst, & Caceres, 2011; Blankenship et al., 2000; Delor & Hubert, 2000; Fleming & Ledogar, 2008; Luthar & Cicchetti, 2000; Luthar, Cicchetti, & Becker, 2000; Parsons, 1951). Community-based participatory research (Baskin, 2005; Horowitz, Robinson, & Seifer, 2009; Israel, Schulz, Parker, & Becker, 1998; Minkler & Wallerstein, 2008) and ethnography (Charmaz & Mitchell, 2001; Creswell, 2007) were used to support the implementation of the study.

The sample for the individual interview and participant observation components of the study were adult IPLWH who had been suggested by their health service provider to begin or consider taking ARV therapy and who were living in the Cities of Saskatoon and/or Prince Albert in Saskatchewan, a province that is over-represented in the HIV epidemic in Canada (Public Health Agency of Canada, 2014). Indigenous sharing circle participants comprised IPLWH, health and social service providers, researchers and government officials. An Indigenous sharing circle is a term used to describe a form of focus group interview that is appropriate to Indigenous people (Baskin, 2005; Lavalley, 2009; Rothe, Ozegovic, & Carroll, 2009; Wilson, 2008). All individual interview and Indigenous sharing circle study participants completed a short socio-demographic and health survey. Those who took part in the participant observation sessions were not asked to complete a survey so as not to disrupt their healthcare appointment, which was used as the venue for the participant observation component of the study. Participants were recruited by means of

study flyers posted and left on waiting room tables at community partner agencies. Potential participants contacted the investigator who explained the study to them and determined whether they were eligible to enroll in the study based on the following inclusion criteria: IPLWH age 18 years or greater who were eligible to receive ARV therapy, and key informants, all of whom had been living in the Saskatoon and/or Prince Albert area for at least a year prior to enrolling in the study (and for the key informants, had been working with IPLWH for at least the past year). Voluntary and informed consent to take part in the study was sought from each potential study participant. Study participants received a cash incentive (CAD\$20 per hour), coverage of travel expenses (CAD\$20 total), childcare expenses (CAD\$40 total if applicable), a small tobacco bundle, and for sharing circle participants, a gift of a traditional Indigenous feast was provided. No identifying information was collected in the study. Participants were assigned a pseudonym that was used for the consent form and throughout their participation in the study. Nominal codes were used when providing data exemplars in any written reports.

The individual interviews involving 20 IPLWH, and an eight-person IPLWH-specific Indigenous sharing circle interview were used in the analysis for this report of the study. Most of the study participants were female (16 participants out of 28), age 30 to 39 years (15 participants out of 28), of First Nation ancestry (22 participants out of 28), and had an education level of elementary school or lower (15 participants out of 28). The majority of participants reported a total household income of less than CAD\$20,000 per year (25 participants out of 28) and all lived in an urban environment. The majority of the participants who took part in the individual interview component of the study reported having a substance use disorder (19 participants out of 20) and, in most cases, were people who inject drugs (PWID) (11 participants out of 20). All interviews were audio-recorded and transcribed verbatim. Study participants had the option to review their individual interview transcript. A local traditional ceremonial Indigenous helper (i.e., an Elder) opened and closed the sharing circle and provided smudging. Smudging is a cultural ceremony commonly practiced among Indigenous peoples where traditional, medicinal plants and herbs are burned in order to spiritually connect one with the Creator and Mother Earth (National Aboriginal Health Organization, (n.d.); Wright et al., 2011).

An integrative approach was used to organize the data according to both pre-existing theoretical categories and explanations of the phenomenon arising from the data (Borkan, 1999; Bradley, Curry, & Devers, 2007; Miller & Crabtree, 1999; Ryan & Bernard, 2003). Once the data were categorized according to the taxonomy of the Behavioral Model for Health Services Use (Andersen, 2008), they were further analyzed inductively. This procedure is known as a “phased style” of analysis (Miller & Crabtree, 1999). A phased approach to analysis was used to see patterns in the data that might help the researcher understand what structures and mechanisms were contributing to the research phenomenon. The data were analysed for themes (Braun & Clarke, 2006).

