

The Indigenous Red Ribbon Storytelling Study: A Qualitative Analysis of Indigenous Peoples' Experiences Living with HIV and Use of Antiretroviral Therapy in Canada

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International Indigenous Pre-conference on HIV & AIDS, 17-19 July, 2014, Sydney, Australia



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Background to the Study

- ARV can be effectively managed by ARV therapy (Hogg et al., 1997; Palella et al., 1998; Walensky et al., 2006)
- High burden of HIV-specific morbidity and mortality among Indigenous populations in Canada (Public Health Agency of Canada, 2012c)
- HIV drug resistance is associated with sub-optimal ARV therapy and non-adherence to ARV therapy (Little et al., 2002; Public Health Agency of Canada, 2012a; Wainberg & Friedland, 1998).
- Timely ARV therapy along with current prevention efforts can decrease HIV transmission (Attia, Egger, Muller, Zwahlen, & Low, 2009; Castilla et al., 2005; Cohen et al., 2011; Das et al., 2010; Donnell et al., 2010; Montaner et al., 2010)

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Research Problem

- Indigenous peoples living with HIV (IPLWH) are less likely than non-indigenous people living with HIV to access and adhere to antiretroviral (ARV) therapy (C. L. Miller et al., 2006a; Wood et al., 2003; Wood et al., 2006)
 - Most studies to date aim for generalization and do not focus enough on the contextual factors

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The Indigenous Red Ribbon Storytelling Study: Overview

- The Indigenous Red Ribbon Storytelling Study (IRRSS)
 - A three-year PhD research project (2012 to 2014)
- The IRRSS is a collaborative effort
 - Eleven community partners based in the Province of Saskatchewan, Canada
 - A doctoral candidate, Dalla School of Public Health, University of Toronto
- To examine how IPLWH construct and understand their experiences of ARV therapy.

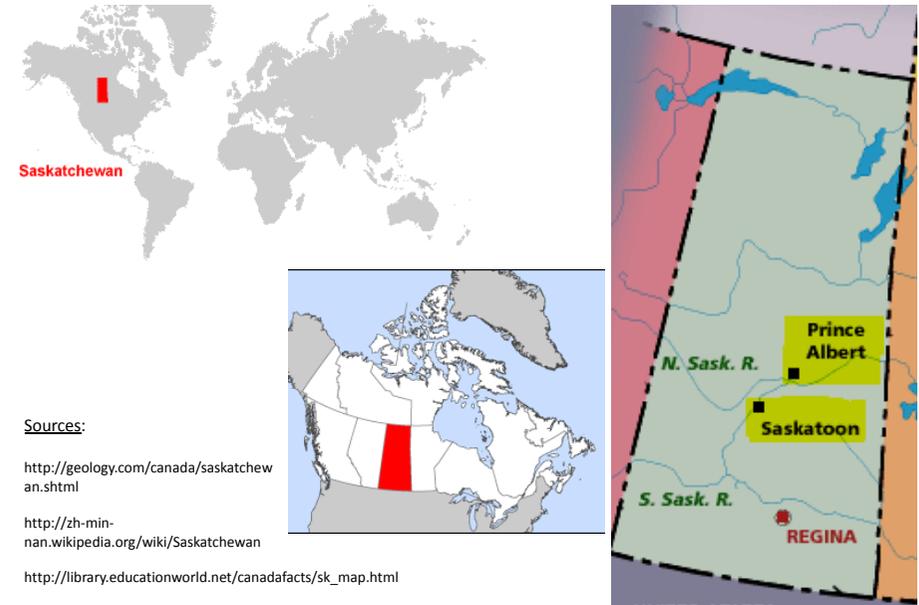
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Study Design

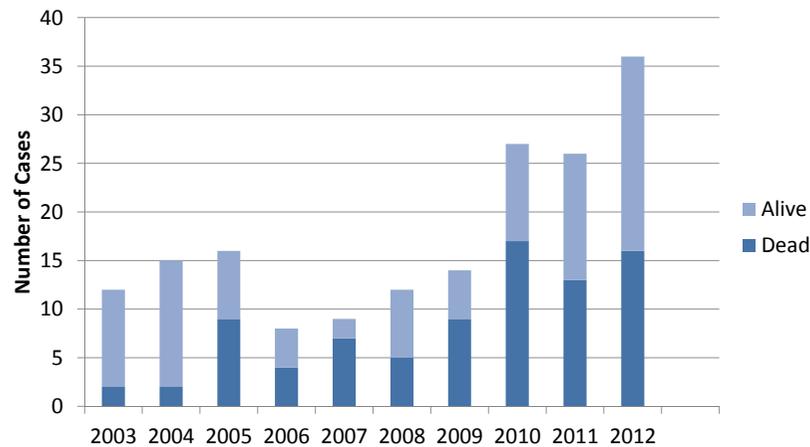
- Critical, indigenous qualitative research
 - Ethnography, Indigenous storytelling and sharing circles
- Community-based participatory research orientation
- Indigenous values
 - Tobacco offerings
 - Indigenous Elders and smudging
 - Gift-giving
 - Traditional indigenous feasts
- Behavioural Model of Health Services Use (Andersen, 2008)
- Sensitizing concepts
 - Structure vulnerability and resilience
 - Access, acceptance and adherence

