

Lessons learned from the Indigenous Red Ribbon Storytelling Study in Canada

Earl Nowgesic, RN, BScN, MHSc, PhD

Assistant Professor

Interim Director, Waakebiness-Bryce Institute for Indigenous Health

Dalla Lana School of Public Health, University of Toronto

Toronto, Ontario

6th International Indigenous Pre-conference on HIV & AIDS:

An affiliated independent event of the 21st International AIDS Conference (AIDS 2016)

July 16, 2016, Durban, South Africa

Waakebiness-Bryce Institute for Indigenous Health

Feasting and Celebrating
the Founding of
**The Waakebiness-Bryce
Institute for Indigenous Health**
Monday, March 23, 2015





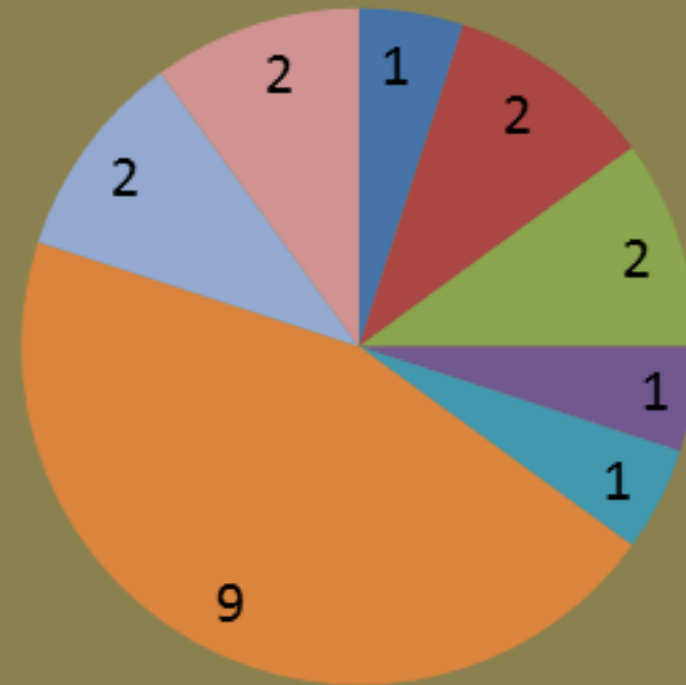
What does the Institute do?

- Cultivate partnerships
- Conduct research
- Provide training opportunities
 - targeted towards innovative interventions
 - address Indigenous health inequities
 - contribute to thriving Indigenous communities, nationally and internationally
- Support faculty and trainees
- Provide seed funding to various initiatives

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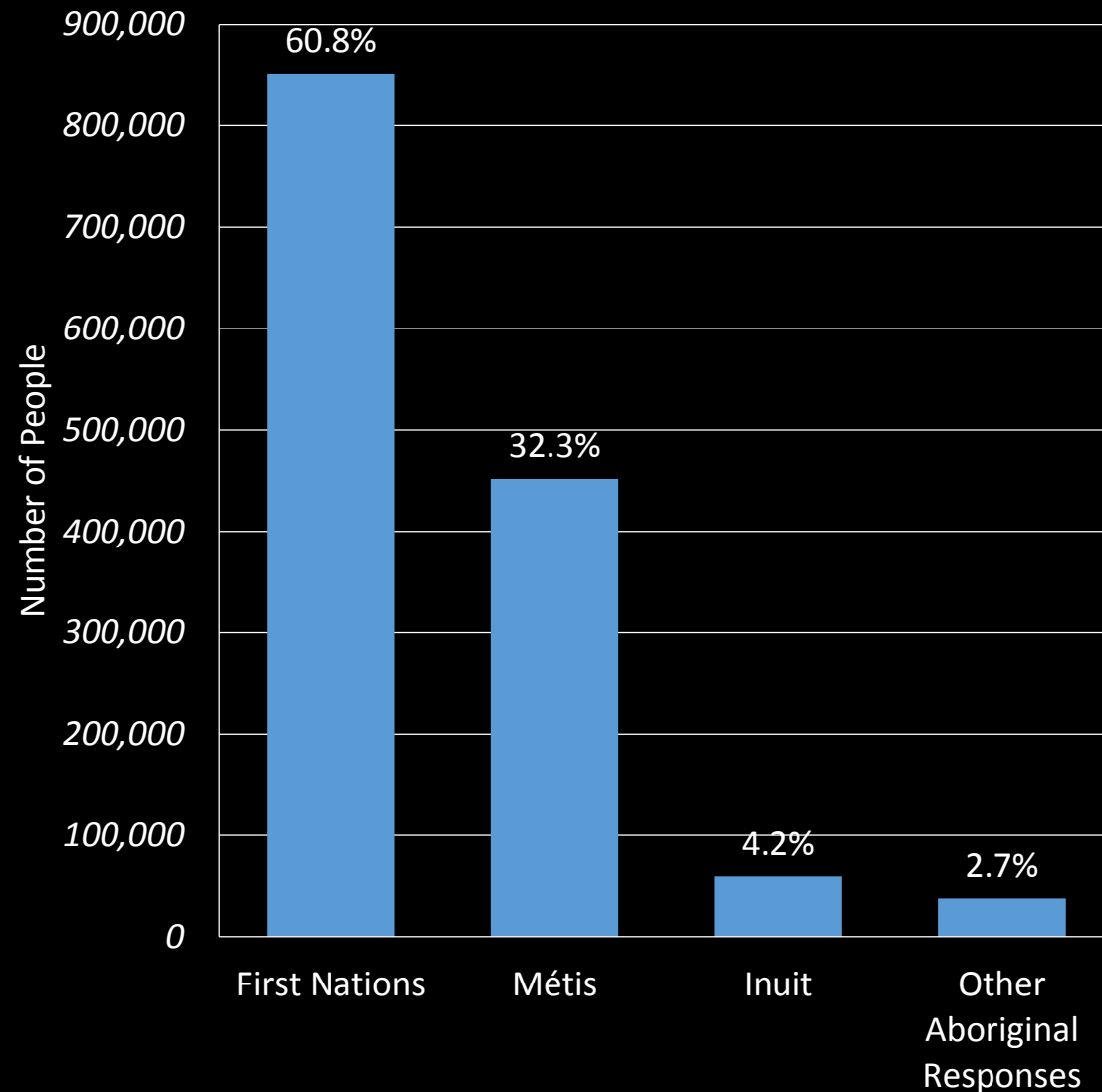