To ensure that our study’s research process maintained a quality of scientific excellence and community relevance, we used the criteria of trustworthiness (Guba & Lincoln, 1989; Lincoln & Guba, 1985) and authenticity (Guba & Lincoln, 1989), along with other criteria such as the co-

construction of meaning of the phenomenon with the study participants (Morrow, 2005) and praxis (i.e., integrating theory and practice) (Patton, 2002).

## **COLLABORATIVE RESEARCH**

The study was a collaborative effort among an investigator, 10 IPLWH, and 11 community partners, all of whom comprised the planning team of the study. The 11 community partners included: (1) AIDS Saskatoon and its 601 Outreach Centre and 601 North; (2) the Co-operative Health Centre, Prince Albert Community Clinic; (3) the Health Canada, First Nations and Inuit Health Branch, Saskatchewan Region; (4) the Indian Métis Friendship Centre of Prince Albert; (5) the Saskatoon Friendship Inn; (6) the Saskatoon Indian and Métis Friendship Centre; (7) the Saskatoon Tribal Council, Health & Family Services; (8) the Saskatoon Westside Community Clinic; (9) the Prince Albert Access Place and Outreach Services; (10) the Prince Albert Métis Women's Association; and (11) the Saskatoon HIV/AIDS Research Endeavour.

The majority of the community partners (at least seven of the 11 partners) included Aboriginal representatives. Collectively, the community partners and IPLWH worked with the investigator to determine the research agenda, plan and organize the research process, analyze the data and disseminate the research findings. Two IPLWH and other key informants (e.g. health service providers) helped develop the interview questions that were used in the study in order to conduct the individual interviews with IPLWH study participants. Eight IPLWH reflected upon the preliminary findings of the study and developed practical recommendations that might be considered by multi-stakeholder groups to help improve the lives of IPLWH.

Under the guidance of a research agreement, the community partners and the investigator worked together to conduct the study, which respected Indigenous self-determination (First Nations Information Governance Centre, 2013). The study was planned and implemented in accordance with Indigenous community and institutional protocols and the policy document, *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada, 2014). The University of Toronto and the University of Saskatchewan provided ethics approval for the study. Written operational approvals for the study were received from the Prince Albert Parkland Health Region, the Saskatoon Health Region, and the Saskatoon Community Clinic.

## **RESULTS**

Our study results are based on the data that were collected from the IPLWH participants of the study.

### **Choosing Between Active Substance Use Disorder and ARV Therapy**

For many study participants, living with a substance use disorder was an aspect of their lives that they could not ignore. They voiced that living with a substance use disorder was a part of who

they were and, as such, accessing ARV therapy needed to take into account their substance use disorder from a holistic healthcare perspective. Those living with an active substance use disorder and using their drug of choice had unique personal and social circumstances that could be perceived by others, particularly those who do not have a substance use disorder, as outside the social norm. Many participants living with a substance use disorder acknowledged their preoccupation with satisfying their desires. Their disorder was the basis on which they viewed themselves and the world around them. Such ideologies need to be understood in the context of their HIV care and treatment plans.

### *FEELING MISUNDERSTOOD AS A PERSON RECOVERING FROM A SUBSTANCE USE DISORDER*

Study participants with a drug use disorder spoke about their physicians denying them ARV therapy. These physicians denied participants access to ARV therapy because they held the view that the participants' recovery was not at a stage where they could entirely abstain from using their drug of choice. This situation was described in an interview with one participant:

*Interviewer: Did you feel that that you were being judged by the doctor?*

*Participant: Yeah. I got a massive scolding from him. Yeah. He said, "If you don't straighten out then I'm not going to give you your ARV therapy." I've had him say that once before, just because I had a struggling addiction problem. Before it used to be cocaine. And this was a few years back. He told me, "You got to come back with a clean piss test or I'm not even giving you your meds." At that time, it was when I was just coming out of a bad period. And my CD4 count was low again (Reth: Male, age 30-39 years.)*

Reth got upset when his physician scolded him for not adhering to his ARVs because he felt as if he was being judged when his physician spoke to him in a condescending manner. Many participants said that they did not like being judged and, in fact, some participants said that they felt contempt for those who judged them. Reth also shared that he believed that his physician did not think that Reth was taking his health and wellbeing seriously and that the physician did not appreciate and understand Reth's unique life circumstances. These circumstances included all of the following: living with depression; being in transition with his biological family and adopted family and work friends; supporting his friends and family, while at the same time being ignored by his friends and family; and having unreliable social supports. Instead of giving tough love, the participant shared, physicians needed to demonstrate compassion towards their clients, particularly since physicians were supposed to be professionals.