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Study Setting: Canada, Saskatchewan - Cities of Saskatoon and Prince Albert



AIDS Cases in Saskatchewan, Life Status by Year of Diagnosis, 2003-2012



(Saskatchewan Ministry of Health, 2013)

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Study Sample: Individual Interviews

- 20 participants: IPLWH (14 First Nations and 6 Metis)
- Average age range 30 to 39 years
- 12 females and 8 males
- Majority (17) identified as heterosexual
- All lived off reserve: Cities of Saskatoon (16) and Prince Albert (4)
- Most (11) lived in stable housing
- Highest education for most (11) was elementary school
- Most (17) had income level of \$20,000 per year or less
- Most (12) were diagnosed HIV positive in the last 5 years
- Most (14) had taken or were taking ARV therapy
- Most reported a drug (19) and/or alcohol use disorder (13)
- Most (11) injected street drugs
- Most (17) reported history of Hepatitis C Virus infection
- Most (14) volunteered a history of methadone maintenance therapy

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Data Collection, Management and Analysis

- Informed consent and traditional offering of tobacco
- Twenty individual IPLWH interviews
 - lasting on average one hour
- Six IPLWH participant observation periods
 - lasting up to one hour
- Two 1.5-hour indigenous sharing circles
 - comprising a total of 15 key informants including IPLWH
- Survey of socio-demographic and health information
- A priori and inductive data coding
- Thematic analysis

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Study Findings: Themes

- The notion of *holistic health care**
- The relevance of *culture**, family and spirituality
- *Trust** and respect

**Given our limited time today, I will share only a few selected findings from the individual interviews.*

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Culture: Accessing Knowledge as a Collective (1)

Culture-wise, uh, we don't really... like...we're so... far set back. Like, uh-h... culture-wise if we, uh, need to... As a people we need to-o... help each other more. Like, uh-h (long pause) like, uh, we have lack of information. People... dropping out of school early. Uh-h... drinking. A lot of drug use. You know what I mean? Like, we need to teach our people... schooling is the way. Uh, there... you know. Safe protection. Use... if you're a drug addict, use (knocks on the table) clean needles; use stuff. We need advocates, people talking about this, people going out to schools. People talking about... I don't know. Like, I don't know. That kind of stuff. Because when I was younger, no one taught me about this. (Participant_36071: Male, age 30-39 years.)

If it can... help me, then I'll... I'm all for it. If not, then... I probably won't even bother with it at all (long pause) (clears throat) Like, I know a lot of people that have this and... know quite a few that have passed on already. (Participant_85366: Male, age 40-49 years.)

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Culture: Accessing Knowledge as a Collective (2)

I had all kinds of misconceptions to... um, from, um, people, um... you know, that were scared of HIV and... you know, just, uh... just of kind of, um, information that's out there... without, 'cause I never did any research, I just... other people's opinions, just talking about it and... so I just stereotyped... um... thoughts and feelings about, um... people with HIV. And so once, once I was, um... once it explained, I thought, I thought you could never, um... I was under the impression that once you got HIV you get... your life was, um... you only have a certain amount of time to live... and then you were gonna, eventually get, get AIDS and die from it. I didn't realize the med-, medication they give you out was at the point where it is today. (Participant_42167: Male, age 50+ years.)

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Culture: Accessing Knowledge as a Collective (3)

What I'd, like, to say about this is... we need to... as a people, as a... culture, as a... like... even... ourselves, we need to heal... and we need to talk about... to these people. It's okay to have HIV; it's okay. We need (claps hands) antiretro drugs. We need to help more people. There is... it's not a death sentence no more. It's... we need to help people... and... (claps hands) basically, um... like... we need advocates. People to tell... our younger children... "Look it (knocks on the wall) this is how we got HIV. Look it (knocks on the wall)... th-, this is how we're getting our lives back together" (knocks on table) And, uh... we need to prevent this... from spreading... to our people until we're wiped out. And that's, and I like this study because... it's going to help us. And I'm glad for you... for doing this study. Like... I wanted somebody, like... to come along and actually do this... and... help. I don't know; I'm a very open person. So, like, I have a big heart. I just said, like... and I'm, glad you're here... talking, like... and I'm glad I'm telling you about this. You know what I mean? (Participant_36071: Male, age 30-39 years.)

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Trust and Holistic Health Care: The Efficiency of Health Services (1)

Interviewer: Tell me about any barriers or facilitators, like the bad things or the good things, that relate to you accessing and then also, once you have access to it, do you accept it?