- AB
- BC
- MB
- NU
- NWT
- ON
- QC
- SK

Population in Canada

- Total 33 million in 2011
 - 4.3% Aboriginal
 - 95.7% Non-Aboriginal
- Identity population grew from 2006 to 2011
 - 20.1% Aboriginal
 - 5.2% Non-Aboriginal
- Aboriginal group identity population increased from 2006 to 2011
 - 22.9% First Nations
 - 16.3% Métis
 - 18.1% Inuit

Aboriginal Population Only in 2011



HIV Among Aboriginal Populations: Burden of Illness in Canada in 2014

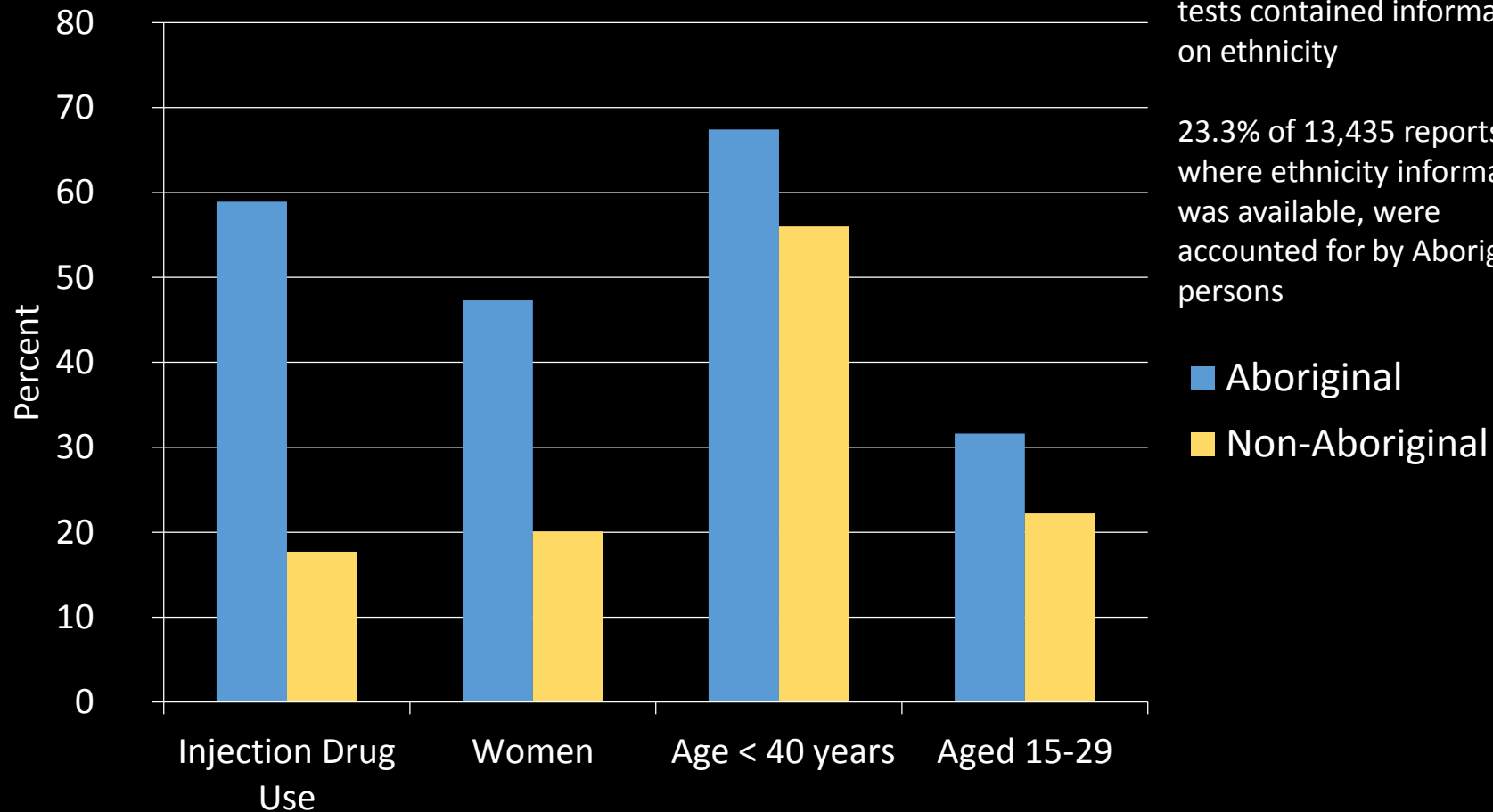
- Estimate of 75,500 (range: 63,400 to 87,600) people living with HIV in Canada in 2014
 - Aboriginal people accounted for 9.1% of all prevalent infections
- Among all Canadians, new HIV infections were estimated at 2,570 (range: 1,940 to 3,200) in 2014
 - Aboriginal persons accounted for 10.8% of all incident HIV infections

(Public Health Agency of Canada, 2015)

Surveillance: Positive HIV Tests Reported to the Public Health Agency of Canada between 1998 to 2012*

*38% of 35,319 positive HIV tests contained information on ethnicity

23.3% of 13,435 reports, where ethnicity information was available, were accounted for by Aboriginal persons



(Public Health Agency of Canada, 2014)

The Importance of Antiretroviral Therapy Among Indigenous Peoples Living With HIV

- HIV can be effectively managed by antiretroviral (ARV) therapy
(Hogg et al., 1997; Palella et al., 1998; Walensky et al., 2006)
- 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)
- 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).