The stage of recovery from drug use disorder at which the physician threatened to deny Reth his ARV therapy was unclear. Was the physician scolding the participant as a way to encourage the participant to abstain from using his drug of choice? Or was the physician simply impatient with a client and insensitive to the many challenges faced by such clients when trying to control their drug use disorder? What Reth did make clear was that he felt his circumstances merited a more nurturing environment.

Most study participants knew that a substance use disorder was a chronic disease with no cure and that the process of coping with a substance use disorder demanded great effort to say the least. Relapses were a normal part of recovery. As described by another participant: “Sometimes I have my slips [relapses], sometimes I don't and I don't plan to have them. They just happen.” (Switie: Female, age 30-39 years.) Through such relapses, IPLWH with a substance use disorder learned to cope with their disease and learned how to manage any further decline in their disease trajectory: “And I haven't had that much slips since February. I had, like, two slips since February and now it's only, like, a onetime use and that's it.” (Switie: Female, age 30-39 years.) What seemed to help Switie cope with her substance use disorder was the one-on-one counselling that she received from her therapist, and at times she also made reference to the principles of a 12-Step Program based upon the philosophy of Alcoholics and Narcotics Anonymous.

For someone with a substance use disorder, emotions can override rational thinking. Particularly at the beginning of their recovery from a substance use disorder, they are learning to think before acting, rather than reacting emotionally to a situation. During this learning process, empathy from health professionals is crucial, although challenging at times.

#### *FEELING COERCED INTO USING ANTIRETROVIRAL THERAPY*

In an interview with another participant, she described some medical practices pertaining to the co-administration of methadone maintenance therapy (MMT) and ARV therapy:

*Interviewer: Sometimes some people say that health professionals are pushy. “Go on this medication and go on that medication.”*

*Participant: I know people where I get my methadone think that too because you go there and they have to take their ARV with their methadone, and basically, it's like they won't get their methadone unless they take that ARV. It's because they don't take it every day. And they don't get their methadone unless they swallow their five ARV pills a day with their methadone. The pharmacist gives the ARV pills to them with their methadone. And basically it's, like, they can't refuse or they don't get methadone and that doesn't seem right. (Pila: Female, age 40-49 years.)*

Pila reported that some people who were recovering from a drug use disorder did not get their daily, directly observed MMT from the pharmacist until they consumed their ARVs. She believed that such a tactic was wrong and that physicians were too authoritative when they denied a person with a drug use disorder access to MMT if they refused to take their ARV therapy under a pharmacist's supervision. A question that one needs to ask is: Do IPLWH believe they are required to take their ARVs, or is it just that they are given their MMT and ARV therapy at the same time? The other potential issue is how pharmacists might interpret daily dispensing, as they might instruct one to take his or her ARVs in order to receive the methadone, though that might not have been the prescription order from the physician.

## SOCIAL ACTION TO SUPPORT INDIGENOUS PEOPLES LIVING WITH HIV AND A SUBSTANCE USE DISORDER

For the study participants it was evident that innovative solutions were required to address ARV therapy use among IPLWH who were living with a substance use disorder. Participants felt that health service providers should not prejudge them based on their substance use disorder. Health service providers should treat them with empathy, and engage them in a caring fashion. Health service providers need to understand that IPLWH who are living with an active substance use disorder should not necessarily be coerced into accessing or denied access to ARV therapy.

### LIMITATIONS

Given that our study used critical Indigenous qualitative research, our intent for this study was never to generalize our study findings statistically. One limitation of our study, as presented here, was that the study findings were limited to data generated from interviews conducted with IPLWH and did not include other data sources such as individual interviews conducted with health service providers. If we had individually interviewed health service providers, such additional data might have provided another layer of analytic insight to further explain the phenomenon.