Participant: Oh, um... uh... the barriers is, uh... like, blood work. It takes so lon-n-n-g, man. You know what I mean? Has to be shipped to B.C-C., Vancou-, you know... and then it has to come back here. We have to find the right kind of drugs to put you on. The barr... like... we should have this in every city. Everyplace... where we can just... do it and... you know. Get this... stuff started, because... maybe... the time that person... is diagnosed they're already had full-blown AIDS... and... they have to get... those drugs right away. That's the barriers. (Participant_36071: Male, age 30-39 years.)

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Trust and Holistic Health Care: The Efficiency of Health Services (2)

Participant: I'm not even too sure what my count is. That's what I'm curious about. Like, I'm still like... you know... in that kind of process. Like... they been taking a whole bunch of blood off of me and... you know, then... their, uh... still is, like, it's slow (chuckles) The doctors are slow.

Interviewer: So maybe because you don't know what your blood results are, like, the.

Participant: Mhmm.

Interviewer: Your CD4 count?

Participant: Yeah. That's what I want to know. I just didn't, uh... check it out now. I'm supposed to, like, go for another blood test so... xxx xxx, like, "How many times?" How much do they have to take off... off of me (chuckles)? (Participant_13729: Female, age 30-39 years.)

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Trust and Holistic Health Care: The Efficiency of Health Services (3)

Participant: Well, they just told me that... you know, they... um... my thoughts is, like... I don't know... they just tell me-e, um... what's going on, but they haven't, I don't know. They're just like... they're slow (chuckles) That's all I xxx.

Interviewer: So it would nice if they speed it up a bit-

Participant: (overlapping) Yeah-h. Yeah. So, you know, and then... you know right away (snaps fingers) before it's too late, you know. Do this right away, you know. You know... do... they're the ones that's supposed to-o... y-, you know, help you and... what you need and that (long pause) And slow about it. 'Cause I had actually pneumonia. They didn't know what it was. I had an infection anyways. I'm, I'm... I don't know. They just said I had pneumonia (chuckles) They said, uh... the doctor put you in here, you know. Um... and said because you could have died. And they're telling me... like, holy. (Participant_13729: Female, age 30-39 years.)

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Trust and Holistic Health Care: The Efficiency of Health Services (4)

F**k. All I just found out is I'm HIV positive. What do I do from here? They didn't tell me about antiretro drugs. They didn't tell me about nothing. They just said, "Oh... you're HIV positive. Okay. Live your life". F**k. You know what I mean. Like, holy s**t.
(Participant_36071: Male, age 30-39 years.)

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Trust and Holistic Health Care: The Efficiency of Health Services (5)

Well sometimes I-I-I... when I phone the clinic and I tell them that I need more... medication... and sometimes when I go there, they tell me that I have to go back the next day, or else the next day, to come and pick it up and I tell them that I don't have enough... treatment to that to... kind of... make it last. 'Cause... every time when you miss, like, they tell me if I miss... a dose and that, I have to... double the dose for next time. So sometimes I don't really... want to do that 'cause it... makes it... makes me feel a little bit more sicker. So, uh... I try... I try to, like, get them... I try to like. They tell me to phone, like, two days ahead, so... sometimes I phone, three days ahead... and, uh... that kinda helps me with that. (Participant_75877: Male, age 18-19 years.)

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Discussion

- Holistic health care
 - Health services (Newman et al., 2007)
- Access to care
 - Viral load testing (Plitt et al., 2009)
- Health disparities
 - Wealth and power (Jones, 2006)
- Culture

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For next time: Other findings

- Family
- Spirituality
- Respect
- And more on culture, trust, and holistic health care

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Acknowledgements (1)

- Study participants
- Community partners
 - AIDS Saskatoon, 601 Outreach Centre & 601 North
 - Co-operative Health Centre Prince Albert Community Clinic
 - Health Canada, First Nations and Inuit Health Branch, Saskatchewan Region
 - Indian Metis Friendship Centre of Prince Albert
 - Saskatoon Friendship Inn
 - Saskatoon HIV/AIDS Research Endeavour
 - Saskatoon Indian and Metis Friendship Centre
 - Saskatoon Tribal Council, Health & Family Services Inc.
 - Saskatoon Westside Community Clinic
 - Prince Albert Access Place and Outreach Services
 - Prince Albert Metis Women's Association Inc.
- Elders
 - Senator Nora Cummings
 - Maria Linklater
 - Walter Linklater
 - Louise McKinney
 - Sandra Mirasty
 - Loretta Wilson

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Acknowledgements (2)

- Operational Approvals
 - Prince Albert Parkland Health Region
 - Saskatoon Community Clinic (Community Health Services [Saskatoon] Association Ltd.)
 - Saskatoon Health Region
- Ethics Approvals
 - University of Toronto, HIV Research Ethics Board
 - University of Saskatchewan, Behavioural Research Ethics Board
- Fellowship Programs
 - Canadian Institutes of Health Research (CIHR) Health Services and Population Health HIV/AIDS Priority Announcement
 - The CIHR Social Research Centre in HIV Prevention

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Cairns HIV Hub Conference, 28-29, July 2014, Cairns, Australia

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