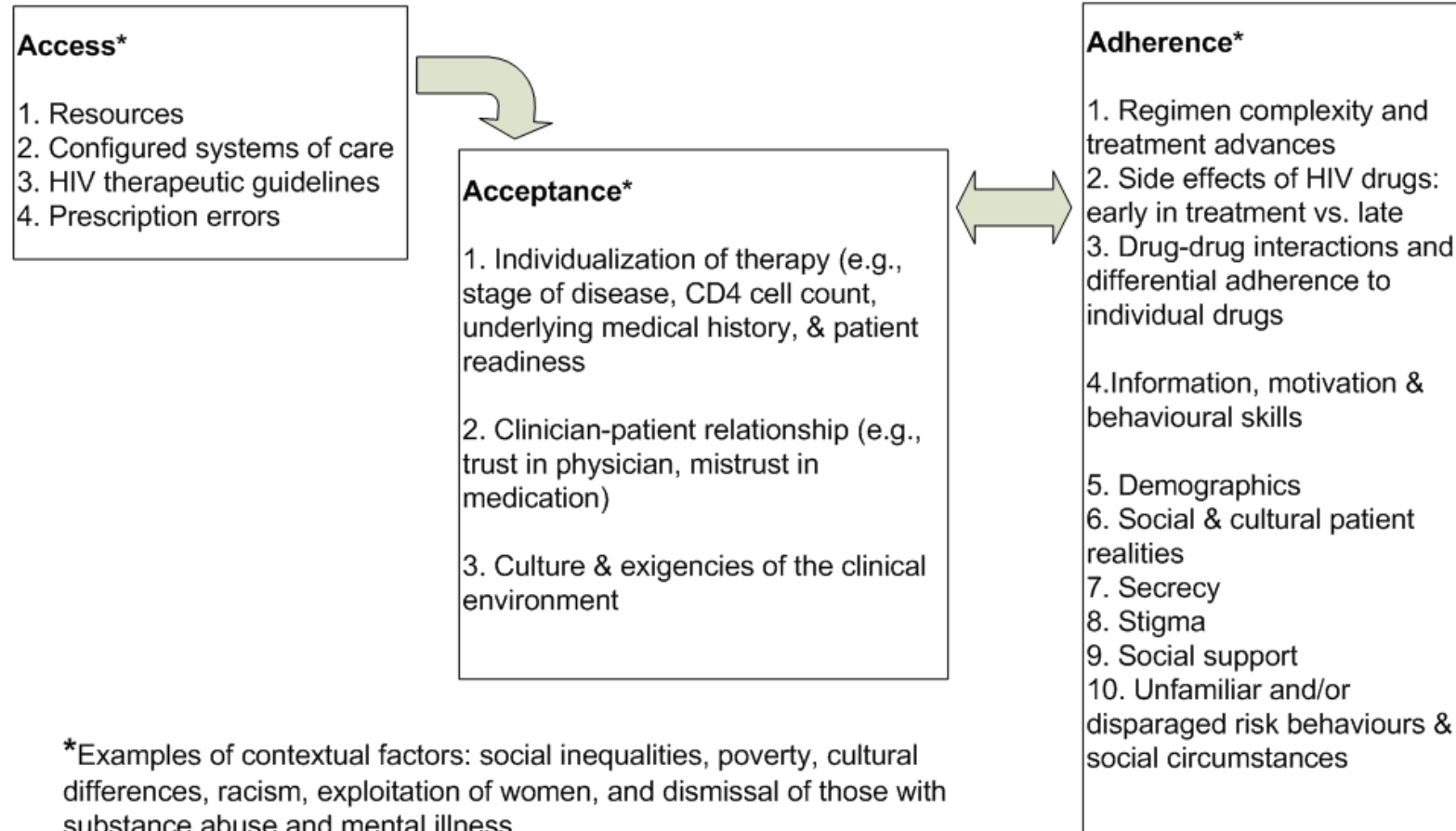
HIV Drug Resistance in Canada

(Source: Public Health Agency of Canada, 2012a)

- In Canada, from 1999 to 2008, 9.8% of newly diagnosed, treatment-naïve people were HIV drug-resistant
- “Some of the increase observed for the time period 2004-2008 [in Canada] was likely due to an increase primarily in the province of Saskatchewan during each of those years”
(p. 18)
- In Saskatchewan, there was an increased trend in HIV drug resistance from 1999 to 2008 ($p < 0.0001$).
 - Overall transmitted drug resistance was estimated at 15.1%

HIV Drug Therapy: The Interstices between Access, Acceptance and Adherence

(adapted from Friedland, 2006)



Health care: Antiretroviral Therapy among Indigenous Persons Living with HIV/AIDS

Study	Purpose	Design	Sample	Results
Wood et al., 2003	To evaluate access to ARV therapy among persons who have died of HIV/AIDS and to determine associated factors	-Quantitative study -1995 to 2001	<ul style="list-style-type: none"> • British Columbia • Aboriginal and non-Aboriginal 	<ul style="list-style-type: none"> • Aboriginal negatively associated with <u>receiving</u> HIV treatment before death
Wood et al., 2006	To examine the time to ARV therapy initiation among a cohort of ART naïve IDUs	-Quantitative study (prospective cohort) -1996 to 2003	<ul style="list-style-type: none"> • Vancouver • Street outreach • Aboriginal and non-Aboriginal 	<ul style="list-style-type: none"> • <u>Rate of ARV therapy use</u> among Aboriginal (29%) and non-Aboriginal (53%)
Miller et. al., 2006	To provide a profile of Aboriginal people initiating ARV therapy and their response to treatment	-Quantitative study -1996 to 2002	<ul style="list-style-type: none"> • British Columbia • 892 participants (16% Aboriginal) 	<ul style="list-style-type: none"> • Aboriginal less likely <u>adherence</u> to ARV therapy • Aboriginal more likely : female, poor, IDU, HCV, and unstable housing • Aboriginal more likely: double vs. triple ARV therapy and have MD less experienced treating HIV