### DISCUSSION

Accessing ARV therapy within the context of living with a substance use disorder was an overarching theme throughout our study. Given their situation, participants in our study felt they had to choose between living with their active substance use disorder and using ARV therapy. They spoke of health service providers refusing them and other IPLWH access to ARV therapy because their stage of addiction recovery was not considered optimal, or at least not at a point sufficient for IPLWH to be expected to maintain an adequate level of adherence to their ARV therapy for it to be effective. Should IPLWH who are living with an active substance use disorder be deprived ARV therapy if such deprivation contributes to their further deterioration, their HIV morbidity and possibly their death? A study conducted in North America among 662 providers with 5.3% of the study population recruited from Canada found that “HIV providers are significantly less likely to recommend [ARV] therapy at any CD4+ cell count for patients who engage in any injection drug use” (Westergaard, Ambrose, Mehta, & Kirk, 2012, pp. 9-10). Although some researchers (Kerr et al., 2004; Moore et al., 2010) found HIV-infected PWID to have decreased adherence to ARV therapy, others (Mann et al., 2012) reported that adherence to ARV therapy among PWID had improved over years, adding that this was likely due to newer ARVs with less toxicity and a decreased pill burden. Furthermore, a meta-analysis of 38 studies (Malta, Magnanini, Strathdee, & Bastos, 2010) found “that adherence to [Highly Active Antiretroviral Therapy] among HIV-positive drug users falls within the range observed among [people living with HIV/AIDS] in general, which is approximately 60%” (p. 739). There will still be significant inter-provider variability, but if Indigenous peoples living with a substance use disorder and HIV are willing to try ARV therapy and if they understand the importance of adherence to such therapy, the adherence threshold is much lower than it once was. That said,

there still are Indigenous peoples living with HIV and a substance use disorder whose lives appear too chaotic to adhere to ARV therapy. This is where daily dispensing of ARV therapy with MMT can be a useful approach to help them with their ARV therapy adherence.

In our study, participants felt that relapsing into substance use was a normal part of a recovery process where they learned to cope with their disorder over time, thereby improving their chances of abstaining permanently from drugs and alcohol. Many participants believed ARV therapy use needed to take into account their substance use disorder, whether they were actively using substances or not. Health service providers working with IPLWH who have a substance use disorder must be willing and ready first to offer treatment for the substance use disorder rather than simply cutting IPLWH off from their ARV therapy. If one or multiple forms of treatment for a substance use disorder fail, does the fault rest entirely with the client? Does a health service provider have the authority to deny such a client access to ARV therapy? Despite their own awareness of the chronic nature of a substance use disorder, participants in our study believed that they needed to persevere in trying to manage their ARV therapy use to the best of their ability. To them, in this context, the current provision of holistic health care was hypothetical at best.

Although not within the scope of this component of our study dealing with access to ARV therapy, an interesting question is whether ARV therapy use assists with recovery from a substance use disorder. It seems sociologically plausible that IPLWH who are living with an active substance use disorder, who are using their drug of choice, and who are receiving ARV therapy might become motivated to persevere as a result of their improved health. And the subsequent trust established between them and their health service providers could possibly assist them with their recovery from a substance use disorder.

## **DIRECTIONS FOR FUTURE RESEARCH**

To our knowledge, our study was the first qualitative study in Canada that investigated access to ARV therapy exclusively among IPLWH. Given that the participants mainly included women and First Nations Peoples, future research could be dedicated to studies examining access to ARV therapy among males and individuals of Métis and/or Inuit ancestry and in other communities across the country.

## **CONCLUSION**

Our study argued that IPLWH who are living with a substance use disorder have unique circumstances surrounding their access to ARV therapy. A concerted effort among IPLWH and health service providers is required for IPLWH with a substance use disorder to access ARV therapy.

For IPLWH who are living with a substance use disorder, emphasis should be placed on strengthening the healthcare and social welfare systems. A focus on these issues provides great potential to redistribute existing resources so that health services for IPLWH are made more

equitable and so that only demographic and need variables drive access to ARV therapy among this population.

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