Study Setting: Saskatchewan - Cities of Saskatoon and Prince Albert

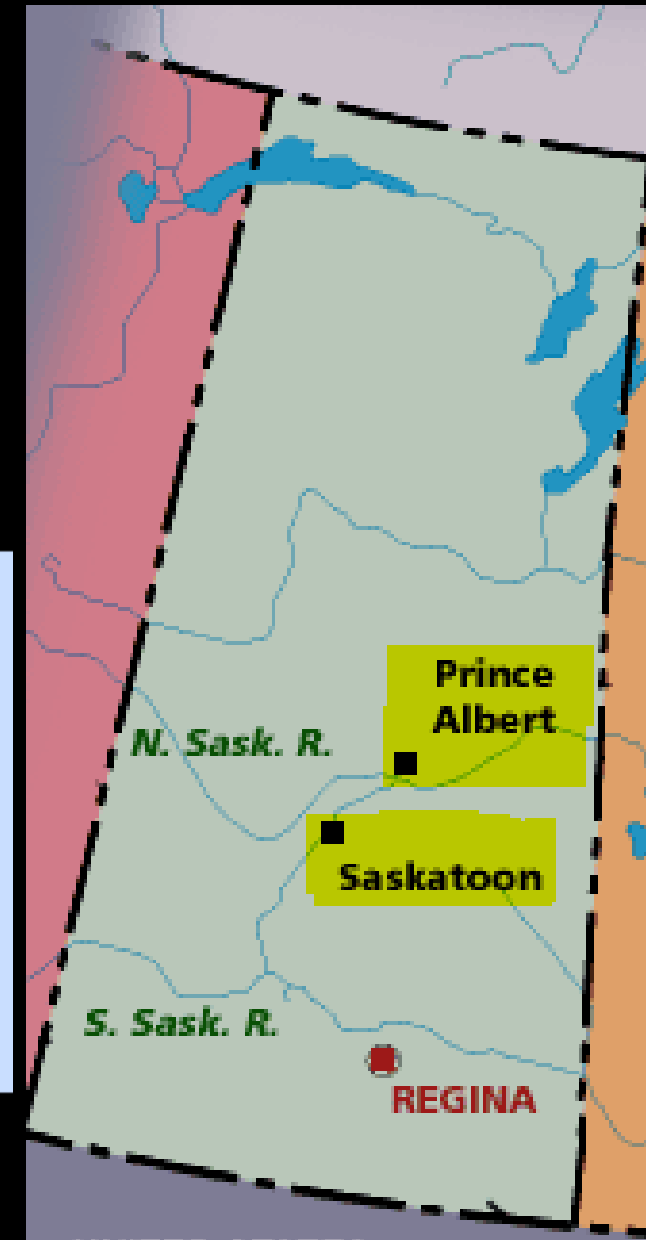


Sources:

<http://geology.com/canada/saskatchewan.shtml>

<http://zh-min-nan.wikipedia.org/wiki/Saskatchewan>

http://library.educationworld.net/canadafacts/sk_map.html

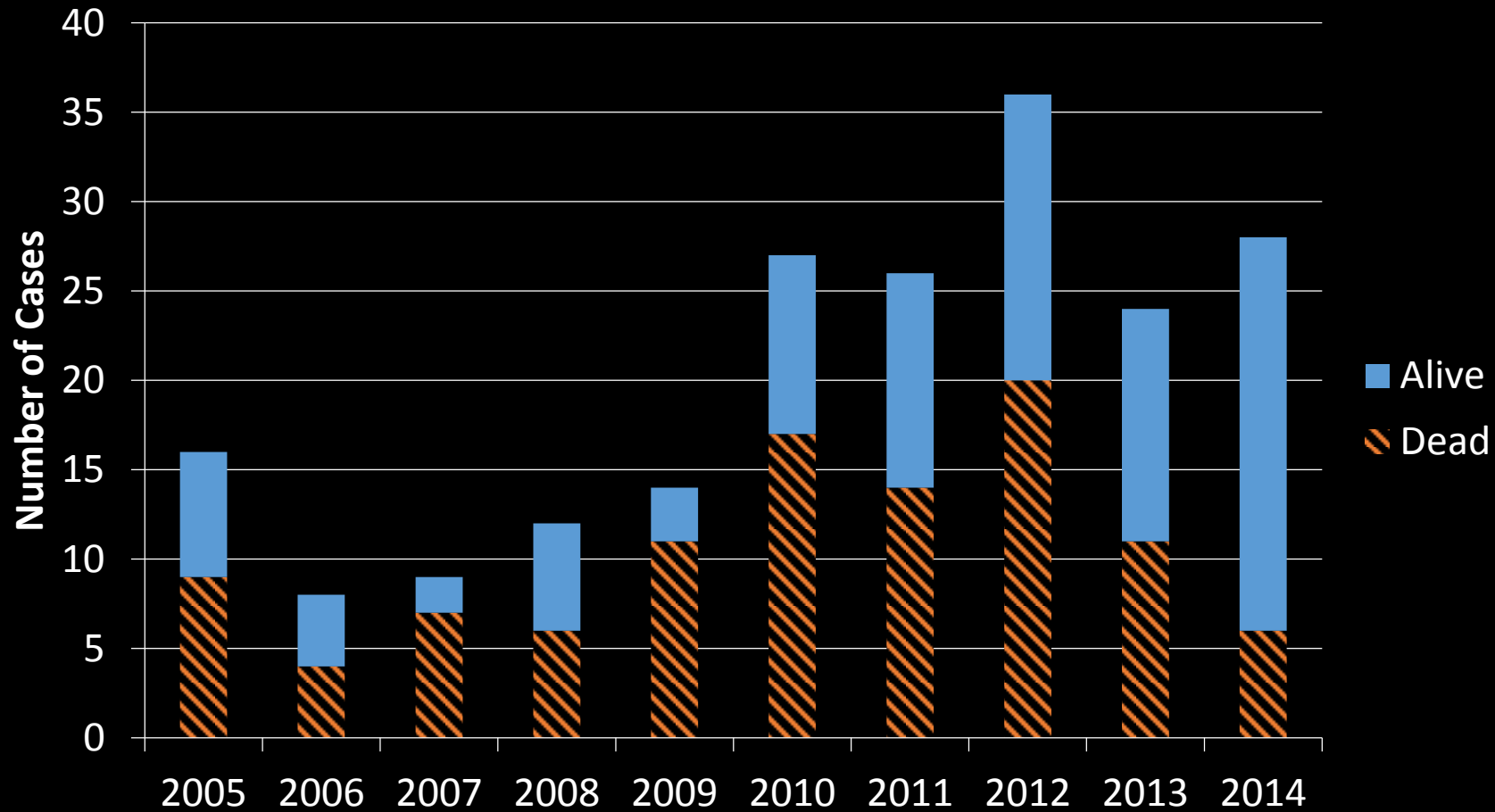


Burden of HIV in Saskatchewan

- In Saskatchewan, the HIV diagnosis rate was 1.7 times the national average in 2014
 - Saskatchewan: 9.8 per 100,000
 - Canada: 5.8 per 100,000
- In 2014, 71% (79/112) of newly diagnosed HIV cases were of Aboriginal ethnicity
- In 2011, Aboriginal identity population in Saskatchewan was 16% (157,740/1,008,760)

(Public Health Agency of Canada, 2015; Saskatchewan Ministry of Health 2015; Statistics Canada, 2015)

AIDS Cases in Saskatchewan (Life Status by Year of Diagnosis, 2005-2014)



(Saskatchewan Ministry of Health , 2015)

Health Care for Indigenous Peoples

- Time between diagnosis and first viral load test among HIV infected persons (Plitt et al., 2009)
 - Aboriginal persons had longer median time to care at 38 days in comparison to non-Aboriginal groups (i.e. Caucasian, 27 days; Asian, 22 days; African-Caribbean, 20 days; and others, 19 days)
 - Longer time to care for Aboriginal Peoples Living With HIV (APLWH) in comparison to Caucasian PLWH (AHR=0.82, 95% CI [0.68, 1.01])
- Decreased baseline HIV drug resistance testing (AOR=0.55, 95% CI [0.33, 0.91]) (Eyawo et al., 2011)

Indigenous Culture: Mobilizing as a Nation

(Nowgesic, 2015)

Participant: F**k. All I just found out is I'm HIV positive. What do I do from here? They didn't tell me about [antiretroviral therapy]. They didn't tell me about nothing. They just said, "Oh, you're HIV positive. Okay, live your life." F**k. Like, holy sh*t. (Flen: Male, age 30-39 years.)

The Timeliness of the Provision of Health Services and its Impact on Trust

(Nowgesic, 2015)

Participant: The barriers is the blood work. It takes so long. It has to be shipped to B.C., Vancouver, and then it has to come back here [Saskatchewan]. “We have to find the right kind of drugs to put you on.” We should have [HIV biomarker testing] in every city. Because the time that person is diagnosed, they already had full-blown AIDS and they have to get [antiretroviral therapy] right away. That's the barriers. (Flen: Male, age 30-39 years.)

Indigenous Red Ribbon Storytelling Study, 2013-2015

(Nowgesic, 2015)

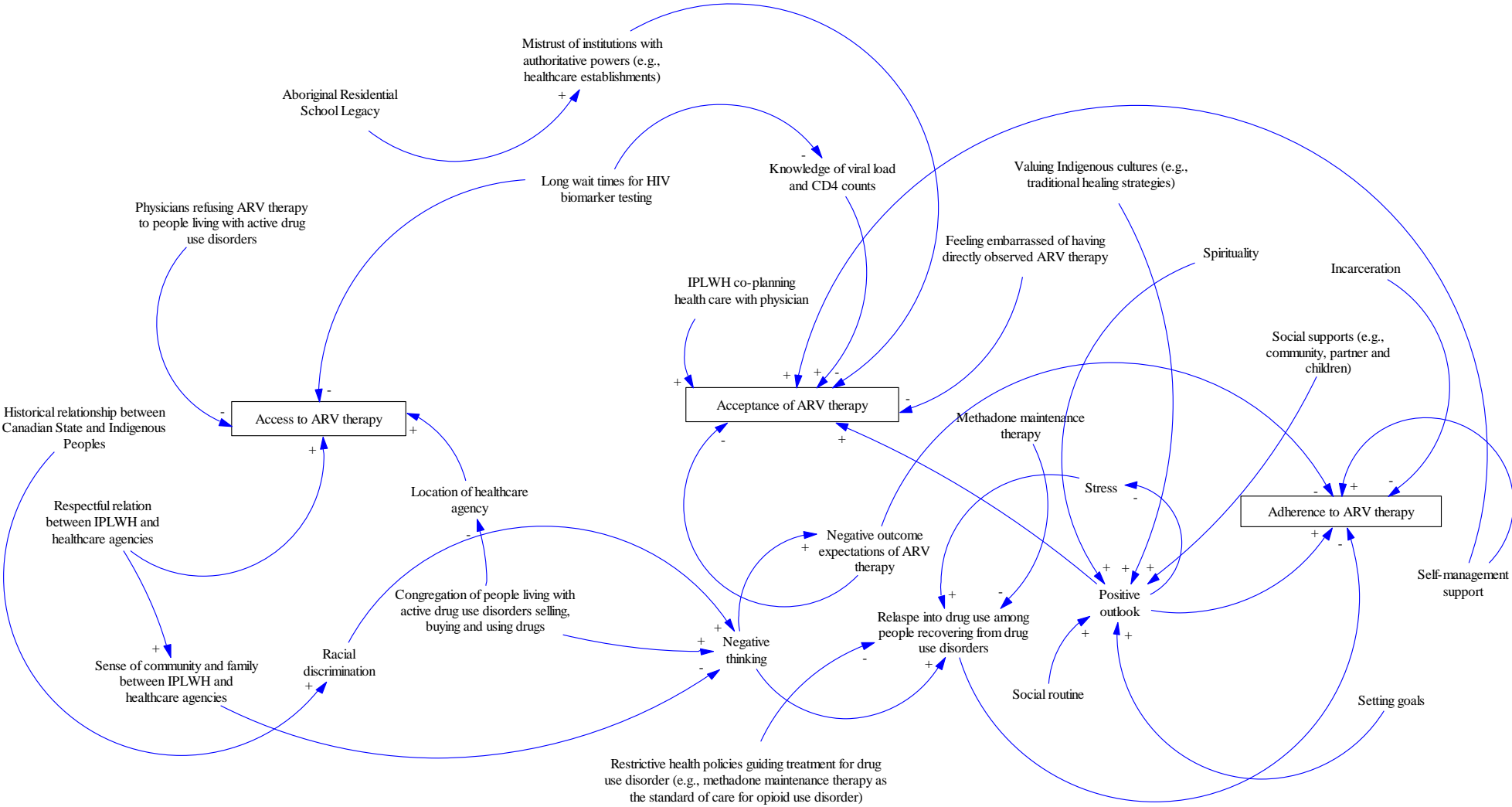
- Partnership among 11 groups in Saskatchewan
- Research question: How do Indigenous Peoples Living With HIV (IPLWH) construct and understand their experiences pertaining to antiretroviral (ARV) therapy?
- 20 study participants
 - IPLWH (14 First Nations and 6 Metis)
 - Average age range 30 to 39 years
 - 12 females and 8 males
 - All (20) lived off reserve (16 in Saskatoon and 4 in Prince Albert)
 - Most (17) identified as heterosexual
 - Most (14) had taken or were taking ARV therapy
 - Most reported substance use disorders
 - Drug use disorder (19) and/or alcohol use disorder (13)
 - Most (11) injected street drugs
 - Most (17) had Hepatitis C virus infection

Indigenous Red Ribbon Storytelling Study: Findings - Themes

(Nowgesic, 2015)

- The value of trust
- The relevance of culture
- The notion of holistic health care
- The importance of family and friends
- The value placed on respect

Factors Affecting Antiretroviral Therapy Use among Urban Indigenous Peoples Living With HIV in Saskatchewan



Source: Nowgesic, E.F. (2015). *Antiretroviral Therapy Access, Acceptance and Adherence among Urban Indigenous Peoples Living with HIV in Saskatchewan: The Indigenous Red Ribbon Storytelling Study*. (Doctoral dissertation, University of Toronto) © Copyright by Earl Frederick Nowgesic, 2015.

Feeling Misunderstood as a Person Recovering from a Substance Use Disorder

(Nowgesic, 2015)

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 [antiretroviral] 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.)

Feeling Coerced into Using Methadone Maintenance Therapy

(Nowgesic, 2015)

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 [antiretroviral] 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.)

Cross-cultural Challenges

(Nowgesic, 2015)

Participant: That's why I am glad that I met the [Indigenous] Elder here today because I wanted to meet an Elder. There's so much stuff that I want to do, but I just don't know about how to go about doing it.

(Indime: Female, age 30-39 years.)

The Aboriginal Residential School Legacy and its Effect on Trust and Self-Help (1)

(Nowgesic, 2015)

Participant: [Aboriginal residential school] really did affect me a lot. I couldn't believe some of the stuff I went through, especially when you get taken away from your own family. I wasn't even six years old when they come and got me and my older brother. Just, literally took us away. Priests, nun, RCMP [and] social service. Come get you in the Fall; bring you back in the Spring. You get to go home and you're not allowed to talk to your own language. I could talk five languages when I was a kid. Now, I can [only] talk [one dialect of] Cree. (Clom: Male, age 40-49 years.)

Participant: [Healthcare providers are] more pushy than anything. They'll demand that you take [antiretrovirals]. (Clom: Male, age 40-49 years.)

The Aboriginal Residential School Legacy and its Effect on Trust and Self-Help (2)

(Nowgesic, 2015)

Interviewer: Do you ever think about First Nation culture and how that could either affect you in using or not using ARV therapy?

Participant: I kind of think [if it] went down to that traditional way then the Elder would be all for it. They'd be pushing you toward it.

Interviewer: [Did] your grandparents [who] raised you believe in their culture?

Participant: Yeah. They probably would have pushed me toward [using antiretroviral (ARV) therapy]. I won't say no to anything if it has to do with our culture. If it's positive, I'll do it. If it's not positive, then I won't do it. But I'm looking more into [accepting ARVs] than anything (tapping hand on table). (Clom: Male, age 40-49 years.)

Being Discriminated Against by One's Own Community

(Nowgesic, 2015)

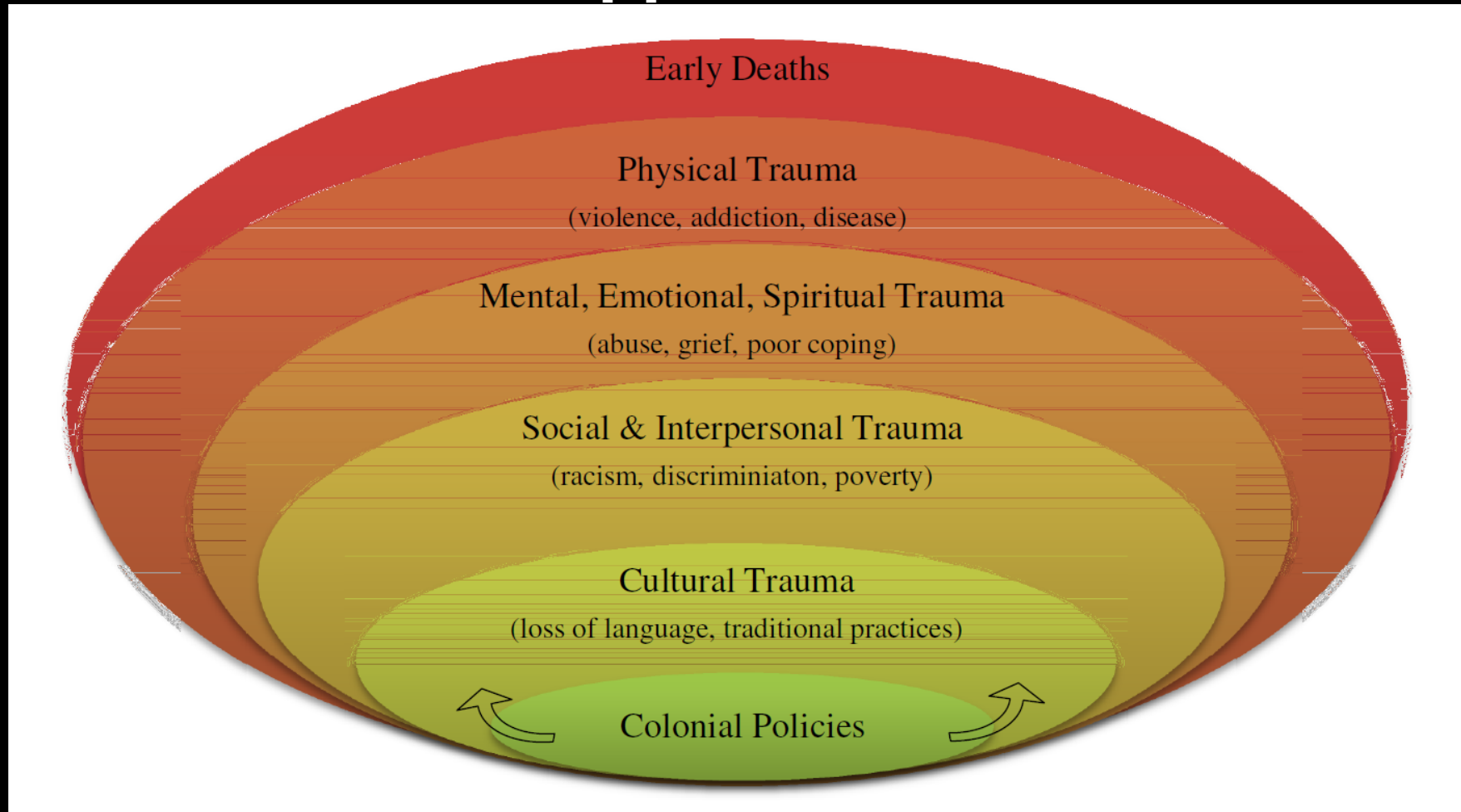
Participant: 'Cause even some of the Elders, they don't understand 'cause they are so set in their ways and they don't want to come around and try and understand. So it's hard to try and trust somebody to go and try and offer tobacco and talk to them about it. 'Cause I don't know what they're going to say to me. Like maybe they'll just tell me to go away, and they don't want nothing to do with me. But I'm trying my best to stay positive and think everything is going to be okay for me. (Queete: Female, aged 30-39 years.)

Adhering to ARV Therapy: The Consolations of Faith, Hope and Spiritual Practices

(Nowgesic, 2015)

Participant: The most important thing what I would like for doctors is to incorporate that spiritual, mental and physical. Especially with Natives, I think that would go a long way. “Well, let's ask the Creator. Let's sit down and bring an Elder in or a pastor”. Whatever the person's spirituality is. I know that nurses incorporate like [mental health and addictions nurses], which is good. And I think a person needs to have a full circle walk just to keep them balanced (Reth: Male, aged 30-39 years.)

Root Cause of Premature Death through a Ripple Effect



Source: Shah, Klair and Reeves, n.d. Early death among members of Toronto's Aboriginal Community: Walking in their shoes. Retrieved January 31, 2016, from <http://www.toronto.ca/legdocs/mmis/2013/hl/bgrd/backgroundfile-64668.pdf>

Determinants of Health for Aboriginal People

- Indian Act, 1876
 - administration of program and assimilation (Waldram, Herring, & Young, 2007)
 - Aboriginal residential school system (DeGagne, 2007)
- “It was the federal government’s new ‘Indian Health Policy’, unveiled in 1979, that sparked the process of self-determination in Aboriginal health care...What was required was increased input by Aboriginal people themselves” (Waldram, Herring, & Young, 2007, p. 264)
- Royal Commission on Aboriginal Peoples, 1991
 - Aboriginal Healing Foundation, 1998
 - Intergenerational legacy of abuse (DeGagne, 2007)
- Truth and Reconciliation Commission (TRC), 2008
 - TRC report released in 2015

Indigenous Red Ribbon Storytelling Study: Findings - Themes

(Nowgesic, 2015)

- The value of trust
 - Timeliness of the provision of health services
- The relevance of culture
 - Knowledge as a collective
 - After-effects of the Aboriginal Residential School legacy
- The notion of holistic health care
 - Living with a substance use disorder
 - Quest for peace of mind
- The importance of family and friends
 - Self-regulation
- The value placed on respect
 - Effect of incarceration and law enforcement

Decolonizing Health Care and Health Systems: Respecting An Indigenous Theoretical Paradigm



Aboriginal Health Nursing and Aboriginal Health: Charting Policy Direction for Nursing in Canada

(Canadian Nurses Association, 2014)

- “to provide a document to guide policy development for strengthening and improving aboriginal health nursing, aboriginal health leadership and aboriginal health” (p. 1)
 - Present to Aboriginal Nurses Association of Canada national forum, 2013
 - Feedback from Canadian Nurses Association’s
 - member jurisdictions
 - Canadian Network of Nursing Specialities



Canadian Nurses Association

Aboriginal Health Nursing and Health Advisory Group

(Membership as of 2015)

- Lisa Bourgue Bearskin, RN, PhD
- Sherri Di Lallo, RN, MN
- Tania Dick, MN-NP(F)
- Bernice Downey RN, PhD
- Fjola Hart-Wasekeesikaw, RN, MN
- Julie Lys, NP
- Earl Nowgesic, RN, PhD
- Lisa Perley-Dutcher RN, MN

Priority Areas For Strategic Action

(Canadian Nurses Association, 2014)

- Integration of Indigenous ways of knowing and being
 - Primary and foundational to other priorities
- Addressing institutional barriers to Aboriginal Health Nursing and Aboriginal health
 - Racism in policy and practice (e.g., lack of dedicated enrollment places for Aboriginal nurses students)
 - Lack of implementing policies
- Education: recruitment and retention
 - Champions among faculty
 - Policies to recruit Aboriginal faculty
- Practicing nurses: recruitment and retention
 - Continuing education and professional development
 - Mentoring from community Elders
- Building capacity for leadership and advocacy

Indigenous Red Ribbon Storytelling Study: Discussion (2)

- “HIV providers are significantly less likely to recommend [antiretroviral] therapy at any CD4+ cell count for patients who engage in any injection drug use” (Westergaard, Ambrose, Mehta, & Kirk, 2012, pp. 9-10)
- HIV-infected people who inject drugs (PWID) have decreased adherence to ARV therapy (Kerr et al., 2004; Moore et al., 2010)
- Adherence to ARV therapy among PWID has improved over the years
 - likely due to newer ARVs with less toxicity and a decreased pill burden (Mann et al., 2012)
- “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%” (Malta, Magnanini, Strathdee, & Bastos, 2010, p. 739)

IRRSS: Discussion (2)

- Culture and Indigenous spirituality
 - “It is the intimate relationship that [Indigenous] people establish with place and with the environment and with all of the things that make them or give them life” (Cajete, 2000, p. 184).
- Disconnection from spirituality
 - Difficulty adhering to ARV therapy (Milligan and Lavoie, (2012)
- Spirituality is important
 - Supports ARV therapy adherence (Ka’opua and Muller, 2004)

IRRSS: Discussion (3)

- “reconnecting to community was often described as a key source of strength” (Cain et al., 2013, p. 821)
- Aboriginal Healing Foundation (DeGagne, 2007)
 - “culture is good medicine”

IRRSS: Discussion (4)

- Indigenous peoples' experience of health disparities today is associated with their historical and their current position within the socio-structural environment, a social system based on the historical relationship between the Nation State and Indigenous peoples (Adelson, 2005; King et al., 2009; Waldram et al., 2007)
- People who inject drugs living in Saskatoon faced discrimination based on their race where such discrimination acted as a barrier to them accessing health services (Lang et al., 2013)

Social Determinants of Health for Aboriginal People: Culture, Poverty and Self-Determination

Study	Purpose	Design	Sample	Results
(DeGagne, 2007)	To evaluate community initiatives supported by the Aboriginal Healing Foundation (AHF)	<p>Process and Outcome Evaluation</p> <p>1998 to 2005</p> <p>Mixed methods (i.e. quantitative & qualitative)</p>	<ul style="list-style-type: none"> • National. • 1447 completed individual participant questionnaires • 103 completed project questionnaires • 5 focus groups • AHF staff and board members • 27 commissioned research studies 	<p>Projects most effective included use of:</p> <ul style="list-style-type: none"> • Elders • Traditional ceremonies • Individual counseling • Western healing strategies used in conjunction with Aboriginal cultural practices
(Larkin et al., 2007)	To understand the structure and essence of Aboriginal youth's lived experience of HIV in order to support HIV prevention education	Qualitative Study	<ul style="list-style-type: none"> • 48 Aboriginal males & females • Aged 14 to 29 years • Living in Toronto 	<ul style="list-style-type: none"> • Some youth understood HIV to be associated with the effects of colonialism • Aboriginal youth were concerned about the effects of HIV on their communities within the context of structural inequities (e.g. poverty)
(Chandler and Lalonde, 1998)	To investigate protective factors against suicide among First Nations communities	1987 to 1992	<ul style="list-style-type: none"> • 29 tribal councils 	<ul style="list-style-type: none"> • In comparison to tribal councils with less control of community-level variables, (i.e. markers of cultural continuity), those tribal councils who had more control also had lower suicide rates

Indigenous Red Ribbon Storytelling Study: Recommendations (1)

(Nowgesic, 20015)

1. Policy makers and health service providers should involve Indigenous Peoples Living With HIV (IPLWH) to a greater and more meaningful extent in all affairs affecting them
 - For example, the VANDU model (Vancouver Area Network of Drug Users)
2. Health service providers should not prejudge IPLWH who are living with a substance use disorder
 - IPLWH being under the influence of substances

Indigenous Red Ribbon Storytelling Study: Recommendations (2)

(Nowgesic, 20015)

3. Health service providers should help Indigenous Peoples Living With HIV (IPLWH) who are new in their recovery process from a substance use disorder to mobilize resources to help them succeed in the recovery process
 - Healthy living environments
 - Continuity of care
4. Policy makers and health service providers should help IPLWH who are living with a substance use disorder to keep their family together, which includes taking into account the broader social determinants of health such as the importance of family cohesion
 - Health and social service provides (e.g., childcare authorities)
 - Coping skills
 - Child-rearing knowledge, skills and abilities

Indigenous Red Ribbon Storytelling Study: Recommendations (3)

(Nowgesic, 20015)

5. Policy makers and health service providers should support Indigenous Peoples Living With HIV (IPLWH) with their antiretroviral therapy use by ensuring that Indigenous cultural values, beliefs and customs are an integral part of health services
 - For example, involving Indigenous Elders and sweat lodge ceremonies
 - Health disciplines specializing in Indigenous health
6. Policy makers should ensure that health clinics have all the various necessary types of health service providers to meet the needs of IPLWH from a holistic perspective, including a full-time Indigenous Elder-in-residence who specializes in providing HIV support to IPLWH within the context of Indigenous traditions
 - Holistic approach to health care (e.g., spiritual and mental components)
 - Integrated healthcare system (e.g., health records; and types health services, health professions and disciplines)

Conclusion



Acknowledgements (1)

- Study participants of the Indigenous Red Ribbon Storytelling Study (IRRSS)
- Community partners of the IRRSS
 - 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

Acknowledgements (2)

- Operational Approvals for the Indigenous Red Ribbon Storytelling Study (IRRSS)
 - Prince Albert Parkland Health Region
 - Saskatoon Community Clinic (Community Health Services [Saskatoon] Association Ltd.)
 - Saskatoon Health Region
- Ethics Approvals for the IRRSS
 - 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
 - Ontario HIV Treatment Network Universities Without Walls
 - The CIHR Social Research Centre in HIV Prevention
 - University of Toronto/McMaster University CIHR Indigenous Health Research Development Program Graduate Scholarship and Research Support
- Others

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Assistant Professor

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